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THE CAREGIVING RELATIONSHIP

**PALLIATIVE CAREGIVERS' RELATIONSHIPS
WITH PATIENTS AND FAMILIES**

VOLUME 2: THE APPENDICES

PETER A. STEHLE

**THESIS SUBMITTED IN FULFILMENT OF THE PhD
IN PSYCHOTHERAPY AND COUNSELLING AT
THE SCHOOL OF PSYCHOTHERAPY AND COUNSELLING
AT REGENT'S COLLEGE, LONDON**

VALIDATED BY CITY UNIVERSITY, LONDON

DECEMBER 2001

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APPENDIX 1

PILOT STUDY

HOSPICE A

CO-ORDINATOR: SENIOR HOSPICE PHYSICIAN

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
P 1	12.09.95	f	Social Worker
P 2	12.09.95	f	Secretary
P 3	12.09.95	f	Bereavement Service Manager
P 4	13.09.95	m	Volunteer
P 5	13.09.95	m	Hospice Physician
P 6	13.09.95	f	Macmillan Home Care Nurse
P 7	14.09.95	f	Senior Nurse/Executive Manager
P 8	14.09.95	f	Hospice Nurse
P 9	15.09.95	f	Macmillan Home Care Nurse
P10	15.09.95	m	Hospice Chaplain

**PRE-QUESTIONNAIRE
FOCUS GROUP MEETING
HOSPICE A**

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
F 1	01.10.97	f	Senior Nurse/Executive Manager
F 2	01.10.97	m	Hospice Chaplain
F 3	01.10.97	f	Macmillan Home Care Nurse
F 4	01.10.97	f	Hospice Nurse
F 5	01.10.97	m	Volunteer
F 6	01.10.97	f	Secretary
F 7	01.10.97	f	Social Worker
F 8	01.10.97	f	Co-Ordinator

**FOCUS GROUP MEETING
HOSPICE A**

CO-ORDINATOR: SENIOR HOSPICE PHYSICIAN

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
F 1	01.10.97	f	Senior Nurse / Executive Manager
F 2	01.10.97	m	Hospice Chaplain
F 3	01.10.97	f	Macmillan Home Care Nurse
F 4	01.10.97	f	Hospice Nurse
F 5	01.10.97	m	Volunteer
F 6	01.10.97	f	Secretary
F 7	01.10.97	f	Social Worker

FOLLOW-UP STUDY

HOSPICE A

CO-ORDINATOR: SENIOR HOSPICE PHYSICIAN

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
S 1	04.11.97	f	Home Care Sister
S 2	04.11.97	f	Patient/Family Counsellor
S 3	05.11.97	f	Home Care Sister
S 4	05.11.97	f	Consultant in Palliative Medicine
S 5	05.11.97	f	Hospice Nurse
S 6	06.11.97	f	Locum Consultant in Palliative Medicine
S 7	06.11.97	f	Ward Sister
S 8	07.11.97	f	Volunteer Counsellor

FOLLOW-UP STUDY

HOSPICE B

CO-ORDINATOR: HOSPICE PHYSICIAN

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
C 1	11.11.97	f	Senior Staff Nurse
C 2	11.11.97	m	Volunteer
C 3	11.11.97	f	Hospice Physician
C 4	12.11.97	f	Matron
C 5	12.11.97	f	Hospice Administrator

FOLLOW-UP STUDY

HOSPICE C

CO-ORDINATOR: MEDICAL DIRECTOR

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
W 1	18.11.97	m	Volunteer
W 2	18.11.97	f	Home Care Specialist Nurse
W 3	19.11.97	m	Tutor and Lecturer in Palliative Care
W 4	19.11.97	f	Social Worker and Counsellor
W 5	19.11.97	f	Retired Nurse Manager
W 6	20.11.97	f	Home Care Specialist Nurse
W 7	20.11.97	f	Home Care Specialist Nurse

FOLLOW-UP STUDY

HOSPICE D

CO-ORDINATOR: MEDICAL DIRECTOR

CODE OF PARTICIPANT	INTERVIEW DATE	SEX	OCCUPATION
A 1	24.11.97	m	Medical Director
A 2	24.11.97	f	Sister
A 3	25.11.97	f	Hospice Nurse
A 4	25.11.97	f	Counsellor
A 5	26.11.97	f	Hospice Nurse
A 6	27.11.97	f	Sister

General Description of Pilot Study

Aims of the Study

The general purpose of the pilot study is to *generate ideas from the perspectives of the participating care workers* on what issues and topics in palliative and terminal care work are most relevant for further investigation. It is anticipated that a *general* exploration of the experiences of the carers will reveal *specific* aspects well worthwhile to investigate further and in greater depth. The focus of the study is on the individual experiences, attitudes, and thoughts of the carer and not on patients, relatives, organizations, or training aspects of care work. The main focus is on exploring and clarifying the *experience* of working with terminally ill patients and what effect this has on the carer.

Structure and Method

The principal data collection strategy of the pilot study is individual, face-to-face interviews with a number of care workers who volunteered to participate in the study. Each interview will last for about an hour *and will be audiotaped to facilitate analysis. All data collected will be treated confidentially and all participating individuals and organizations will remain anonymous.*

Benefits to Participants

Since the data collected in the pilot study will determine the nature and scope of a major follow-up inquiry, participants will have a direct influence on the overall research design of this inquiry. This means that their voices will be heard, that issues that concern them as individuals and as professionals will be addressed in the study. The outcome thus will be directly relevant to them. The researcher will be happy to submit a written report to the participants and/or give talks which will highlight the results of the study once it is completed.

Standard Ethics Protocol

My name is Peter Stehle. I am doing research on the topic of terminal care practice for a Ph.D. degree in psychotherapy and counselling at the School of Psychotherapy and Counselling, Regent's College, London. My supervisor is Dr. Ernesto Spinelli, Director of the Ph.D. Programme, and he may be contacted at this phone number: 0171-487 7406 should you have any questions.

Thank you for your willingness to participate in this research project. Your participation is very much appreciated. Before we start the interview, I would like to reassure you that as a participant in this project you have several very definite rights:

- First, your participation in this interview is entirely voluntary.**
- You are free to refuse to answer any questions at any time.**
- You are free to withdraw from the interview at any time.**

This interview will be kept strictly confidential and will be available only to Dr. Spinelli and myself.

Excerpts of this interview may be made part of a research report, but under no circumstances will your name or identifying characteristics be included in this report.

I would be grateful if you would sign this form to show that you have read this protocol and agree with its contents.

..... (Signed)

..... (Name Printed)

.....(Date)

Please send me a report on the results of this research project. (Circle one)

Yes

No

Address for those requesting research report:

.....

.....

.....(Postcode)

Contact Letter for Focus Group Interview

**Peter A. Stehle, AdvDipExPsych, M.A., B.A., B.Sc.
Registered Psychotherapist (UKCP)
2, The Clock Tower, Holly Hill, London, NW3 6UD
0171-431 6155**

September 8, 1997

Dear

Thank you for your willingness to participate in a Focus Group Meeting on October 1, 1997 between 2.00 and 4.00 PM at (hospice). I greatly value your participation and am grateful for the contribution you are making to the research I am engaged in.

(Name) kindly pointed out to me that the Summary Report of the pilot study in which you collaborated needed some clarification. I should mention at this point that the report primarily attempted to satisfy academic demands which accounts for the language used and the - at times - somewhat elaborate discussions. It also summarizes the data and analyses of the three papers prededing it of which you did not receive a copy. I think it would be best if I answered any questions you may have about the report in person. I shall be in ... the whole day of October 1, including the evening, and am at your disposal. Please feel free to contact me.

The purpose of our meeting on October 1st is to lay the groundwork for the design of an interview schedule and questions to be asked which will be used in a series of interviews at (hospice) and three other hospices in Great Britain. These interviews will form the basis of my PhD thesis and subsequent publication(s).

The topic (the focus) of our group meeting is *the relationships and communication with patients and families*. The emphasis in the explorations of this topic should be on *personal experience* (i.e. what it is like to relate/communicate with patients and families); the aim is to *share and compare* as many different experiences as possible.

As a way of preparing for the meeting and for focusing the discussions, I suggest that you take a few minutes time before the meeting to note down some thoughts on the questionnaire enclosed with this letter. This will also be helpful to me in the subsequent analysis of the discussion.

Since I shall participate as little as at all possible in the group discussion, one of the members of the group should take over as moderator. I shall ask (name) if she would be willing to do this. If you have any objections to audio taping the discussion, please let me or (name) know before we meet.

Let me emphasize again that I come to (hospice) *to learn from you* and that I greatly appreciate your willingness to participate in this research. I am very much looking forward to meeting you again.

With kind regards,

Peter A. Stehle

Pre-Questionnaire for Focus Group Interview

QUESTIONNAIRE FOCUS GROUP MEETING SWANSEA, OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

Commitment: A strong sense of involvement and long term engagement, a commitment to serve, to participate in a network of caring and reciprocal relationship, a sense of responsibility for the quality of life of patients.

Intimacy: A feeling of attachment and closeness, a concern for the welfare of patients and families, valuing them, sharing of self, giving support, affiliation.

Emotionality: Reacting emotionally, being emotionally involved in the situation of patients and families, experiencing as a consequence strong emotions and affects at times.

Thank-you Letter to Participants of Focus Group Meeting

**Peter A. Stehle, AdvDipExPsych, M.A., B.A., B.Sc.
Registered Psychotherapist (UKCP)
2, The Clock Tower, Holly Hill, London, NW3 6UD
0171-431 6155**

October 13, 1997

Dear

Thank you for participating in the focus group meeting at (hospice) on October 1 and for noting down some thoughts on the questionnaire. The discussion, I believe, threw some light on the complex topic of relationships with patients and families and touched on some issues which may well be worthwhile to investigate further in subsequent interviews.

I greatly valued your contribution! If you have any additional thoughts about the topic which were not covered in the discussion, I appreciate if you would note them down and send them to me in the SAE. I very much enjoyed seeing you again.

With kind regards,

Peter Stehle

Address



**School of
Psychotherapy
and Counselling**

Regent's College
Inner Circle
Regent's Park
London NW1 4NS

Tel: 0171-487 7406
Fax: 0171-487 7406

Dean: Prof. Emmy
van Deurzen-Smith

Date

Dear

Thank you for your interest in my doctoral research on the experience of relating and communicating with patients and their relatives. I value the unique contribution that you can make to my study and I am excited about the possibility of your participation in it.

The research approach I am using is a qualitative (phenomenological) one through which I am seeking comprehensive descriptions of your experience. In this way I hope to illuminate or answer such questions as: "What is the experience like? What dimensions connected with the experience stand out? How does the experience affect the people involved in it?"

Through your participation as a co-researcher, I hope to learn to understand the essence of relating and communicating with patients and their relatives as it reveals itself in your experience. You will be asked to recall specific episodes, situations, or events that you experienced in relating and communicating. I am seeking vivid, accurate, and comprehensive portrayals of what these experiences were like for you: your thoughts, feelings, and behaviours, as well as portrayals of situations, events, and people connected with your experience.

I value your participation and thank you for the commitment of time, energy, and effort. If you have any further questions before signing the enclosed release form or if there is a problem with the date and time of our meeting, I can be reached on 0171-431 6155. The supervisor of this study, Dr. Ernesto Spinelli, the new Dean of the School of Psychotherapy and Counselling, Regent's College, will also be happy to answer any questions you may have about this project. You can reach him on 0171-487 7406.

Please bring a signed copy of the release form with you to our meeting. The second form is for you to keep.

With kind regards,
Yours sincerely,

Peter A. Stehle

Participant Release Agreement

PARTICIPANT RELEASE AGREEMENT

I agree to participate in a research study on *my experience of relating and communicating with patients and their relatives at work*. I understand the purpose and nature of this study and I am participating voluntarily. I grant permission for the data to be used in the process of completing a Ph.D. degree, including a thesis and any other future publication. I agree to meet at on, 1997 at for an interview of one hours. I grant permission to tape-record this interview. The interview will be kept strictly confidential and will be available only to the researcher, his assistant, and the supervisor of the research study. Excerpts of the interview may be made part of the thesis and other publications, but under no circumstances will any names or identifying characteristics be included in these reports.

Name: _____

Occupation: _____

Years in palliative/hospice care work: _____

Date: _____

Signature: _____

Please send me a report on the results of this research study (circle one): Yes No

Thank-you letter to Participants of Follow-up Study

**Peter A. Stehle, AdvDipExPsych., M.A., B.A., B.Sc.
Registered Psychotherapist (UKCP)
2, The Clock Tower, Holly Hill, Hampstead, London NW3 6UD
0171-431 6155**

Name
Address

-
-
-

November 24, 1997

Dear

Thank you for meeting with me and for sharing some of your experiences in the interview. I have enjoyed talking to you.

If any questions should arise during or after transcribing the interview, I would like to write to you again for clarification. Later in 1998, I may also send you a one-page summary of the interview and ask for your comments. If you do not wish to be contacted again, please let me know. Should you have any questions or comments in the meantime, please do not hesitate to contact me.

I have greatly valued your participation in this research and your willingness to share your experience.

With kind regards,
Yours sincerely,

Peter A. Stehle

APPENDIX 2

DOCUMENT 1

Protocol P 1

0001 R I think I probably have to explain a bit more of what
0002 I am trying to do ...
0003 I Ahm, what ...
0004 R I am doing research on the impact working in palliative
0005 care has on the carers. I have looked through some
0006 of the previous research that has been done and I
0007 noticed that it mostly seems to start with an idea or a
0008 concept like stress and then they research it. Well, I
0009 am trying to go first to the people involved in this work
0010 and ask them: Is this worthwhile to investigate, or is it
0011 not worthwhile ... So basically what I like to know from
0012 you ... What comes to your mind working in this field
0013 over the years ... What is interesting for you ...
0014 I Ah, ... you mean as opposed to working in ...
0015 R Yes ... Say, for instance, as opposed to working in a
0016 different part of the hospital ...
0017 I Well, I think basically, it is quite a difficult job in that
0018 you are [...]. If you look at it over a long period of time
0019 - ahm - you are helping people to live with a limited
0020 period of time and then they die. So, that's the end of it.
0021 If you are helping children than you can follow things
0022 through and you can see there is [...]. But people
0023 who are going to die ... that is going to stop and that
0024 happens frequently in the case of a hospice and you're
0025 starting all over again and that's a difficult thing to cope
0026 with. And so there is a stress, an underlying stress all
0027 the time. Which is ... I suppose we all find ways of
0028 coping ... I was talking to my husband last night about
0029 the fact that you were coming today and I think he
0030 feels very strongly that ... hmmm... working in a hospice
0031 is something you should do for a short period of time
0032 ... and
0033 R And to change to something ...

0034 I And then change to something else. Or you should do two
0035 or three years and then have a sabbatical. And I thought
0036 about that and you wonder then how much *you* need to
0037 do the work and how much the work needs you, basically.
0038 Because you think of being motivated and going over to
0039 the other wards for six months, say every three years you
0040 have six months off ... ahm ... what would you do in those
0041 six months to have a complete break from the stress you
0042 work in, in a case like this ... I don't know ... ahm, I
0043 think a lot depends on ... I mean we obviously made
0044 choices coming to work in a place like this and we always
0045 think we get some job satisfaction out of it. But I think
0046 at the same time it does take a lot out of you and because
0047 of the anguish people feel when they are dying ... the feelings
0048 of the family ... ahm ... the feeling that you can't put things
0049 right, basically. I think ... you know, I am a social worker
0050 and I have been in social work since I left school, more
0051 or less, I mean ... that is what I wanted to do and this is
0052 what I've always done ... ahm ... ahm ... You start off by
0053 caring for people ... ahm ... care what happens to them
0054 and you sort of got a list of problems when you meet
0055 somebody and then you set about trying to help with the
0056 problems and basically, I think that somebody who's
0057 doing work with families coping with death very often
0058 listens to [...].
0059 Probably it's just a question of containing the situation
0060 ... ahm ... ahm ... just being there to help people through
0061 it, you know, you can't go in and say: "There is this ...
0062 and this ... and this." And you can't sort it because they
0063 often [...] death is what is going to happen and there is
0064 nothing you can do about it. So, a lot of what you feel
0065 is as caring person ... ahm ... You know there is nothing
0066 you can do basically because you can't help the patients
0067 with what they're really frightened of or dreading. I mean
0068 you could do it to a certain extent, you can help people ...
0069 ahm ... talk about their feelings, you can be with them,
0070 you can look at all the other problems that there are ...
0071 Trying to help with those and basically, I think, that's

0072 what you can concentrate on ... ahm ... so you get
0073 satisfaction out of that ... ahm ...

0074 R [...] I wondered about that ... Because in recent
0075 weeks I have talked to some McMillan nurses who
0076 had done a quantitative study ... These nurses said
0077 that working with terminal patients is regarded
0078 as *both* highly stressful and a significant source
0079 of job satisfaction ... And this is interesting ...

0080 I Yeah, well, I think perhaps, I mean it is stressful and I
0081 know what I've been through in the five years I've
0082 been here ... ahm ... My blood pressure is quite high
0083 ... I'm in the menopause the same time and I know
0084 that this is a problem ... My hair is gotten white (laughs)
0085 ... You know, it is, it is a stressful job ... ahm ...
0086 purely because the nature of the beast, really. But you
0087 feel also you think you are able to do something ...
0088 There is a time when they really need it ... Now,
0089 prior to working here I worked on the council ward
0090 in Singleton and I was there for about ten years. So I
0091 had a lot to do with people who were terminally ill
0092 before I came here. And ... ahm ... what I found
0093 was that a lot of people couldn't relate to somebody
0094 who is dying because of the very fact that they were
0095 dying. It seemed to put a barrier between them and
0096 ... ahm ... That seemed to be the most in their minds.
0097 A common sort of comment you seem to have from
0098 people when you worked in that place ... ahm ... So
0099 somehow you got to feel easy and comfortable about
0100 being with someone who is ... who is ... dying and
0101 being with the family who are in a very ... in a crisis
0102 situation, basically. So that involved over the period
0103 I was in Singleton and so I do feel comfortable how
0104 the people were here ...

0105 R Say, a trainee who goes from the point of being highly
0106 uncomfortable - scared? to the point where they
0107 feel comfortable ...

0108 I I think that again is something you got to work out for
0109 yourself ... ahm ... I think if you got a religious faith

0110 it helps ... ahm ... I don't know whether you are a
0111 religious person ... but ... if you look at the teaching
0112 of Christ ... ahm ... I think one of the main things
0113 that he said was that if you do something for somebody
0114 who's poor or sick that you do it for me ... and very often
0115 we get people who are very difficult to cope with ...
0116 A very difficult situation. I think if you've got that
0117 remark in your mind then it is helpful in coping with
0118 someone ... ahm ... I tend to be a very practical person,
0119 not a great thinker, and intellectual. But I can overlook
0120 my stress and go in and look at what needs to be done
0121 on a practical basis ... ahm ... I think that helps very often
0122 with people who are in this sort of situation ... ahm ...
0123 You know, before you can talk about all the feelings
0124 and what needs to be done you need to sort out the
0125 fact that the electricity has been cut off, because
0126 of nonpayment of a bill, you got to look at the
0127 practical ... at the practical aspects ... and sort those,
0128 I mean if somebody is worried about how they
0129 gonna pay for the kids, the school uniforms, because
0130 they can't work anymore, because they are sick ...
0131 ahm ... something that's got to be tackled and once
0132 you talk ... you talk to people and you get to know
0133 people it doesn't matter whether they are dying or
0134 not because they are people, aren't they? And they
0135 are people with a problem and you try to help
0136 them ... ahm ... that something you got to work
0137 out for yourself ... whether you feel ... ahm ... it
0138 comes with meeting a lot of people in these
0139 circumstances, it comes with ... ahm ... experience,
0140 basically. I think. We have students here from
0141 Swansea University and from Bangor. I usually
0142 have two a year ... ahm ... now they ask to come
0143 here, they are not forced to come here, basically.
0144 There is an interest in working here that ... they
0145 are always frightened of going onto the ward
0146 the first time and meeting people and then you
0147 can see the relief on their face when they come

0148 back and they realize that they are no different
0149 from anybody else. You know there seems to
0150 be this sort of conspiracy around ... what ...
0151 dying people are like, and what hospices are
0152 like ...

0153 R ... Yes ... As you said before ... This sort of barrier
0154 between ...

0155 I Yes, your expectations, really ... ahm ... we are not
0156 founded in anything once you get down to the
0157 nitty gritty of sitting with them ... ahm ... and it
0158 is obviously a great problem for them that they
0159 are dying but life goes on whilst they are dying,
0160 so you just got to cope with that ... ahm ...

0161 I think a lot of the stress ... I'm talking too much
0162 now ... (laughs) ... of the job because of every-
0163 body else's stress levels in a place like this ...

0164 I don't know if you have been in a hospice before
0165 ... that ... ahm ... I think because everybody's
0166 individual feelings ... you know ... and you are
0167 you are soaking this up and ... ahm ... every-
0168 body is feeling the same way ... the intensity
0169 ... of feeling all the time ... which is normal ...

0170 I mean in normal life you have one or two
0171 bereavements and this is a horrible thing to go
0172 through, and you do and go on. But here it's
0173 happening every day ... So, you've got all
0174 this feeling, all this anguish ... and as caring
0175 people ... you know ... that must affect,
0176 mustn't it? So we tend to be quite difficult
0177 with each other (laughs) and I think a lot of
0178 the stress comes out of that, basically ... ahm
0179 ... and you can't do much with it because ...
0180 there is no facility to do that. I mean you just
0181 got to get on with it. And I think what I found
0182 since I've been here is that in turn we are all
0183 made to be the scapegoat and you really got
0184 to be pretty tough to cope with that. Basically,
0185 we are all very sensitive people or we wouldn't

0186 care about other people. So ... ahm ... I think
0187 that's part of the stress ... I put that down to
0188 a lack of communication ... We are busy all
0189 the time ... ahm ... and we don't look at our
0190 own feelings and what needs to be done with
0191 them because we are concentrating too much
0192 on helping the patient ... I think that's a
0193 problem.

0194 R What do you think accounts for this high rate
0195 of job satisfaction? ... The rates are higher for
0196 hospice work than for nurses working in other
0197 wards of the hospital ... working with patients
0198 is rated high in level of job satisfaction ...

0199 I Ah ... I don't know really. It is a difficult fact to
0200 analyze. I think maybe it's the fact that when
0201 you're dying ... ahm ... I think it's quite
0202 accurate to say that 99 percent of the people
0203 know that they are dying ... ahm ... but I
0204 think when people are dying [...] and you
0205 don't see them as they want the world to see
0206 them ... You see them as they are because
0207 there is no need for any pretence anymore ...
0208 ahm ... So it is easier to relate to somebody
0209 when the barriers are down and ... The rela-
0210 tionship that you can build up with somebody
0211 tends to be very strong ... only for a short
0212 period of time ... So, I think as a carer you
0213 are getting a lot back from them because ...
0214 you're going in as a helpful person and they
0215 want the help at that time ... Very often, as a
0216 social worker, if you are going into child abuse
0217 cases or whatever ... you know ... they don't
0218 want to see you ... They don't want to know
0219 you, you know ... They couldn't care less if
0220 they saw you again. So you're going in on a
0221 different footing, when you go see our patients
0222 ... ahm ... they really want your help at that
0223 point. So, obviously, you feel good about that

0224 ... ahm ...
0225 R You're needed ...
0226 I Yes! You're needed ... And you could provide
0227 quite a lot of things that they need ... I mean, I
0228 can personally as a social worker, because I
0229 can do a lot of practical things ... like ... ah ...
0230 get money for them ... and [...] practical things
0231 that they [...]. So it's all good things that are
0232 coming back, and because it's [...] and because
0233 they are dying ... ahm ... There are these
0234 charities that you can tap and get money for
0235 people. And ... So it all keeps flooding in ...
0236 ahm ... People I work with ... are willing to
0237 help me because they know that I am working
0238 with dying people ... So it's not as negative a
0239 job as a social worker, as it would be [...]
0240 you know, soon as you say you're working in
0241 a hospice then you know that the people at
0242 the other end of the phone are sympathetic ...
0243 and they want to help. So ... ahm ... you know
0244 you get satisfaction out of knowing that you
0245 can help at a time when people greatly need
0246 it, basically. And also that the patient and the
0247 patient's family want the help ... ahm ... and
0248 that's nice as far as social work is concerned
0249 (laughs) because very often, you know, I
0250 started out in child care ... Sometimes you
0251 really had to stick your foot in the door to get
0252 in and then it was very difficult to build up a
0253 relationship whereby you could work with the
0254 families and get something positive going ...
0255 you don't have that at all here ... You know that
0256 you go to the door and somebody says: "Go -
0257 bugger off. I don't want to see you ...". They
0258 are very happy to see you, you are part of a
0259 supportive network and ... they feel the
0260 nurses are phantastic they are in there all the
0261 time ... ahm ... They give a 24-hour service.

0262 People don't feel isolated. People can't believe
0263 that there are people who are actually going
0264 to be helpful when they're needed ... They
0265 never had this before. And there is a lot
0266 positive ... ahm ... stuff coming back actually
0267 from the patients and from the families, that's
0268 nice! You know, you get a lot of satisfaction
0269 out of this. So all the shenanigans you get
0270 with colleagues ... ahm ... it's a next morning
0271 irritation if you look at it because you know
0272 what I find is if one patient says to me "Thank
0273 you. I appreciate that," you know, it may not
0274 be every week, just once a month or what-
0275 ever ... but that's enough to keep you going
0276 and so you get the next little pad on the back
0277 which we all need if we do this job. You
0278 don't get that from the directors here or ...
0279 well occasionally from the other staff. But if
0280 you get that from the patient that gives you a
0281 lot of satisfaction. I think if you look at other
0282 types of social work ... ahm ... you haven't
0283 got that feedback, basically ... particularly in
0284 in a hospital ward ... situation ... where it's
0285 crisis ...
0286 R ... There is sort of a special relationship, isn't there?
0287 I I think so ...
0288 R Between the carer and the patient. Is it easier to
0289 establish this relationship for the carer after
0290 the initial uncomfortableness has receded
0291 somewhat?
0292 I Well, I think so, because they come halfway to-
0293 wards you, you know ... A lot got to do with
0294 the Macmillan concept. Everybody sees that
0295 as positive ... ahm ... think within it there seem
0296 to be angels in uniforms, basically. So ... ahm
0297 ... if you look part of them that gives you a
0298 good introduction into people's lives, basically.
0299 ... Ahm ... So you're halfway there before you

0300 started ... It's not difficult ... to build a relation-
0301 ship ... ahm ... here is where ... Did you have
0302 a look around the ward?
0303 R Ah ... no, I did not ...
0304 I People get more nursing care, more individual care,
0305 more attention in the hospice than they get in
0306 an ordinary, general ward ... you know. The
0307 levelling of staff is slightly higher ... ahm ... and
0308 that's a positive thing as well, so it's ... it's ...
0309 you know, the whole package of care is a good
0310 one ... ahm ... and really, I think, if you're told
0311 you've got cancer, it's devastating, you're scared
0312 stiff and then you've got all these people coming
0313 along and say: "Yes, we know about that. We
0314 experienced it before." That, you know, "We
0315 can help you to cope with it." That lifts the burden
0316 from people because they know there is some-
0317 body else who's been through that and may
0318 understand because it's no good to talk to some-
0319 body that you feel does not understand ... ahm
0320 ... [...]. When you look at it, when you follow
0321 it through in your own mind ... You are alone,
0322 aren't you? Nobody can come with you when
0323 you die ... ahm ... it's something you have to do
0324 on your own ... it's very frightening ... it's the
0325 fear of the unknown .. Again if you got a
0326 religious faith then you get some comfort out
0327 it ... ahm ... we've got an excellent Church of
0328 England minister here ... He helps with the
0329 spiritual side of it ... ahm ... So, it's all a
0330 positive thing ... The relationship bit isn't diffi-
0331 cult because they see you as a positive person
0332 before you even walk through the door ...
0333 you know ... The doctors are ok, the nurses
0334 are good ... they are great ... and the last one
0335 to come in is the social worker and ... ahm ...
0336 because it's been a good experience to start
0337 with, it tends to carry on ... so ... from that

0338 point of view it's a nice place to work ...
0339 because you're not having to force yourself
0340 on people but at the same time you have
0341 people in a period when they feel they need
0342 somebody to sit there and look them in the
0343 eye and not frightened that they are dying
0344 ... you know ... That is a very important
0345 thing, I think ... and not be frightened of it ...
0346 R ... It's very interesting what you say ... Especially
0347 about these positive aspects ... They keep
0348 mentioning them in the research ... but they
0349 don't explain them ...
0350 I Well, I think it's difficult to explain ... but ...
0351 [...] you know ... I mean you get married ...
0352 ahm ... So you got a deep relationship with
0353 someone ... have kids ... you have the same
0354 sort of thing ... and things happen ... you
0355 tend to stick by ... whoever it is ... and work
0356 through the problem ... and I think with our
0357 patients ... I mean the worst thing that can
0358 possibly happen to you is happening ... You've
0359 got a disease that not only gonna kill you but
0360 is very painful ... I mean you've got to have a
0361 lot of nasty treatments ... ahm ... and you've
0362 got people that are going to stick by you ... for
0363 a whole lot of time ... that doesn't happen any-
0364 where else ... You know, you go through all
0365 the stages in your life, people come and go,
0366 but on this one, when you are referred here,
0367 then we are with you until you die ... and that
0368 can't be a bad thing ... you know, because we
0369 stick with people ... and that again, I think, is
0370 positive ... which is one thing which I didn't
0371 like in Singleton ... you know in the general
0372 hospital when I worked there ... We obviously
0373 saw people with cancer in the much earlier
0374 stage ... but you do your little bit to help them
0375 ... and you don't know what happens to them

0376 afterwards ... Ahm ... what I like about being
0377 here is ... You are here with them to the end
0378 ... and even afterwards with the family ... ahm
0379 ... We had one case the other day where ...
0380 I don't know ... everything just went in the right
0381 way ... He was a young chap of ... ah ... he
0382 was only 31 and very good looking, pleasant,
0383 intelligent young man ... ahm ... who went
0384 totally bananas when he was told that ... he
0385 had a brain tumor, actually ... that they couldn't
0386 do anything else for him ... ahm ... and we all
0387 worked together as a team with him and his
0388 mum because he couldn't cope on his own ...
0389 We were all with him from the very beginning
0390 ... ahm ... through the fear, the anger ... the
0391 thing it really was fear ... ahm ... He was with
0392 [...] and me and his mum, and he was running
0393 around like a scorched cat and this was
0394 awful to see ... ahm ... but everything was
0395 done calmly and quietly and in its own time ...
0396 and he died about three weeks ago ... You
0397 know, looking back over that period and the
0398 way that we all helped ... it was a good thing
0399 to be part of ... It doesn't always happen like
0400 that ... but if you only get one out of ten, then
0401 you actually feel you're doing something, don't
0402 you? And I think we obviously need to feel that
0403 we are making a mark somewhere, that what
0404 we do does have an effect ... a positive effect
0405 ... ahm ... That's all you can hope for, basically
0406 ...
0407 R ... Sort of a justification ...
0408 I Well, I think so ... you know, you've got two types
0409 of people really ... The ones that go after money,
0410 they make what they got and ... ahm ... I don't
0411 know, but a lot of people get a lot of satisfaction
0412 out of that ... And other poeple who just want
0413 to do something to help ... their fellow human

0414 beings. [...] But I think in a case like this you
0415 can do something that is going to help ... but
0416 what you're left with is the emptiness when the
0417 person dies ... I mean like in the case of the
0418 young man. ... There was a long period of
0419 time ... about a year, I think ... in palliative
0420 care and ... I am going to see his mother on
0421 Friday, actually, and I only spoke to him
0422 shortly before he died ... It was a dreadful
0423 ... I am thinking about my own half with it. I
0424 was absolutely shattered after that ... going to
0425 my car ... I drove over the court and I just
0426 crashed ... I was totally spaced out, really
0427 because it was good for her because the
0428 feeling was good, you know, when I was
0429 coming she often showed pictures when he
0430 was a boy, before all this stuff happened ...
0431 ahm ... She needed to do that, she needed
0432 to talk about him and it was ... ahm ... very
0433 intense but really feel at the end of something
0434 like that ... You, you done something to help
0435 ... You know, because we rush around all
0436 day doing this, doing that a bit and hardly
0437 any of it is of any significance. But that meant
0438 something to her and for just that alone it be
0439 an hour and a half but it is important to some-
0440 body, and that's what I get my satisfaction
0441 out of ... Now, it doesn't always work like
0442 that, you know, you can do your best to help
0443 some people [...] but it is nice to know now
0444 and again it was you who did it and that was
0445 very positive ... I mean that's what I need,
0446 actually.

0447 R ... Yes ... This is interesting ... I've got here a
0448 quote you can take a look at ... from a
0449 recent paper ... and maybe you have some
0450 comments on this ...

0451 I Hmmh ... I think you've got two ... [...] ahm ...

0452 Before you start ... you've got to have your
0453 own idea of what death is ... and what life
0454 is ...
0455 R ... You work it through? Before ...
0456 I Before you're coming to a place like this?
0457 Because ... if you're dealing with something
0458 dying ... ahm ... how can I put this ... to
0459 explain ... Very often people say to you:
0460 "Well, what do you think about death?
0461 What do you think will happen after it?"
0462 I mean they usually say ... well ... ahm ...
0463 "Tell me a little bit more about what you
0464 think" ... I mean I don't come out to report
0465 what I think about things ... But I ... I worked
0466 that out a long time ago ... when I was in
0467 Singleton ... ahm ... Because I've got to have
0468 a good feeling in my mind about what's going
0469 to happen to them ... I mean if I thought life
0470 finishes with death ... that there is nothing
0471 else afterwards ... ahm ... you are holding on
0472 to nothing, really ... I mean what's the point
0473 of making somebody's last few months very
0474 comfortable and then they die and that's it
0475 ... ahm ... And you forget about it ... And
0476 their lives didn't have any meanings ... or ...
0477 aren't part of something that's continuing ...
0478 ahm ...
0479 R ... Part of something greater?
0480 I Well, yes! ... You feel you are part of everything
0481 that's going on ... I've got to feel comfortable
0482 with what I think about death and what I think
0483 happens afterwards ... I think, before I can be
0484 comfortable with somebody else going through
0485 that sort of situation ... if that makes sense ...
0486 R Yes ... it makes sense ... I wonder how many of
0487 the carers do this consciously ... Or does
0488 this happen due to the work, due to the
0489 experience ... automatically, so to speak ...

0490 I Well, I can only speak for myself, basically ...
0491 in that ... I worked it out for myself ... ahm
0492 ... it's something I am comfortable with and
0493 it's ... it's ... you know, I am Welsh ... You
0494 are brought up from being little in the Non-
0495 Conformist Church ... And it's brainwashing
0496 of a sort ... But it's very difficult when the
0497 chips are down (laughs) ... to forget what
0498 you were taught as a little one ... ahm ...
0499 The power of prayer ... I think if you are
0500 seeing somebody ... you know ... there is
0501 nothing else you can do for them ... and
0502 they are in pain ... and they're suffering ...
0503 and what else do you do with your feelings?
0504 You've got to do something for this ... if it
0505 is only prayer ... you know what I mean ...
0506 It's a difficult one I mean, I, you know, I
0507 am interested in religion ... I have a fairly
0508 strong religious faith ... So that gives me a
0509 lot of strength and comfort ... and ... ahm
0510 ... it's there, it's part of me ... it's part of the
0511 [...] I am gone through between the work
0512 I am doing ... ahm ... But yes, I would agree
0513 with that ... You've got to ... You can't just
0514 go horsing in ... Anything and just do it ...
0515 can you? Because people soon know, I
0516 think, I am talking now as a social worker ...
0517 If you're not in [...] you know, they know if
0518 you don't care ... it's ... it's ... it's the feeling
0519 about them ... you know, I am a caring
0520 person ... because you're talking to me, you're
0521 learning about me ... You know, I am not
0522 bullshitting about what I am saying ... ahm
0523 ... and you need to be almost [...] when you
0524 are trying to help somebody ... or you're
0525 not going to help them ... basically ... I don't
0526 think so ... And if you are going to do that
0527 you're in a lot of trouble yourself ... because

0528 ahm ... Well, I found it very difficult to be
 0529 anything I wouldn't ... what I am ... which I
 0530 suppose is a crossover at caring ... But, ah ...
 0531 yes ... But I can't give you my philosophy
 0532 (laughs) ... because I'm not great enough
 0533 (laughs) to do that ...
 0534 R ... It's part of my interest in this research ...
 0535 this personal philosophy ... that carers seem
 0536 to develop ... I imagine it could be part of a
 0537 coping strategy ... having a philosophy to fall
 0538 back on ...
 0539 I It's very difficult to put in words, isn't it? Ahm ...
 0540 I suppose you could do it if you sat down and
 0541 thought about it ... But I know so many
 0542 things about life that ... If you ever take and
 0543 use part of yourself or you disregard as not
 0544 real ... that in time just becomes a part of
 0545 what you live ... your doing ... projecting ...
 0546 ahm ... because you've got a free choice on
 0547 what you wish to become a part of ... ahm
 0548 ...
 0549 R Well, I think, this will be helpful ... What would
 0550 you say ... say as a closing statement ... Say
 0551 you would be doing what I am doing ... what
 0552 would you find interesting to look at ... in
 0553 relation to the work you are doing here ...
 0554 I Ahm I suppose looking at gaps ... in what's
 0555 happening ... in this sort of situation ... ahm
 0556 ... I think we spend so much time actually
 0557 doing the work in care with people that we
 0558 care about ... but we don't do enough caring
 0559 for ourselves or for our colleagues ... People
 0560 that we ... I think there should be some sort
 0561 of support system in this sort of situation ...
 0562 ahm ... whereby it would make me a better
 0563 social worker ... in order to cope with what
 0564 happens here ... and ... to go back to what
 0565 my husband said ... You need to have that

0566 breather because it's such demanding work,
0567 basically, over long periods of time but you
0568 get hooked on it ... Well, you know, when
0569 I thought about ... Well, yes, he said go ...
0570 the [...] for six months and just forget about
0571 it ... I won't forget about it, you know ... If
0572 you're worried about people here ... what
0573 they won't be getting ... the sort of service
0574 I can provide ... I am not saying I am
0575 brilliant or I am better than anybody else ...
0576 But I care about what I do ... and I do the
0577 best I can ... under the circumstances ... ahm
0578 ... yeah, I think, that's basically where ... you
0579 know, when you're looking at how you can
0580 help the carers ... while actually working with
0581 people then there needs to be some sort of ...
0582 And I don't know what the answer is ... I
0583 don't know it you know [...]. But she has
0584 written this book about her time in this
0585 hospice ... But they have the same problems
0586 ... I think they tried a lot of other things ...
0587 Ahm ... from private psychotherapy ... to
0588 group work to this to that and yet all these
0589 little intrigues and nastinesses ... spats ... and
0590 this ... went on ... because of the intensity of
0591 the work that we are doing here ... I just
0592 think if there was some way of helping people
0593 cope with their feelings ... And I don't know
0594 how to do it ... you know where it ...
0595 chucking mud at the wall ... bashing ... it just
0596 ... ahm ... I don't know, I think if research
0597 went that way a little bit ... to find out how
0598 carers can be helped, basically, ahm ... Not
0599 because we're odd people. I am quite sure
0600 none of us are ... ahm ... that because ...
0601 somebody should care for us ... in a way ...
0602 ahm ... enough to say: Yeah, you're carrying
0603 all this around ... all this stress ... all these

0604 feelings ... basically ... and what can we do
0605 with them to make you function better as a
0606 social worker because, really, it's just what
0607 I do as social worker which is important
0608 here ... not what I am as a person ... Does
0609 that make sense?
0610 R Ahm ...
0611 I You're totally confused, aren't you (laughs)?
0612 R Well, yes ...
0613 I (Laughter): It will get worse (laughter) ...
0614 R Well, I want to thank you ... I am sure this will
0615 be helpful.

NOTES

1. Short pauses are indicated by a comma (,), longer pauses by three full stops (...).
2. [...] indicates indecipherable parts on the tape, mostly because either the informant murmured or because of traffic noise.
3. The quote mentioned was typed on an index card and handed over to the informant.
It reads:

"A personal philosophy regarding illness, death, and one's role in caring for dying persons and their families is essential for the mature caregiver in his field. This philosophy may or may not be related to one's religious and/or spiritual beliefs."

Mary L S Vachon: "Staff Stress in Hospice/Palliative Care: A Review," in *Palliative Medicine* 1995; 9: 91-122.

DOCUMENT 2

**Extracted Meaning Units
of Protocol P 1**

DISCRIMINATED MEANING

UNITS [1]

PROTOCOL 1 OF PILOT STUDY 1

ALL CONSTITUENTS PRESENT IN
A'S [2] DESCRIPTION AND
EXPRESSED AS MUCH AS POSSIBLE
IN A'S LANGUAGE

0017-0024

(1) [3] * (As compared to working in a different ward of the hospital) A finds that working in the hospice is a (more) difficult job because looking at it over a long period of time *one is helping people to live with a limited time and then they die. And that is the end of it [4].* Dying is going to stop (it does not continue indeterminately) and so one cannot (as with working with children, for example) *follow things through* (see what happens to them).

0024-0025

(2) (After a patient dies) *one has to start*

**EXPERIENTIAL THEMES AND
ISSUES**

PROTOCOL 1 OF PILOT STUDY 1

CONSTITUENTS OF DESCRIPTION
EXPRESSED MORE DIRECTLY TO
REVEAL POSSIBLE CATEGORIES
OF EXPERIENCING

(1) Building and being in relationships with people who with some certainty only have a short time yet to live. Knowing that in all probability the relationship will end soon but not knowing when this will be; coming to the end and suddenly it is all over;

(2) Having to start and go through the whole

all over again (with another patient)
and this is experienced as difficult to
cope with.

process all over again with another person;
doing this over a long period of time with
many people;

0026-0027

(3) *And so there is a stress, an under-
lying stress all the time.*

(3) Experiencing as a consequence constant
underlying negative emotions;

0028-0042

(4) A's husband feels strongly that one
should work in a hospice for (only)
a short time and then change to
something else; or one should take
a sabbatical from time to time. A
thought about this and wonders *how
much she needs to do the work
and how much the work needs her.*
A also wonders *what she would
have to do to have a complete
break from the stress of the work*
in case she went on a sabbatical.

(4) At the same time wondering whether one
could get out of the situation, even for a short
time, if the opportunity was there; wondering
whether one *needs* to be in the situation,
whether one could *forget about it* if one
left;

0045-0049

(5) A thinks that although coming to work
in a hospice is based on choice and
there is always the expectation of
some job satisfaction, it is still very
stressful because 1. the anguish

(5) Although going to work at hospice is
based on choice and involves the expectation
of job satisfaction, it is still a very stressful
job because the anguish the dying feel, the
feelings of the families, and the caregivers'

people feel when they are dying,
2. the feelings of the family, and 3.
*the feeling that one cannot put
things right* (for the patients and
their families).

feelings that they cannot put things right for
them;

0052-0067

(6) In other social work cases, A starts
off, after meeting a client, by setting
up a list of problems and then helps
the client to solve these problems.
Working with terminal patients, how-
ever, is different: A cannot sort out
the problems *because death is what
is going to happen and there is
nothing that can be done about it,
one cannot help the patients with
what they are really frightened of
or dreading*. Working with terminal
patients becomes *a question of con-
taining the situation, of just being
there to help people through*.

(6) Because death is what is going to happen,
and there is nothing that can be done about
death; one cannot help the dying with what
they are really frightened of; all one can do is
to contain the situation, being there to help
them through;

0067-0088

(7) A gets (job) satisfaction, however,
from the (limited) help that she can
provide: talking with the patients
about their feelings, being with

(7) But still getting some personal satisfaction
from the little things one can do: talking with
the dying about their feelings, being with
them, and sorting out other problems they

them, and trying to sort out all the other problems that are there. A feels that *the satisfaction comes from being able to do something at a time when (the patients and their families) really need the help.*

- (8) Prior to coming to work at the hospice, A worked for then years on a ward at another hospital and had a lot to do with people who were terminally ill. A found that *a lot of people there (staff) could not relate to somebody who was dying because of the very fact that they were dying. It seemed to put a barrier between them and (the patients). And that (barrier) seemed to be most in their minds because it was commonly commented upon.*

0098-0104

- (9) A feels that *somehow one (as a staff member) has got to feel easy and comfortable about being with someone who is dying and being with the family in a crisis situation.*

have; the satisfaction comes from being able to help at a time when help is really needed;

- (8) But not all the caregivers who work with the dying are comfortable with the situation; many cannot relate to the dying *because* they are dying - dying itself becomes a barrier; and this seems to be of great concern to them because they often talk about it;

- (9) But in this work one *has* to feel at ease and comfortable being with the dying and their families;

0105-0109

(10) * (Feeling easy and comfortable about being with somebody who is dying and with their families) *is something each person has to work out for him- or herself.*

(10) And each one of the caregivers has to work out for herself how she achieves this;

0109-0110

(11) This "working out for oneself" is made easier, A thinks, if the person has a *religious faith.*

(11) It becomes easier if one has a religious faith;

0118-0131

(12) As a very practical person, A tends to approach the situation, dying patients and their families are in, *by focusing on the practical aspects that need to be sorted out.*

(12) And if one focuses on the practical aspects of the situation;

0131-0137

(13) When A talks to these people and gets to know them *it does not matter (to A) whether they are dying or not because she experiences them as people (not as terminal patients), and as people who have a problem one can try to help with.*

(13) In any case, when one gets to *know* the dying, it does not really matter whether they are dying or not, because one relates to them as people, and as people who have a problem one can help with;

0137-0140

(14) * (Feeling easy and comfortable about being with somebody who is dying and their families) A thinks, *comes with meeting a lot of people in these circumstances, it comes with experience.*

(14) Being at ease and comfortable with the dying comes with time, with meeting many people who are in this situation, and it comes with the experience of working with them;

0140-0153

(15) University students assigned to A on a voluntary placement in the hospice *are always frightened of going onto the ward the first time* and meeting people. When they come back from the ward, there is relief in their faces *because they have realized that patients are not different from anybody else.* There seem to be, A thinks, *a conspiracy around what dying people are like and what hospices are like.*

(15) Trainees, who just start out in the field, are often frightened to go onto the ward for the first time and meet the dying, and they are relieved when they realize that the dying are not different from the rest of the people; there seems to be a conspiracy around, about what the dying are like;

0155

(16) * (The barrier between the caregivers and the patients and their families) *is the expectation* of the caregivers.

(16) The barrier between the dying and the caregivers who cannot relate to them are the expectations of the latter;

0155-0157

(17) A thinks, that *we are not grounded in anything once we get down to the nitty gritty of sitting with the dying.*

(17) One needs to be grounded in something when one talks to the dying;

0157-0159

(18) A thinks, that *it is a great problem for patients that they are dying but life goes on whilst they are dying and the helper has to cope with that.*

(18) It is a great problem for the dying that life goes on whilst they are dying; this is something the caregiver has to cope with;

0161-0178

(19) A thinks that a lot of the stress the individual staff member experiences working in a hospice is due to *everybody else's stress level there*. All are soaking up what is happening, all have the same feelings. *An intensity of feelings all the time* because in a hospice, unlike the world outside where one or two bereavements in a lifetime is normal, *death happens every day and with it come all the feelings, all the anguish*. This affects the staff *and so they tend to be quite difficult with each other.*

(19) People who work with the dying are exposed to and absorb all that is going on around them, all that is happening there; unlike in the outside world, death is a daily occurrence in their world; and with death comes intense feelings and anguish; all share these feelings and the intensity of these feelings and they tend, therefore, to be quite difficult with each other;

0179-0181

(20) A thinks, that there is not much that the staff can do with the stress *because there are no facilities to do so*. They just have to get on with it.

(20) And there is nothing one can do with these feelings, with the stress one experiences, because there are not facilities available where it can be worked through; so one just has to get on with ones work;

0181-0187

(21) Since coming to the hospice A found that *in turn each staff member is made to be the scapegoat* and that one has to be pretty tough to cope with that and that this is also part of the stress. The reason for this *is a lack of communication* (between staff members).

(21) And so, each one in turn, is blamed for what is happening, is made into a scapegoat, and one has to cope with that; and this adds to the stress one experiences;

0188-1093

(22) A thinks that one of the problems is that members of staff *concentrate too much on helping the patient, being busy all the time*, and that they do not take time *to look at their own feelings and what needs to be done with them*.

(22) The reason that this happens is due to a lack of communication, one concentrates so much on helping the dying, on being busy all the time, that one does not take the time to look at ones own feelings and what needs to be done with them;

0199-0212

(23) * (A thinks that the high rate of job satisfaction reported by staff working with terminal patients) may be due to the fact *that it is easier to relate to someone who's condition does away with the need for any pretence*, that the barriers are down, and that this relationship, although limited to a short period of time (because of their condition), *tends to be very strong*.

(23) It is not difficult to relate to someone who is dying because the dying have no need for any pretence, and although such a relationship is only of short duration, it tends to be very strong;

0201-0203

(24) A thinks it is quite accurate to say that *99 percent of the people know that they are dying*.

(24) And 99 percent of the dying know that they are dying;

0203-0206

(25) Members of staff *see the dying as they are, they do not see them as they (the patients) want the world to see them*.

(25) And working with them, one sees them *as they are*, not as they want the world to see them;

0212-0224

(26) *Caregivers get a lot back from terminal patients because they really want their help at that point (in their lives) and this makes the caregivers feel good. A contrasts this (work) relationship with*

(26) It is a satisfying and rewarding experience to work with the dying and their families because they are eager to see the caregiver, want to get to know her, and are glad when she comes again;

working on child abuse cases where the parties involved *do not want to see the social worker, do not want to know him or her, and could not care less if they see him or her again.*

0226-0232

(27) * (A feels *needed* by her patients) and she can provide a lot of practical things, like money, for instance, for them. *So it is all good things that are coming back (to the patients), it all keeps flooding in.*

(27) One feels *needed*, and one *can* do things for them, there is a flow of good things towards them;

0236-0243

(28) *Outside agencies, like charities, are (more) willing to help because they know they are dealing with someone who is working with the dying.*

(28) Even outside agencies, like charities, are more willing to help when they know they are helping someone who works with the dying;

0244-0246

(29) *A gets satisfaction out of knowing that she can help at a time when people really need it.*

(29) And it is a very positive experience to help at a time when help is really needed;

0249-0265

(30) In contrast to social work in child

(30) And the dying and their families cannot

care where it was very difficult to build up a relationship through which one could work with the families and get something positive going, *patients and their families are happy to see A* because she is part of a supportive network that gives a 24-hour service and *they cannot believe that there are people who are actually going to be helpful when they are needed. They never had this before.*

believe that there are people who are willing to help whenever help is needed, 24-hours a day; they never have experienced anything like this before;

0265-0285

(31) There is a lot of positive feedback from patients and their families and when one patient says to A once in a while: "Thank you, I appreciate that" it is enough to keep her going until the next pad on the back. *There is a lot of satisfaction in that for A and she does not get this from the directors of the hospice and only occasionally from the other staff.*

(31) Their gratitude for the help they receive is what keeps one going and what makes the work satisfying; one does not get this sort of appreciation from one's superiors and only occasionally from colleagues;

0286-0301

(32) * (A thinks that there is a special relationship between the caregiver and the patient and that this relationship is easier to establish

(32) It is easier to establish a relationship with the dying if one feels comfortable and at ease with them because in that case they

after the caregiver has overcome his or her initial uncomfortableness) *because (the patients) come halfway toward the caregiver then*. A thinks this has a lot to do with the *Macmillan concept, if one looks part of them*, it gives one a good introduction into people's lives and one is halfway there before one starts. *It is not difficult to establish a relationship (under these circumstances)*.

come halfway toward one; it also helps if one is part of a recognized team, like the Macmillan nurses;

0301-0310

(33) (As compared to a general ward of the hospital) patients get more *nursing care, more individual care, more attention* in the hospice because (for one thing) the levelling of staff is slightly higher. *And this is a positive thing*.

(33) The positive aspects of hospice care are that the patient gets more *nursing care, more individual care, and more attention* than in a general ward;

0310-0319

(34) A thinks if people are told they got cancer, they are devastated, scared stiff, and then all the (hospice) people come along and say: "Yes, we know about that. We can help you cope with it. We experienced it before" *and that this lifts the burden from people be-*

(34) People who are diagnosed as having cancer feel devastated and frightened and it is, therefore, a relief to them when they meet someone who has experience with cancer, and who can help them cope because she has helped others and may understand, therefore, how they feel;

cause they know there is somebody else who's been through that and may understand (their feelings).

0318-0319

(35) (When you are in that situation) *it is no good to talk to somebody that you feel does not understand.*

(35) Because it does not help to talk to somebody who one feels does not understand;

0321-0325

(36) (In this situation) *you are alone. Nobody can come with you when you die. It is something you have to do on your own. It is very frightening. It is the fear of the unknown.*

(36) Because one is alone, nobody can come with one when one dies, one has to do it on one's own, and it is very frightening, one fears the unknown;

0325-0327

(37) *Again, if you got a religious faith, then you get some comfort out of it.*

(37) And it helps if one has a religious faith one can draw comfort from;

0330-0337

(38) The relationship (with these patients) is not difficult for A *because she feels she is seen as a positive person before she even walks through the door.* The doctors are ok, the nurses are great, and the last one to come is the social worker and *because it has been a good experience*

(38) The dying perceive caregivers as positive people, if their experience with them has been positive in the beginning, it tend to continue to be positive;

(for the patient) to start with, it tends to carry on.

0340-3045

(39) *(The patients) are in a period when they feel they need somebody to sit there and look them in the eye and not be frightened (about) that they are dying. Not to be frightened of it is very important.*

(39) They are in a situation where they need a person to sit by them, look them into the eyes, and not be frightened that they are dying; it is very important for them that this person is not frightened;

0346-0367

(40) * *(The positive aspects of working in a hospice) are difficult to explain for A, but for the patients (that come there) the worst thing that can possibly happen to them is happening. They have a disease that is not only going to kill them but is very painful (because of the treatments). And the people (of the hospice) are going to stick by the patients, for a whole lot of time. And this does not happen anywhere else. In all other stages of life, people come and go, but on this one, they are with them (the patients) until they die. And this is perceived as positive by A.*

(40) They are aware that the worst thing that can possibly happen to them *is* happening, that they have an illness that may be fatal and that is painful at the same time, but they know that there are people who will not leave them, who will be with them until they die;

0370-0378

(41) While working on a general ward in another hospital with patients with cancer in a much earlier stage, A did not like *that she did not know what happened to her patients after she did her part of helping them*. What she likes about working in the hospice is that *she is with her patients to the end, and even afterwards with the family*.

(41) One likes to know what happened to people after one has done one's part of helping them, one likes to be with them to the end, and support their families afterwards;

0379-0399

(42) A recalls a case (of dying) *where everything just went in the right way*. The patient was a 31-year-old man, very good looking, pleasant, intelligent, who had a brain tumour. The patient was told (by the doctors) that they could not do anything else for him. The patient was very upset and could not cope on his own, so (the staff of the hospice) worked together as a team with him and his mother. (The staff) was with him from the very beginning (of referral), through the fear and anger, until he died. Everything was done calmly and quietly and in its own time (by the staff). *A feels that it was a*

(42) There are deaths where everything goes the right way, where everything is gone through in a calm and quiet manner, in a supportive team, and one feels good to be part of it because one feels that one actually is doing something worthwhile; but not all death are like this;

good thing to be part of. But it does not always happen like that, (yet) if it is only one in ten (like this) A feels that she is actually doing something.

0402-0405

(43) *We obviously need to feel that we are making a mark somewhere, that what we do does have an effect, a positive effect. (And) that is all we can hope for, basically.*

(43) It is important that one feels that one is making a mark somewhere, that what one does has effect, has a positive effect, for that is all one can hope for;

0408-0414

(44) A thinks there are two types of people (basically): The ones who go after money and (seem to) get a lot of satisfaction out of it and the ones *who just want to do something to help their fellow human beings.*

(44) Caregivers are basically oriented to helping their fellow human beings;

0414-0417

(45) But even if you can do something to help (a patient), *what you are left with is the emptiness when the person dies.*

(45) But when a patient dies, all that remains is a feeling of emptiness;

0417-0434

(46) (Referring back to the case of the

(46) And the time shortly before a patient dies

young man with brain tumour who died) A recalls that she spoke to him shortly before he died and that it was *dreadful* for her, that she was *absolutely shattered* (after he died), that she went to her car, drove over the court, and *just crashed*, that she was *totally spaced out*, that it was *very intense what she felt at the end of something like that*.

0435-0437

(47) *We rush around all day doing this, doing that a bit and hardly any of it is of any significance.*

0438-0443

(48) That it meant something (to the mother of the young man who died), that it was important for her that A took the time (and listened to her and look at the pictures) *is what A gets her satisfaction out of.*

0443-0446

(49) *It is nice to know now and again it was you who did it and that was very positive. I mean that's what I*

can be very harrowing for the caregiver, involving intense emotions;

(47) While normally one tends to run around all day, doing this and doing that, and hardly any of it has any significance;

(48) One gets real satisfaction from doing something that is of value to someone else;

(49) And one needs to feel that what one does is important and means something to another person;

need, actually.

0451-0467

(50) * (A was handed a quotation from a recent paper on palliative medicine and asked to comment on it). A commented that *before one starts* (on a job like this) *one should have one's own idea(s) of what death is, and life (worked out)* because one may be asked by the patients and/or their families what one's position is in regard to death and dying. And that A worked it out (for herself) a long time ago when she worked at the other hospital.

(50) Caregivers need to work out their stance toward dying and death before getting involved in hospice work because they may be asked by patients and their families what their position is on these matters;

0467-0472

(51) A had to work it out for herself *because she has got to have a good feeling in her mind about what is going to happen to (the dying patients)*. If she thought life ends with death, that there is nothing afterwards, *she would have nothing to hold on to.*

(51) One should work out ones position in regard to dying and death because one needs a positive attitude in regard to what happens after a patient dies; if one thinks life ends with death, one would have nothing to hold onto;

0472-0475

(52) *What is the point of making some-*

(52) For what would be the point of making

*body's last few months very comfortable and then they die and that is it.
And you forget about it.*

0476-0477

(53) *And their lives did not have any meaning or are not part of something that is continuing.*

0479-0481

(54) ** (Part of something greater) part of everything that (continues) going on.*

0481-0485

(55) *I have got to feel comfortable with what I think about death and what I think happens afterwards before I can be comfortable with somebody else going through this sort of situation.*

0486-0498

(56) ** (Asked about the process of working out one's position in regard to dying and death) A referred to her upbringing in the non-conformist*

someone's last few months very comfortable and then they die and that is it;

(53) If life ends with death, and you can forget about a person after he died, there is no meaning to his life, it is not part of something that continues;

(54) Part of something greater, part of something that continues after death;

(55) One has to feel comfortable with what one thinks about death and about what happens after death, before one can feel comfortable with someone who is dying;

(56) The process of working out one's position in regard to dying and death may be influenced by one's religious upbringing, and although one may not think much of it, it is

(name) church and although she considers it *brainwashing of a sort*, it is very difficult (for her) when the chips are down to forget what (she) was taught as a child.

0499-0503

(57) For A, the *power of prayer* helps (even if it is *only* prayer) when she sees (a patient) for whom nothing else can be done and they are in pain and they suffer. *What else would she do with her feelings?*

0507-0508

(58) A gets a lot of strength and comfort out of her fairly strong religious faith.

0512-0518

(59) * (A agrees that the caregiver needs a personal philosophy regarding illness and death) because one cannot just go horsing in and do things. People soon know, and they know if one does not care.

very hard in critical situations to forget what one was taught as a child;

(57) One may use prayer as a way of coping with one's feelings when one deals with patients for whom nothing can be done anymore and who are in pain and suffer;

(58) One can draw a lot of strength and comfort out of one's religious faith;

(59) Caregivers need to develop a personal philosophy in regard to illness and death because they cannot enter such a situation heedlessly, the people involved will soon recognize it and they also recognize if one does not care;

0519-0526

(60) *(If you are not (a real) and caring person and when the patients do not perceive you as such) when you are trying to help them, you are not going to help them.*

(60) Caregivers must be authentic and caring people, and they must be perceived as such, otherwise the help they provide is not going to help the dying and their families;

0526-0529

(61) *And if you are going to do that, you are in a lot of trouble yourself.*
A finds it very difficult (for her) *to be anything (other) than what she is.*

(61) And if they are heedless, and not authentic and caring, they are in a lot of trouble themselves;

0541-0547

(62) *One has a choice of what one wishes to become part of and (whatever) part of oneself one takes and uses (or disregards as not real) it will in time become part of what one lives and does.*

(62) Everyone has a choice of what they want to become a part of, as they have a choice of what part of themselves they want to use and develop, or reject as inauthentic, and whatever is chosen becomes part of that person's life and action

0549-0559

(63) * (Asked about what she would investigate if she would do research in the field of palliative care) A suggests *looking at the gaps of what is happening: The gap between spending so much time (and effort) caring for*

(63) One should investigate the discrepancy of caregivers spending so much time and effort on caring for their patients and so little on caring for themselves or their colleagues;

the patients and *not enough* (time and effort on) *caring for themselves and their colleagues.*

0560-0564

(64) There should be some sort of *support system* (in palliative care), in order to cope with what is happening, *whereby the caregiver would become a better caregiver.*

0565-0567

(65) The caregivers should have *a break* because (looking at it) over a long period of time, the work is very demanding.

0568-0577

(66) *But you get hooked on it.* A thinks that even if she took six months off, *she would not forget about it, she would be worried about (the patients in the hospice).* What they will not be getting, the sort of service she can provide.

0579-0581

(67) *Looking at how one could help the caregiver* while actually working with

(64) There should be a support system which helps caregivers to cope with the effects of their work, so they can become better caregivers;

(65) Caregivers should have regular breaks because over time the work becomes very stressful;

(66) But one becomes addicted to the work, so even with a break one may not be able to forget about one's patients, be worried about that they are getting the best care;

(67) To investigate how one could help the caregiver with the actual work of caring for

(the patients).

the patients;

0585-0591

(68) (A lot of things are tried in (other) hospices, from private psychotherapy to group work) *and yet all these little intrigues, nastinesses, spats, went on because of the intensity of the work.*

(68) Because the intensity of feeling engendered by this work leads to little intrigues, nastinesses, and spats among colleagues;

0592-0593

(69) *Helping (the caregivers) cope with their feelings and how it can be done.*

(69) To investigate how these feelings could be worked through;

0597-0606

(70) *Find out how caregivers can be helped because somebody should care for them and say (to them): Yeah, you are carrying all this around, all this stress, all these feelings, what can we do with them to make you function better as a caregiver.*

(70) So they can function better as caregivers.

NOTES

- [1] *Discriminated meaning units* (also called *significant statement*) is a term adopted from Giorgi's phenomenological research procedure as outlined in Giorgi, A. (ed). (1985). *Phenomenology and Psychological Research*. Pittsburgh, PA: Duquesne University Press.
- [2] 'A' is the first letter of informant P1's Christian name.
- [3] * indicates that the response is prompted by a question rather than being entirely spontaneous.
- [4] Print in *italics* indicates what is considered the core statements of the particular *discriminated meaning unit*.

DOCUMENT 3

Themes - Issues - Impact Lists

EXPERIENTIAL THEMES

ISSUES FOR THE CAREGIVERS

IMPACT ON CARE GIVERS' LIFE-WORLD

1. Entering the field of palliative care;

There may be an initial reluctance to come to work in a hospice but after one starts, there is a strong inclination to continue;

Working in a hospice setting is a very different experience because the common occurrence of death / And as a caregiver one has to learn new things and may feel "a new boy" still after years of working here, although, because of one's profession, one may be considered to be an expert on dying and death which in itself may be disconcerting, and even disturbing;

2. Spiritual concerns and needs of the dying and their families;

Spiritual concerns impinge on patients and their families in this situation and the main one is the search for meaning: the big question of "Why?" / Many patients after coming to the hospice develop spiritual needs and turn to spiritual thoughts and many talk about these issues, although they have not been concerned about them for many years;

Caregivers may be asked questions like: "Why should this happen?" "Why should it happen this way?" "Why should it happen at this time?" "Why should it happen to him?" "Relatives ask these questions much more often than the patients, and although no one can answer those questions, one can deal with them in other ways: Through hope and through gaining peace, although being at peace can at any time be shattered by the pressing question: "What is going to happen to me?"

3. Caregivers involvement with the spiritual concerns and needs of the dying and their families;

Caregivers *are* dealing with spiritual issues in their work in the hospice and it is not known whether they are prepared for this and how they react to questions regarding these issues / As

Caregivers *do* get asked many questions about spiritual matters because they are in close physical contact with the patients due to the nature of their tasks and they tend to

EXPERIENTIAL THEMES

ISSUES FOR THE CAREGIVERS

IMPACT ON CARE GIVERS' LIFE-WORLD

far as the patients are concerned, they may find it very difficult to satisfy their spiritual needs when they enter this stage of their lives, if they do not have a spiritual background in their past;

identify with patients, especially with young patients and young, married patients with families because they themselves are mostly young and the spiritual work caregivers do involves sharing the grief of relatives and the patients who are bereaved as soon as they know that the patient's illness is considered terminal;

4. Spirituality in palliative care settings;

If one is present, is fully open to what is happening in these settings, one can experience something spiritual from all the people there: The volunteers, the staff, visitors, relatives, and patients, and it is *unbelievable* what one can pick up from them;

Working in such a setting is therefore a very enriching experience and one always questions oneself about remaining there: Whether it is because one can help or because the experience is so enriching; but one tends to spend more and more time there because one is in contact with the important things in life and has the opportunity to show love / And one is deeply touched by the immense gratitude patients and their families express for doing even small and trifling things for them;

5. Stress in palliative care settings;

The amount of stress staff experience who work in such a setting depends largely on their personal circumstances: If they have troubles at home, the work stress

If caregivers have many problems in their personal lives, working in such a setting may not help them but if they have worked through their problems and have got over them, they

EXPERIENTIAL THEMES

ISSUES FOR THE CAREGIVERS

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	simply adds to them;	may be stronger as before and grateful for the opportunity to help others;
6. The emotional climate in palliative care settings;	Caregivers coming to work in such a setting are utterly amazed by the emotional climate in such settings: the laughing, the teasing, the lightness, the joy colleagues feel in working there;	And very quickly, the anxiety they felt about coming to work there withers away;
7. Personal qualities of caregivers working in palliative care;	What a person <i>is</i> , is important, for whatever one <i>says</i> is likely to be forgotten, it only carries conviction if the person is in herself the right sort of person;	The right sort of person is geared into life, loves and shows love; and this kind of person has the greatest effect and is of the most help in working in such a setting, and some of the caregivers being attracted to this work already possess some of these characteristics, they are compassionate and loving people who go out to the patients and who have a desire to serve, they often say: "I've been so lucky in my life, been given so much, that I feel I have to give something back."
8. Palliative care work as a way to come to terms with dying and death;	Palliative care settings receive a lot of applications for volunteer work from people who have recently been bereaved;	But they are told to come back in twelve months time if they still feel the same way. Sometimes they come back, sometimes they do not. It is important that people do not come to work at such a setting in order to work out their

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9. Personal changes in caregivers due to working in palliative care;

Working in such a setting changes people;

own problems in regard to dying and death or to find comfort;

Caregivers become more aware of the feelings of others, more aware of the temporary nature of life, of the frailty of life, it encourages them to sort out their values: Things that have been very important for them before coming to work in such a setting tend to fall into the background / But even after years it may still be hard to come to work because one is never actually prepared for what is happening here / Caregivers become aware of their own vulnerability and it is common among them to think that any new ache or pain may be a symptom that they have cancer;

10. Caregivers own stance in regard to dying and death;

Caregivers may be asked all kinds of questions about suffering, dying, death, and life after death by patients and their families and they have to be prepared to answer them;

And this requires that caregivers know where they are standing in regard to this and it is a spiritual stand but everyone has a spiritual side to their nature;

11. The effect the death of others has on the caregivers;

If a patient dies who has contributed a great deal to other patients and the staff, caregivers are very upset and feel very deflated, even if they know that the patient was going to die / If they have a death in their

But it also prepares caregivers for the time when a death occurs in their own family, they are much better prepared but only if they can see death coming, one is never prepared for a sudden death /

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	<p>own family, it is very hard for them to come back to work because the deaths of patients remind them of their own relative and it brings back memories of their own experience;</p>	<p>But even being better prepared to face death, does not make it less painful;</p>
<p>12. Coping with the death of others / working in palliative care;</p>	<p>Caregivers should share their feelings with their colleagues, no one is letting anyone down by doing so / And they should not feel that they have to consider working in palliative care for the rest of their lives, that they led down anyone if they leave;</p>	<p>For it is, after all, a job, caregivers who stay on for a long time enjoy their work and feel rewarded but it may be more than just a job for them because there seems to be a great deal of happiness amongst those who stay / It may be the proximity and intimacy with each other that makes the work so rewarding;</p>
<p>13. Caregivers' interactions with patients;</p>	<p>Caregivers are encouraged to sit and talk with patients, to take the time to do so;</p>	<p>Some patients are very popular with the caregivers while others are less outgoing and do not want to talk, some patients do not want to be touched, others assign a great importance to touching, holding and embracing and caregivers do not always realize which patient wants to be touched and which ones do not;</p>
<p>14. Caregivers' interactions with the dying and their families in crises situations</p>	<p>In moments of crises there is a strong urge for caregivers to <i>do</i> something although there may be nothing to do in this situation, or not very much;</p>	<p>This is a very exposed position for caregivers to be in and it is still important that they just <i>be</i> there even if nothing can be done / Patients and relatives sometimes</p>

**EXPERIENTIAL
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become angry in this
situation and turn on the
caregivers who have to
absorb the anger.

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IMPACT ON CARE GIVERS' LIFE-WORLD

1. The death of patients;

Working in a hospice is working in a high-stress environment because the occurrence of death / The main issue for caregivers is to cope with the death of patients to whom they have become attached;

Caregivers *inevitably* become attached to patients because they have been with them for a prolonged time and/or because the patient is quite young / especially if there is a rapid deterioration and death comes fast;

2. The coping mechanisms which enable caregivers to come to terms with the death of patients;

How do caregivers *actually* cope with the deaths of patients;

Caregivers *do* generally cope but they may not necessarily know *how* they do it;

3. The most commonly used coping strategy in palliative care, and possibly the most effective

is a great deal of mutual support among caregivers / it also helps to limit the time spend at work, especially with doctors / and to have a break from time to time;

Seeking support at home, a commonly used strategy in the beginning of working in palliative care, is reduced over time because caregivers find that it creates extra stress if they take their problem home;

4. Counselling and psychotherapy as an aid to coping;

Counselling and psychotherapy are rated highly by caregivers but are rarely used because they demand an extra investment of time;

Caregivers usually work long hours and are not inclined to spend more of their own time on matters related to work / Also there is the deeply felt perception that people who have not actually done care giving work in palliative care would not necessarily be the best to counsel caregivers actually involved in this work;

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5. The discrepancy between the expectations and perceptions of caregivers and what they can actually do for their patients

is the greatest source of stress for the caregivers / When expectations and perceptions are in line with what actually happens there is no stress at all;

When patients die more quickly than caregivers perceive them to, there is the tendency to do something for them, to treat them, and this may make their death more uncomfortable than it should be/ The caregivers are unprepared when death comes and that causes a great deal of stress;

6. The feeling that more should be done for patients, that more should be provided than is actually provided;

To take into consideration alternative approaches / other avenues or modalities of treatment should be investigated;

Because caregivers continue to wonder whether they are actually doing the best that they could be doing for the patients, and this uncertainty is to some extent a source of conflict and stress;

7. Becoming attached to patients versus distancing oneself;

In general, medical caregivers can remain detached from patients, adopt a cold, clinical attitude but in palliative care one cannot distance oneself from patients; if caregivers allow themselves to be detached, the quality of the care they give suffers;

Caregivers see patients as people, not as patients; they *feel* with *people* who face a catastrophic loss and caregivers have to be soft and warm with them, otherwise they are not fulfilling the people's needs;

8. The role of spirituality in palliative care;

The division between spirituality and religion in the field of palliative medicine;

Caregivers want to bring patients to arrive at a point of peace but many people live without any thought of dying and they are not prepared when suddenly confronted with death / And although people *do* have the ability to see and deeply know that they are never really secure in life, they do not think hard enough about

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what it means to them personally / The spiritual side may consist in finding peace, to be able to put things right that need to be put right, to achieve a sense of purpose in life, of what it is all about and what dying is all about;

The surfacing of spiritual issues and concerns in the last phase of life;

Most people seem to only have an impetus to find spiritual peace when they are forced to do so, in other times, life is too busy, there are so many other things to be concerned about;

Working in a hospice setting, caregivers are constantly confronted with dying and death;

They either have to come to terms with death in an active way or they have to push it aside; it is not possible to stay in a sort of limbo situation in this regard / Caregivers somehow have to develop a philosophy of death, they almost automatically think of life and death as something spiritual when working in this setting, and many feel their job is a calling;

EXPERIENTIAL THEMES

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9. The development of a personal philosophy in regard to illness, dying, and death

is essential for the caregivers, otherwise they cannot cope with the experiences they make working in palliative care, or they loose themselves; a personal philosophy is essential, not so much for the patient's benefit but for the caregivers' own survival in the field;

It would be fascinating to know how caregivers *actually* develop such a personal philosophy, as they *do* develop it, and it is put to the test in the setting they work in and it is marginally modified in the light of their work experiences, as well as being grounded and made more secure;

10. Within the field of palliative care, the perception of caregivers who have a clear spiritual, even religious, standpoint is quite high;

It may well be that caregivers who have some sort of considered philosophy of living and dying are more attracted to the field, while those who do not, feel uncomfortable;

Caregivers may find a philosophy that does not extent beyond death is unfulfilling in the sort of work they do in this setting; if one does not believe there is something more, one could find this work insufferably depressing;

11. The conflict between the desire of sharing one's personal philosophy with patients and their absolute right to personal liberty;

Personal philosophies held with conviction quite naturally lead to a desire to propagate them, but patients have to be allowed their own space, allowed to live according to their own rules;

It is difficult for caregivers who hold a strong conviction when patients exercise their absolute right to enter upon the process of dying without any conviction of what they may need to do or of what is going to await them / Patients should have the opportunity to prepare themselves but caregivers are hesitant to impinge upon patients with their own personal philosophy because it is unethical for caregivers to talk to patients who are

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vulnerable at this time,
about their own
philosophy / That one
is putting unacceptable
or unwarranted, uninvited
pressure on patients / Yet
caregivers want the
patients to find a sense of
fulfilment which some of
them (in the eyes of the
caregivers) are clearly
lacking / This situation
creates a basic conflict
and a definite source of
stress.

EXPERIENTIAL THEMES

1. Caregivers entering the field of palliative care;

2. Qualities needed to work in this field;

3. The attraction working in a hospice setting has for the caregivers;

4. The effects working in a hospice setting has on caregivers;

ISSUES FOR THE CAREGIVERS

It may be quite accidentally but there is a strong tendency to continue working in the field even beyond time limits set by oneself;

It is not possible to predict whether someone new to the field will be happy here and stay on / they have to learn to cope with new experiences, and the only way to do this is to share these experiences with more experienced members of staff, to feel part of a team, and this takes time;

It is a relaxed and non-rigid environment, it is not a dark, quiet, subdued place, as public perception sees it, but a place where patients are laughing, enjoying themselves, living their lives;

Working in this field is not just a job, caregivers would not work in this field if they felt that way, working here becomes part of one's life, and one ends up spending more time here than at home / working here can teach one to *live* one's life / members of staff become like a big family;

IMPACT ON CARE GIVERS' LIFE-WORLD

One is attracted by the work and wants to continue doing it, it is the job *itself* that attracts, not career prospects or plans;

What helps one in this work as a caregiver is to be nonjudgemental, open, and to have the ability to get close to other people;

Caregivers are allowed to become closely involved with patients and their families, they become *friends* with them, whereas in other wards of the hospital they are advised to keep a distance;

Working in this field changes a person, one tends to become more quiet, or laid back, worry less about money, become less materialistic / family and friends become more important / one focuses more on the present, makes fewer long-term plans for the future / one becomes less critical of other people, looks differently at relationships, becomes more relaxed and worries less about

EXPERIENTIAL THEMES

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IMPACT ON CARE GIVERS' LIFE-WORLD

5. Working in palliative care as a way of preparing for death within one's own family;

Working in this field does not help if faced with death within one's own family, but it *does* help one to understand what is going on, processes which are not going right, but death in one's own family is a totally new experience regardless of how often one may have experienced it at work;

trivial things / caregivers who work in this field have different attitudes than other people because of the things they see here, they want to get on and live and enjoy their lives;

The caregiver cannot get into a professional mode in this case, but she can help the other members of the family through her knowledge of the processes involved;

6. The experience of stress in working in palliative care;

The public perception, even of the medical profession not working in palliative care, is that working in this field is very stressful;

Yet caregivers generally do not find it very stressful because they usually get more out of the job than they put into it / every job is stressful and the real question is what to do with the stress, to find an outlet, to treat oneself to something, and not add additional stress by engaging in stressful leisure pursuits;

7. The experience of time by caregivers;

One becomes acutely aware of *time* working in this field, of how fast it goes, and of how fast it runs out;

For women working here, if a relationship breaks up, they tend to come to terms with the break-up very quickly, otherwise they feel that they would be wasting time / time passes too quickly, one does not

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8. The fear of death;

Caregivers working in this field are not afraid of death or of the dying process because the suffering can be controlled, and the patients can be made comfortable;

realize how fast it is going, and so many people waste it;

A great deal of the fear by medical staff *not* working in palliative care is due to witnessing patients die badly / it is not death per se that is frightening but pain and inadequately treated pain / what is *really* frightening is to be kept alive by machines or medication, patients in these situations are distressed because their life has been taken away and yet they are still alive / there is a vast difference between just living, existing, and life.

9. Characteristics of patients in hospice care;

Patients are more aware of their rights, they are more demanding, and they fight for themselves, they are much better informed than they used to be and doctors actually listen to them;

Partly responsible for the increased knowledge of patients is the extensive media exposure and coverage of such malignant diseases as AIDS and cancer, and information about new drugs and treatments, and that many people *do* get cured of cancer;

10. Influence of patients on caregivers;

Patients are *living* their lives whereas many healthy people do not / they do not *experience* their illness as terminal, they are not resigned but in a fighting mood, they are much more authentic, open, they talk about their feelings, their fears;

The caregiver basically gets more from the patients than she or he gives, patients teach the caregivers about life and death, working in the field changes the caregivers perception of their own lives, what is important and what is less important;

EXPERIENTIAL THEMES

11. Distancing oneself versus getting close to patients;

12. The effect dying and the death of patients has on the caregivers;

ISSUES FOR THE CAREGIVERS

To work effectively in this field, caregivers have to get involved with people, get close to them, allow them to come into their space;

Each patient is different, and the prospect of death affects each patient differently;

IMPACT ON CARE GIVERS' LIFE-WORLD

It is easy to distance oneself and one is taught to keep a distance when training for general nursing, never to sit on the bed and talk to patients, address them by their surnames as they would address one as "nurse" or "nurse so-and-so", and this creates a distance between patients and caregivers;

Caregivers are affected more by some patients than by others / patients, the caregivers cannot get close to, are difficult to nurse and caregivers tend to feel useless and frustrated / caregivers starting in the field tend to think that if an elderly person dies it is ok because their life is completed but they find that they can be just as upset when an elderly person dies as with a young person, especially if they remind one of one's father or grandfather / whereas with young patients, caregivers tend to detach themselves from them ever so slightly, they treat them differently, as equals, and although they talk more about things, it is more difficult to get close to them / but when a patient dies it is a shock for the caregiver and many younger staff members

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13. Suggested areas
where research may be
of benefit to caregivers;

I) The difference in the
perception of dying by
nurses and doctors, that
patients are dying much
quicker than doctors seem
to realize;

II) The difference in the
perception of dying by
female and male doctors;

III) That there are no male
volunteers working on the
ward sites, that they do
not like to become in-
volved in palliative care;

cannot deal with these
experiences, one is
absolutely devastated
because one feels that a
part of oneself is gone;

With experience, nurses
can fairly accurately predict
when a patient is going to
die, and they generally
recognize four to six hours
earlier than doctors when a
patient enters the terminal
phase;

Patients prefer to be
looked after by women
because there is so much
physical contact, holding
patients, cuddling them and
being cuddled back by
them, holding hands, and
so on.

EXPERIENTIAL THEMES	ISSUES FOR THE CAREGIVERS	IMPACT ON CARE GIVERS' LIFE-WORLD
1. The nature of the caregivers' relationship with the dying;	Building, sustaining, ending such relationships;	Constant, underlying stress / strong commitment to stay in the situation and help as much as possible / feeling the impossibility of <i>really</i> putting things right, but getting personal satisfaction through the limited help one can give;
2. The nature of caregivers' relationship with the families of the dying;	Dealing with families in crises, being involved in the issues faced by the families;	as above;
3. Dying as a barrier: the inability of caregivers to form a relationship with the dying <i>because</i> they are dying;	Strong concern and unease about this / feeling one <i>should</i> feel comfortable and at ease in the situation;	Attempts at resolution: working it through by oneself / feel supported by a religious faith / focus on the practical aspects / adapt to it by repeatedly going through the same situation;
4. Getting to know the dying;	Perceiving them primarily not as dying people but as people who have a problem one can help with / perceiving them to be not different from other people;	Relating to them not as dying but as people who have a problem / focusing on the problems;
5. The relationship with the dying as a source of job-satisfaction;	The ease of relating to the dying because of the absence of any pretence on their part;	Being in relationships which are - although short - highly intense and very strong;
6. Working with the dying and their families as a satisfying and rewarding experience;	Help is greatly appreciated and the caregivers are highly valued by the dying and their families;	One feels one is needed / it is a positive experience to help / outside agencies are sympathetic and co-operative;

EXPERIENTIAL THEMES

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IMPACT ON CARE GIVERS' LIFE-WORLD

7. The gratitude of the dying and their families for the help they receive;

Is a powerful reward for the caregivers / it is what keeps them going and what makes the work satisfying;

Caregivers do not get this appreciation from their superiors and only occasionally from their colleagues;

8. Working in a setting where death or multiple deaths is a daily occurrence;

Being exposed to and having to absorb the intense feelings and anguish death generates / being in a highly intense and emotional environment;

Interpersonal problems with colleagues / communication problems / blaming others / feelings of increased stress / having no time or place to work these feelings through / having to just get on with one's work;

9. Being diagnosed as having cancer / being aware that the worst that can possibly happen *is* happening / that the disease may be fatal and at the same time very painful;

A feeling of devastation, fright, and utter aloneness / a feeling of relief to meet caregivers who have experience with the illness, who will help them to cope, who will not leave them;

The need for a caregiver to sit by them, to look them in the eyes and not be frightened that they are dying;

10. Deaths where everything goes the right way;

Where everything is gone through in a calm and quiet manner, within a supportive team;

Caregivers feel good to be part of such a team, going through such an experience, they feel they are doing something worthwhile;

11. Caregivers' attitudes to death and dying;

Needs to be worked through before getting involved in hospice work / may be influenced by one's religious upbringing;

Caregivers may be asked by the dying and their families what their position is in regard to this matter / caregivers need to have a positive attitude in regard to dying, death, and what happens afterwards /

EXPERIENTIAL THEMES

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IMPACT ON CARE GIVERS' LIFE-WORLD

12. Basic values of caregivers;

It is important to make a mark somewhere / to have a positive effect / to do something of significance: something that is important and means something to another person;

Caregivers need to be comfortable with what they think about death and what happens after death before they can feel comfortable with someone who is dying;

A basic orientation to helping others / getting satisfaction from doing something that is of value to someone else, even though the time before death can be harrowing for the caregiver and all that remains after death is a feeling of emptiness;

13. Caregivers' personal philosophy in regard to death and dying;

A personal philosophy is needed because one cannot enter a situation of terminal illness heedlessly and without concern / caregivers need to be authentic and caring people;

The dying and their families soon realize one's stance, and they recognize if one does not care / caregivers must be perceived as authentic and caring people otherwise the help they provide is not going to help and they can damage themselves;

14. The development of a personal philosophy;

Everyone has a choice of what they want to become a part of, what part of themselves they want to use and develop, or reject as inauthentic;

And whatever is chosen becomes part of that person's life and action;

15. If life ends with death and there is no afterwards;

What is the point of making someone's last few months very comfortable / one can forget about a person after he or she dies / they are not part of something that continues;

There is no meaning to a life / there is nothing one can hold onto;

EXPERIENTIAL THEMES

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16. The role of religious faith for caregivers;

Influenced by one's religious upbringing / one can draw a lot of strength and comfort out of one's religious faith;

It is hard to forget in critical situations what one was taught as a child / one can use prayer as a way of coping with one's feelings;

17. Suggested areas where research may be of benefit for caregivers;

I) The discrepancy between the amount of time and effort spent on caring for patients and the time and effort spent in caring for themselves and caring for their colleagues;

I - IV: to function better as caregivers;

II) The development of a support system to cope with the adverse effects of working in palliative care;

III) To investigate how one could help the caregivers with the actual work of caring for the patients;

IV) To investigate how the intense feelings generated by the work in terminal care may be worked through;

APPENDIX 3

**Pre-Questionnaires for
Focus-Group Interviews**

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Sympathy: Helplessness Hope.
Empathy Inadequacy. Anger.
Egotism. → Humility Fear. (of parent when child was dying)
Guilt

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

W Families unwilling for patient to know Δ
Impossible expectations "I want to see my parents holding hands" when they had had a strong relationship all their lives!
Anger.
Where children, parents, patient have been at different stages in accepting illness causing resentment between them
W Openness, family unit being close & supportive
Faith

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

Commitment: A strong sense of involvement and long term engagement, a commitment to serve, to participate in a network of caring and reciprocal relationship, a sense of responsibility for the quality of life of patients.

Intimacy: A feeling of attachment and closeness, a concern for the welfare of patients and families, valuing them, sharing of self, giving support, affiliation.

Emotionality: Reacting emotionally, being emotionally involved in the situation of patients and families, experiencing as a consequence strong emotions and affects at times.

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Empathy
understanding of one's situation
Time - making sure there is ample time
for patient/family

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

Trying to communicate with patients and families
the way that I would like to be spoken
to - with warmth and understanding. Making
sure there is plenty of time.

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

Commitment: A strong sense of involvement and long term engagement, a commitment to serve, to participate in a network of caring and reciprocal relationship, a sense of responsibility for the quality of life of patients.

Intimacy: A feeling of attachment and closeness, a concern for the welfare of patients and families, valuing them, sharing of self, giving support, affiliation.

Emotionality: Reacting emotionally, being emotionally involved in the situation of patients and families, experiencing as a consequence strong emotions and affects at times.

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Worry
Uncertainty of future
Gratitude (for care)
GRATITUDE

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

Easier
Background of TLC
and compassion

Harder
In Unit environment,
which can be busy and
full of distraction, it can
sometimes feel to pts.
and relatives as though
it were an uncaring
environment.

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

Commitment at all levels v. evident

Intimacy in small subgroups of pt-careers quickly develops

Emotionality inevitable but can sometimes be distressing for carers.

Needed: all encouragement and support for multidisciplinary team working.

Commitment: A strong sense of involvement and long term engagement, a commitment to serve, to participate in a network of caring and reciprocal relationship, a sense of responsibility for the quality of life of patients.

Intimacy: A feeling of attachment and closeness, a concern for the welfare of patients and families, valuing them, sharing of self, giving support, affiliation.

Emotionality: Reacting emotionally, being emotionally involved in the situation of patients and families, experiencing as a consequence strong emotions and affects at times.

QUESTIONNAIRE
FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

What you say should be in words that the patient / family can understand

Change your attitude to match the situation you are going in to

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

The situation you find yourself in when you are trying to communicate

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

- 1 When you think about your experiences of relating communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*)

PRIVACY.

CONFIDENCE

HONESTY

KNOWLEDGE OF PATIENT IN FULL.

AWARENESS OF FAMILY DYNAMICS

? Ascertaining patient's/families awareness of diagnosis and prognosis

- 2 What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

Hard - Sudden unexpected questioning about dying especially when the family was asked that the patient does not know

Dealing with young dying patients and their families

Easier - Discussing diagnosis and prognosis when patients are fully aware of their disease
Having full knowledge of the patient

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Frightening (especially initially)

A sense of responsibility

A desire to help.

A feeling of uncertainty / helplessness ~~some times~~ often

A sense of warmth, pleasure & trust when the relationship is going well

A fear of being overwhelmed

A sense of loss when a patient dies. Sometimes relief.

Intense closeness & intimacy when patients share their feelings & fears

They are all important

2. What kind of things have made relating/communicating with patients and families

either easier for you or harder for you?

- Patients referred by other people e.g. GPs. REFERRAL?
- Patients not being told the truth.
- Patients that are denying the truth. Confusion within families.
- Issues of confidentiality around working in a team -
- A cancer patient may be seen by 20-30 professionals during the course of the illness. What issues should one discuss within a team meeting?
- Physical issues - loss of hearing / speech.
- An open family situation where the illness & its implications are discussed openly.
- A patient that is accepting and open, even when the outlook is very poor. Self internal.

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Some people are suspicious of Clergy, only an open friendliness can break this down.

The need to appear confident

"Being there."

Touch.

The importance of a basic smiling happiness (fun).

Being unafraid of silences

Costly in time, effort, attention, emotionally, even intellectually. Can be very living!

2. What kind of things have made relating/communicating with patients and families

(E) (H)
either easier for you or harder for you?

- E. The support of other staff.
- E. The recognition that religion has something to say in a dying situation.
- E. A shared vulnerability.
- E. A confident Faith.
- H. Heavy Learning
- H. Deafness!
- H. Personal inadequacies - Shyness, impatience etc
- H. R.

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

It is hard to balance one commitment with another. A need for priorities.

We tend to avoid too deep an intimacy for fear of hurting people (or ourselves!) when relationships have to end after a death. We cannot go on & on piling up more & more intimate relationships. Nevertheless, intimacy is important as an expression of self-giving. It can arise unbidden & needs to be balanced with a degree of detachment.

Emotionality arises very largely unbidden. It is important it should be expressed, & people appreciate a degree of shared emotion. But too much emotion robs people of ~~the~~ the

(P. 2.0)

The strength & support they look
for from us.

We can be afraid of emotionality in
such a way as to make us run away
from the situations which produce it.

QUESTIONNAIRE

FOCUS GROUP MEETING

OCTOBER 1, 1997

1. When you think about your experiences of relating/communicating with patients and families, what comes to mind? (Simply note down some words or phrases and underline the ones you consider *important*).

Empathy - Listening
- Open mindedness - Caring
Non judgmental attitude - Sharing
Goin' the extra mile
Acceptance
"There but for the grace of God" - - - - -
In every face I see the face of Christ

2. What kind of things have made relating/communicating with patients and families either easier for you or harder for you?

Easier - my need to help people - my ability to sort out problems based on years of experience

Harder - going through personal grief - very emotional
Having personal problems makes the [unclear] stressful

3. The analyses of the interviews of the pilot study in which you participated suggested that there are three aspects which appear to be typical of caregivers' experiences of relating with patients and families: commitment, intimacy, and emotionality (see page 3 for a general description of these terms).

Do you have any comments on these aspects?

Does your experience suggest any others?

Transcript of Focus-Group Interview

Transcript of Focus-Group Interview

Moderator: A Senior Hospice Physician (M)

Group Members:

F1 (Senior Nurse/Executive Manager)

F2 (Hospice Chaplain)

F3 (Macmillan Home Care Nurse)

F4 (Hospice Nurse)

F5 (Male Volunteer)

F6 (Hospice Secretary)

F7 (Social Worker)

M = You have received some questions. This is really about your experiences in relating to patients, things which are rather important to you. Maybe, if we could start, possibly looking at the first question. "When you think about your experiences of relating/communicating with patients and families. What comes to mind?"

F4: From being on the ward, (one) not always got the privacy to actually discuss what the patient wants to discuss ... quite often the patient will ask, not always at appropriate times, ... when we give out lunches, and the patient (is) with other patients, relatives of the patient, (or) other members of staff actually in the room.

M: From feeling the experience, how is that for you?

F4: It makes you feel a bit uncomfortable because you want to be honest with patients and their relatives, you don't want to back away, but you are aware that the other people are hearing what you are saying, trying not to listen, but hearing what you say, and (you are) quite torn between opening up to the patient and actually backing off a little bit at the same time.

F2: It is especially difficult if someone is a bit deaf, and you get deafness, of course

F1: Patients are probably aware of the situation and what you (can do). Because, I think, when you actually are a patient, I think, if somebody does draw your curtains around you, it does what we say it does, it really gives the illusion of a bit of privacy ... the feelings (of patients and families) (are) probably totally different to actually what the staff's are.

F4: It's very difficult, I mean, ... you cannot move them out of the situation they are in when they are asking, because you could easily lose them ... you sort of have to make the best of it with the situation because they have asked in an open forum.

M: What actually happened in your situation?

F4: ... just have to cry ... I just have to turn off the conversation ... actually I crash ... we were there, you know, were there for her. I think, she wanted to make a statement and leave it at that but wanted somebody to be with her, not walk away.

Other participants: Yesses.

F3: You know I have been in situations where the patients were asking a lot of questions, we try and make it as private the conversation ...

M: There's the initial privacy and then stopping

F3: Yeah, knowing what we went through, continue, and now [we are not allowed] to stop them and trying to know what we are doing in the patient's best interest.

Other participants: Yesses.

F2: She's also mentioned one other thing. It seems to me which is important and that is touch, other than clinical touch, ahem, arm around, you know, taking a hand or whatever.

M: So changing a method of communicating.

F2: Yes, really, that is body language.

F3: I think that you change the way that you deal with people (when you) actually go into particular people's homes, and the type of home you go into, and what you were doing, ... the words that you use in one home probably would be totally different ... because you probably make a judgement of, I mean, what patient and family would understand

M: So you have to assess the situation on its merit or whatever, you have to make some sort of assessment.

F3: And it isn't just the words that you use either, the whole attitude ... can change according to the whole

situation. Some families, some homes will treat you very much in a different ... and take you out of the profession as a sort of matter of fact of what they want you to, what they want you to know and what they want to know from you. You can't always behave in that way in some other homes where they sort of embrace you as a friend take you in as a member of the family and treat you in quite a different way. I think it's much easier sometimes to be in the professional role rather than be taken in as a member of the family, which happens

M: So there are some difficulties you sense if you become a friend rather than a professional person in forming the relationship you want?

F3: I think, it's probably more difficult to be objective ...

M: Which one gives you more satisfaction, which type of situation?

F3: I think, probably the ones where you are treated very much as the professional

Several participants all talk together

M: Gives you more satisfaction?

Several participants: Oh no! Oh no!

F3: It's easier.

Several participants: Yeah, yeah

M: In what way easier then?

F3: What you deal with, whatever problem it is they present you with, and then, fairly often you feel as though it's actually the cut-off-point. You then (do) what they want of you, and you leave.

M: Do you think also, the more emotionally involved you get, the more hurt you are if something bad happens, so you try to protect yourself from that as well?

Several participants: Oh yes, oh yes.

F3: And each time it happens, you get back (to the ward) and do it again.

F2: It's interesting because I find that in my professional role I have to do my best because people's conception of a clergyman of course is like that, and I find that I have to in some sense encourage them to be a bit unprofessional ... to try and ... a bit of a friendliness and because as they can't get anywhere near them. And that's just the difference of people's conception of ... of a [post].

M: ... is the question of trust, isn't it.

Other participants: Yessess, hmmhs.

F6: ... a nurse on the unit, wears the uniform so although you are the nurse, you are also a person outside nursing; whereas you go in to someone dressed as you are. So they don't instantly think you are a nurse, do they? So, the situation is quite different there. Ahem, and I think that's different with families. They take you in as a person, although you are this professional person they initially see you as someone dressed in ordinary clothes; whereas a nurse on the unit ... she is, you know, what she wears. When the rest of us wear ordinary clothes we mingle in with the patients and relatives, especially now in day-care. If someone new came in they wouldn't know who was who.

Other participants: Yesses.

M: If we mingled in with the patients. So that's quite interesting.

F7: But I think people come along with a lot of prejudices as well, don't they? Because, you know, they see nurses as being helpful people. You don't always see social workers as being helpful. And they don't always see ministers as being helpful, so sometimes you've got to get over that ... before you do anything to help them. Hopefully you are accepted by them.

F1: It's part of trust, isn't it? And it doesn't always come straight away. I shouldn't think so anyway.

F7: No I mean, sometimes you face a lot of aggression and unhappiness

F1: Yes, and ... the advantage that we've got ...

F7: Yes, because you can go in and (*two people speaking together*) be recognized very, very quickly. And the things that we don't do, don't ... anyway ... long-term, ... there's a difference. But I am sure, you know, the whole prejudices come up because the name of the unit (hospice) ... Tuesday night when I was trying to persuade a lady to (accept) help ... and she said: "Where are the nurses coming from?" and I said: "(name of hospice)", she said: "Oh, no, no, no." she said. So I said, where would you accept them from? And she was quite willing to accept them from (a hospital) but she did not want them from (the hospice).

M: Because - did she - could you expand on that?

F7: Because, it's ... about the place and when they come into that place, then there is no hope. And. So then you come round, you know, with examples from people who've been in this place for five years, and they are still with us. But it's almost as if you are talking in vain because that's what they

(Several participants talking together)

F1: ... they all know somebody, you know, partner, cousin, ... nurse.

M: Can I ... at all, even though [people] are aware of diagnosis and the implications possibly of diagnosis, even the prognosis

F1: I think that maybe that happens more ... with the family than it does even with the patients, because I think it's the patient that has got major problems ... nobody else is managing, doing anything about. I think that patients get to the point that they don't care where it comes from but as long as you can do something. But I think, you know, relatives have got this view, and I think it's probably due to the fact that up to this time (they managed) (but now) they have to accept that (the hospice) needs to be involved. They can perhaps say to themselves, maybe it's not as bad, maybe the diagnosis isn't right, maybe my relative is going to get over it. But I think once they have to take on board (the hospice), I think they've also got to start taking on board the fact that, you know, this relative is ill, and this relative in the end is going to, you know, die.

F2: You know, the interesting, an interesting thing to me about that conversation that you had, an eighty-four-year old woman, right, eighty-four, had been into hospital before, but it was too painful to think of coming to a place like this, at eighty-four, when you think that the thought of mortality would have beaten around her head a long time, you know, a long time before that, and she would've worked out some way of coping with the fact that she was going to die some day.

F7: I don't think it's actually possible, I mean, ... I think if people have been well, I don't think they see themselves as being as they are, whether it's seventy, eighty, or ninety

F2: Or maybe that something (this hospice) does.

F7: It's always something in the future, isn't it?

(Several participants together)

M: Did you finally tell her that you were from this hospice? How did she react to that?

F7: You know her anyway, I mean

M: Yes, yes

F7: She wasn't very happy ...

F2: We get people coming in here who are terrified of looking around and I find that they gradually relax as they find people laughing and (families) together ... I do think it's important, you know, sort of normal happy surroundings, bright and colourful, and a lot of laughter, not too much, but plenty of it around. I think that that is really what helps.

F7: Yeah, I think that helps the patient but I don't think it helps the relatives. You know, they've got somebody that they love dearly who is dying and they do hear a lot of laughter and ...

F2: That depends

F7: is really quite upsetting.

F4: I also think that the relatives are far more aware of what's going on in other parts of the unit, you know,

they see the other patients equally ... as their own loved ones. It comes across quite a lot when you are actually with a patient and the relatives are there, if the patient wants answers they want them now. Not when you've finished seeing the bloke who is in the corner, they ... and I think they find it quite distressing to actually you know, realize, that you can't, drop, just drop everything and go there, whereas they could at home. They are their solely thought, you know, their loved one, they get twenty-four-hour ... they get more ... they [can] cope. And it comes to a stage that for whatever reason they need to come in, even if it is actually for a short time. Ahem, you know, they feel it's a time for them to take a step back, have a breather - though we are not there solely for that one particular person. Ahem, and [in effect] ... the conversation, when they want to know what's happening, and ... coming home soon, they just want you totally to focus on, you know, that particular relative and, and know every intimate detail about - we don't try when you've got a lot of ill patients, you try to know as much as you can about everyone of them. But they want, they just want you to be one-to-one - and they get frustrated, they get frustrated because you've got all the others whereas they think at home, when the home-care sisters come in, they've got the answers, ... you know

F7: Hopefully.

F4: Yeah, hopefully.

(laughter)

F6: You often, you know, you have patients who have two weeks [to live] and the person they want to speak to primarily is the home cancer staff. Not the whole staff. But they specifically ask for you know the main home care sister because they feel at home it's one-to-one.

(Several participants speaking together.)

F7: ... the patients and the relatives.

F6: And I think that the, you know, its the relatives [to fight it] because when they actually come in visiting and they ... see several people at the time, every time they come in because nobody will or ... I mean the patients to [too] because they, you know, when you're with them you are with them and nobody else, and, I think they appreciate, they also appreciate the time that they're on

their own because at home they probably were [alone] less for any length of time. They are on their own, no ... So they appreciate the time ...

F3: The interesting thing is that ... there are patients, somebody who spent alone a lot of time in home care and also spent a lot of time in the unit. And I think she felt: "I feel as if I am the only one who is ill", regardless that the staff of the unit ...

(Several participants speaking together)

F6: It's giving me such a feeling of security and I mean now that, when, that was the part, I mean she, you know there, I think felt much much more secure when she was in because there were always, you know, staff ... than she actually died in [the home] ...

F3: And she had been ...

F6: She had been, yeah.

F1: But I think this is why relatives get frustrated as well. Because they have given so much at home and perhaps don't feel appreciated by their loved one, because they, they come in, they ... up, ... sleep ... and they, they get a feeling of failure; that comes across when patients come along. Ahem ...

M: What they feel

F1: They feel they've, have let their loved one down, because they haven't been able to do that at home when they were giving them 24-hour-care. And yet, we change shifts, we end up with [them] every minute of those shifts because of the other patients. But they, you know; I often feel that the patients when they come in because they're so desperately ill have been putting on brave faces for their relatives [and] the visitors coming in. And when they come in they can relax and the true illness comes through and it threatens the relatives because the reaction we get: "He was all right at home until he came in here and look at him now." And, you know, they, they put in their fear and their anger really because they don't want to lose their loved one ... and it's just, it's it does take time and it takes patience to, you know, let them think they want to stay and then try to, try to explain that, you know, that it's not because they've come through the doors of the hospice that their condition is

the way it is; that they can actually let go of their illness and, you know, not trying to be smiling, be happy, not complain of pain, be ... then, you know, ...to see them for five minutes ... or a lot longer. They don't have to do that when they're in hospital, they can let ... what they're actually experiencing. And I think that the family do find that difficult.

M: Yeah, it seems that you've got to form different relationships with totally different members of the family, patient and family

Several participants: Yeah, yeah.

F2: I think I'd [like to] come back to this fear of the hospice. I don't, I mean I think in order for people to be quite ... to accept the hospice, you'd have to change people's view about death and [you know] dying. You would have to have people who were, you know, were accepting, "yes, that I am ill", you know death is going to be the end of all of us. And yet, to to maybe actually happen to them ..., but I don't know that you do that because, I mean, ... I think it's very few patients who probably come to an absolute acceptance that they are, you know, dying. And, I mean people sort of know that they are going to, you know, die, but [around] that, it's not something that here, it's something that is at a distance from them. And you, I don't know, do you, people more accepting with within ... you know, that they are going to die ... now?

F7: I don't think they are any more accepting than ... [we/me] in talking so to speak with me than they are with the staff -

"Hmhmh" by several participants

F2: Very often it's the staff who will tell me of problems that someone has, you know, I mean ... But I find that the really difficult people are the relatives. The deep questions which patients sometimes ask, like "Why?" "Why should this happen to me?" "What have I done to deserve this?" Those are the sort of questions which come my way, ahem, but to be honest they come much more from the relatives than from the patients. I do get ... from the patients. But it's interesting that, you know, people's reactions coming here, I suppose it's all different and [so] the relatives probably feel very guilty in the first place that their relatives have to come here ... and they

feel they should be looking after them at home and what I say to them is: "Nobody can go on doing what you've been doing indefinitely day after day after day; that's why they have shifts here and that they ... to some extent. The other thing that I find interesting is that sometimes I will go to a patient and particularly when they've just been visited and somebody is gone out to get a ... and they are coming back later and I [don't know why] 'cause I am a bit foolish but I do, but I ask them sometimes "Do you feel lonely?" And it is amazing how many people will tell you their immediate reaction is "That's right. Dreadfully lonely." And they just had their nearest and dearest there - how, I don't know what the answer to that is.

M: Have you asked them why they feel lonely?

F2: Well, yes, you do ask them why but very often they don't know.

M: No. Hmmh.

F6: Do you think coming to the hospice makes them face up to having a cancer ... You can fool yourself when you are outside of the hospice but as soon as they come in, that's the reality sets in "... I've got this awful cancer and I am going to die". And I think the hospice perhaps represents that making them face up to their diagnosis perhaps a bit more than they would do if they were outside of the hospice, I don't know. I mean I am not a nurse but I think that's one thing that I would, I would think that, you know, I would ask myself if I, if someone referred me to the hospice. I mean you can fool yourself otherwise, I think ... [the unit] you do not say it's cancer, perhaps but the actual, hospice is a hospice for cancer patients. And I do wonder what, you know, it's their state of mind when they come in it changes, I don't know.

F7: I think it's ... really to the difficulty the doctors have in explaining to patients how ill they are, at whatever point they're diagnosed. Ahem, and it is a difficult thing to do, it is that they ... There should be some easier way of facilitating that

M: So that breaking bad news

F7: Yes. Basically because you know, everybody puts it onto somebody else in the case of this [illness] woman

because she is a good example. She was on Ward 2 in single ... and instead of the sister on my ward or one of the oncologists or one of the nurses saying: "We are going to refer you to the hospice" because, I mean, this case it is terminal; she was told "Oh a nurse will call you and see you when you get home" and left in a, left like that. But what did happen was that one of the registrars on the ward, ahem, was responsible to inform the GP, and then it [was] left to the GP to go out and say: "Well you know, we think perhaps the hospice is is a good ... in this case if we refer to them. So, it's just been pushed down the line all the time and this women isn't really to know about it because the GP in this case isn't interested -

F4: (whispered) My God.

M: So that's for the [state] he is, compared to you -

F7: Well, I mean, you know, I am the friend and ... somebody who knows the ins and outs

M: But it effected on your relationship, didn't it?

R: Of course, ... it effected a lot of things. But, you know, things [aren't importantly], so ahem, it's it's very very difficult-

Other participants: Yesses.

M: Are you suggesting

F7: [I don't know] I mean how many people there are who are going to get to a point with it, to a point, where they really are desperately ill before they're brought in. And they go through a lot of suffering where they need [loud coughing] If somebody had the courage to sit them down in the first place and treat them responsibly and intelligently - Because you know this sort of illness can happen to anybody at any time and, ahem, you can't run away from it, it got to be accepted. So if somebody was sort of telling as gently as possible that, ahem, this is the situation you're in at the moment and this is the help you can get -

M: So a lack of communication down the line, ahem, makes your work more difficult and your relationship with patients if if they had, if they had the honest truth before

F7: I think so, but it's the way that they are told ... because I mean we get people with the screaming horrors, don't we when the doctor's gone in, in an open ward, and said: "Oh we've had your results back, it's cancer", ahem, and then walks out! And just leaves them sitting there thinking, well, have I a day or a fortnight, ahem, and everybody else is saying they didn't [... look] and you know they[ve heard what was said]. And you know what do you do with that? You can't discuss it because the doctor finds it too difficult, is gone, ahem, the family are very angry because they weren't there, because the doctor would have found it twice as difficult if he had somebody watching him saying that. I mean ... the poor families, such a mess, basically.

F4: But quite often I think it's left to the doctor that's actually left, to tell the patient ... met the patient once or twice, so there is no kind of relationship, there is no why - is this patient reacting in this way ... people ahem, you know, quite often find that they say: "They didn't even look me in the eye when they told me."

F7: And very often it's a junior doctor

F4: Yeah, and, you know, they have so little to do with these, you know, the poor patient is there ...

F7: But if they haven't got that sort of intelligence from, you know, from their own background and their own experience of life. Surely it should be part of the training earlier of course, for doctors. You know, why do they come into hos- into medicine? Do they come in because they just see, you know, a lot of symptoms over there that they want to sort of get rid off to make that person whole, or do they see that person as a person, who is not just a lot of symptoms but somebody who has got feelings, thoughts, intelligence, and

F2: I think, I think a lot of it is because they take care so much that they, they don't want to hurt and by giving information like that they are hurting themselves and the patient possibly

M: So how do you get round that?

F2: I think the sad thing of ... is that ... I think most hospices have now been going quite a long time and I mean an awful lot have been spoken about, in breaking

... news and, you know, sort of education has been aimed at, but I mean my guess is that, I mean, probably, I mean people on the ordinary sort of wards are only marginally better at it than they actually were I don't know, twenty, twenty-five years ago, I mean - You know, you don't have to tell the patient, you can get the patient to tell you. It's the way you sit down and talk to them and see what they're thinking and what they are frightened about and in a hospice they are intelligent, ...cancer ward that hasn't responded to any of the treatments likely to be something very nasty, isn't it. Ahem, you know, you can get things out of people by talking to them in a certain way and get them to tell you. So you as the doctor as much [anything] they tell you what's wrong with them by the way you're questioning them.

F4: I don't think the time is actually spent with the patient, it's I mean, I, you know, way things are on the ward. I mean I don't think they are creating the sort of working situation where it, it encourages people to be able to, you know, sit and actually listen to the patients, because everybody is so busy haring around from A to B to C ahem, and of course, it's the patients in the end that suffer.

F7: And it's getting worse

Several participants talking together

F4: Worse, yeah, it's not getting any better

M: If you have to break bad news, I mean how does that effect your relationship with the patients, sometimes the family, or both, or. I think in a ward situation and not ... they are coming here

F4: They fear the worst, the worst thing is gonna happen when, you know, when they're actually admitted, and, and usually [about] when we have to tell somebody, that, you know their loved one has actually died, is actually about ... being ... for it. If it gets, it becomes a ... you know, after a while, but after a while you just accept it. The relatives they say it's really ... and and it's the actual way you get used to that reaction, so it ... when somebody is absolutely devastated in some, in some [patients]. You know, obviously we do get unexpected deaths and that's really, hits you, hits you for six, ahem, the fea- you can feel the fear or not wanting

to see that relative ahem to explain what has happened because I think you learn to expect an ... process and it's, you know, ...have to step back. Then you feel as if you're out of control ahem, it is difficult to actually explain to a relative ahem what has happened because quite often if it's a sudden death you don't know ... your second guess at what has happened, ahem, the laughing that I would, you know, want to discuss it [was so ...]. Every relative is and you really feel ... it's not in my role whatsoever. And they should be discussing with the doctor. But quite often I get that ... as well. [Would it be possible to do us a] favour, and, that is, you know, with sudden death there, that was not expected at that time, that's the attitude to the ...

M: And I guess at home care, I mean, people do know the [currencies] and aeh inspections and

F1: I find very often ... that is, it's the [central bond] that you provide

F7: But I must admit that I get shocked [in a thousand] by the patients ... and that ... don't understand why it's like that. ... We know that all the patients are ready ... have got and I often wonder, whether it's, it's a coping mechanism or what it is but I do, I get really shocked by the patients dying.

M: When they actually die suddenly

F7: Yeah, yeah.

F2: If I know, (coughing), I mean I suppose with our ... I mean sudden death is part of ... I mean, it's probably, it isn't what ... in a 98-year ... patient it's only [natural]. You know, you're actually dealing with something that is untoward

F4: Then I ought to make his tea. It often comes to that because you hadn't prepared that ... for that particular

Several participants: Yes, hmmh.

F2: Guilt very often stops us doing things we should do and I am sure that in fairness to doctors ... generous because they are trained to cure and when they can't cure I imagine, they sometimes, they feel guilty. And that's what makes them to run away. But I wonder whether the process of getting the truth across to people bearing the

name (of the hospice) is in itself a, a great help in in, for us at least in getting people to face the truth. ... What the hospice is about, and as soon as it's mentioned to them, they may say "Oh". But why do they? Why? Because they suddenly realize the truth.

F7: It's sort of facing up to their diagnosis, you know

M: And then with the start of the assessment to the situation as it is

F4: It surprises me the number of people who come in who don't seem to realize

F1: It's quite a proportion ...

F4: they don't even know where they are

F7: No, no.

F1: Not as many as we used to. But this is how you [say to/face the] relatives when they come in ..., they are not to be told what's wrong with them ... don't get that, and this really happens, ... question

F4: Well my answer to those relatives would be that I'd be honest with patients because unless I am honest with them they will not trust me, [not even] to look after them, you know, ..., the patient is going to trust me and I am going to be honest with them, so I won't hide behind, you know, a story, just so that the relatives feel better. If a patient asks me in a way that you can see that they know what's going on ... question ... on that, ahem, and I'd say 99% of the time when you actually sit down and talk to the patient they know exactly what's wrong with them but they, you know, there is no further treatment and, they just wanted somebody to be honest with them and say "Well, yes, this is the situation" and because nobody else has actually done that and the relatives, the relatives feel that they know ... that person does, ahem, for saying, they [got to] cope with the knowledge of their illness and I think the only person who can say that is the person himself.

F1: I mean it's, it's incredible ... that you can ... relatives, who when the relative is actually within the hospice, is, is saying that they don't want somebody to be told because I mean, this sort of very, you know, ... that they are in a [queue] and know that they are in a [queue] I

mean, it's really that a lack of communication between between relative and patients, ahem,

F4: Hmmh, hmmh.

F1: I mean in my experience, the ones who come in, not knowing, with relatives they, they are not to know, and more often than not, if I tell the truth where everybody else is discussing what's wrong about it

F4: Yeah,

F1: And it's such a, you know, you can see it, they are working themselves up he's got cancer, he's got c-, you know there are an awful lot of people with cancer and they will hear staff talking about their illness and the other patients' because they're given an opportunity to talk about how they feel it and I, you know, I think this has helped a lot, because if they've been denied that chance to talk about how they're feeling and what they're actually going through, it's coming to a place where people are going to be honest with them, and actually giving them an opportunity to unload on somebody else.

F4: This actually is a good way of getting around families as well, ahem, ... don't want them to know, they mustn't know they've got cancer, they mustn't know ... the hospice, ... they mustn't know ... ahem, and, I really say to them "Well, what do you do, how do you cope with it?" "Oh, I talk to my sister, my father, my mother." Well, how do you think your patient [feels]?" when you turn when they turn round ... "how come that I am getting worse" and you say: "Oh, come on, you be all right." And very often that makes them stand back and at least allow the patient then to say how they're feeling.

Other participants briefly talking together

F7: They don't sort of offer them anything, any information, at least listen to what they are saying rather than trying to perhaps "Oh, you'll be better ..."

F4: ... the loneliness ... and actually listen. Does this tie in somewhere?

F2: Oh, I think it does. (cough). If the person guesses the truth for themselves but nobody tells them then they feel very isolated, I think [without doubt]; 'at sea' as [one would say].

F7: I think the apathy to ... that I think the actual ... or the actual knowledge that, you know, nobody else can go through the illness for you and nobody else can die for you, you know, it's it's very, it's very much 'You' and, I mean, however much everybody else has got empathy, I mean, in the end it's [between] you and you alone.
Ahem

F2: And nobody knows how I am feeling

F7: No, no, no.

F2: I mean nobody can really

F7: You [go on] your own.

F2: Hmmh, yeah.

M: Do you feel sometimes they exclude you from this as well, even though you come very close to these patients, but if, that they exclude you from the big-, biggest experience that they're going through?

F4: [It's there, certainly] and I mean, ahem

F2: A lot of patients shut themselves off as well, towards the end

F4: ... does. The most difficult patient I think wonder ...

F7: 'name'

F4: Him, not, ahem, the other too, ...

F7: That's going back a long time [laughs]

F4: ... she ...on the ... on Ward 5 she was a young woman and she literally accepted everything ...

M: Oh yes.

F4: and just lay there, and caused no end of problems for the staff, for her own family but she was happy, she was contend

M: So how did she make you feel?

F4: Terrible, (laughs) because

F1: I think, I, I think it's much, much [worse than], I mean ... totally contradictory ... it's much much more difficult to deal with people who are totally accepting

Other participants: Yes, yes

F1: than it is with people who are kicking and screaming every inch of the, in a way, because I think (name) has a valid reason why every ... has trouble with (name).

M: Yes, I am sure.

F1: Because he was, he was, totally, I mean he was totally accepting of the fact that had got to die, I mean, I mean it was

F4: The ... of our standards in our [lives]. We all ... won't it? On the day that she decided she ought to say good-bye to everybody, ahem ... And I found that very hard that it was Christmas time and I came up to fetch you as she wanted to see you as well, ahem, and [went in] ... but very close and the only one that she was allowing in there other than the people that she wanted to see were, you know, even when I was trying to back off to give the family time, one of them would be coming out saying: "Mum" you know, "mum wants you", ahem, the other one ... there was too much to ...

Other participants: Yeah, yeah, yeah.

F4: And they said, they ... have to know ... truth ... the things that ... rather bad, and that's so hard. And actually he died on the Monday but I didn't even have the courage at the end of my shift to go and ... because I just, I couldn't, I was so numb and I ... He was so 'Yes I know I am going to die, I know I am going to die, it's going to be very soon, I have to do ... about. I want, you know, people ... with me now. And I just felt if I went in to say Good-bye to him I just start crying and I will be totally useless to him. Because he was so strong and his wife was so brave, she come out of the room we go into the day-room, we both have a cry-in and we go back in. Ahem, and I just couldn't ... it was the end, it was the weekend and then I went back to work and he was actually dying that morning.

Several participants talking together

M: So if you were [worried]

F4: really ... back to her it's very hard

M: actually what we are, but I mean, it's quite a paradox

Several participants: Yes, yes (laughing)

F4: You, you, I suppose one of [being] ... it's you, ahem

(end of side A)

F1: ... that have been totally accepting had had far, sort of far reaching effects on everybody, you know

F4: (interrupts) ... I mean, and, actually [it makes some sense] with her son who was [worried] of [her], and her husband was just a ... in the mortuary ... fairly

F1: Hmmh, hmmh.

F4: But her son was and Anyway, her son had family which was extremely difficult, I mean ... about thirteen, I think ... and

F1: ... [actually his wife left] and

F4: But he still couldn't deal at all with the fact that ... he'd totally excluded his father and his mother

F1: ... (laughs) It's a bit weird, ... patients as to what we ... (laughing) ...

M: Why should this threaten us, because this is what it is, isn't it? If somebody comes to total acceptance

Several participants: Hmmh, hmmh

M: of it, we are threatened.

F1: I think it's a feeling of failure ... and ...

M: Why?

F1: I don't know. It's probably the wrong words but you don't want the patients to ... fight for life. But with total acceptance that seems to go. And, it's as if you don't push them over the edge but it's, it's you are taking life away from them because they totally accept it what is

happening to them and that actually we're letting go through it, they're not actually, you know, fighting.

M: Yeah, I, I think the difficulty is that, I think, we're actually the ... things from the stand [point of view] 'Well'.

Several participants: Hmmh

F1: Maybe you actually talk ..., it's a long ... You know, we are (coughing) and when we are, you know, well, we say, Yes, we only need do A, B, C, D, you know, and we could sort of make quite sort of clear, clear-cut ... decision. And I think the thing is, that if you're faced with [various] pain, things that you were the one who was ill, I think your decisions would be, would be in a totally different. Now I mean I think we probably find it, you know, hard because we're ... well to have somebody who is, who is going to die, to say, "Yes, I'm going to die, I expect it". We can ... that doesn't seem, you know, naturally, doesn't seem right, we feel they should be hanging on, yes, you know, fighting in there.

F2: But I think from the patient's point of view, of course their outlook on everything is, is different.

F3: The other thing is researchers show that the people who don't accept, the people who are angry, people who fight every

Several participants: (loud interruption; laughing, talking briefly together)

F3: I mean it's

F7: I wonder if it's something so that we can't fulfil our role or we feel we're not needed any more if they ... acceptance. That's what we're setting out for, isn't it

Several participants: laughing, talking together

F7: I mean, it's hmmh, hmmh

M: It's interesting how you could be aiming for something and yet, when you got there or at least not when you've got there but when the actual patient has got there

Several participants: Yes, yeah.

M: you actually cannot cope with the fact that they got there.

Several participants: Hmmh.

F7: I think also because it doesn't actually happen that often, it's ... more

Several participants: Oh, yeah.

F2: I suppose that should be ... the question 'Why we're here?' (laughs) 'Why we're doing these things?' and 'Why, why you nurses why am I here [as traveller sort of]?' Is it because we ourselves are being fed? We are in a sense being fed, aren't we, by our patients and their relatives. But what are we being fed with? And are we being fed with something which we find very difficult to be without? In the sense that, ahem, we need to be needed.

Several participants: Yes, yes. That's right.

M: I think that actually goes through all, you know, all through all professions, that have got, you know, a caring element

F2: Yes

M: to them. I mean, I mean if we were working in a factory ... you know, I mean (laughs)

Several participants laugh and briefly talk together

F7: But I mean because, you know, I mean everybody who is a [carer] and I mean you sort of ... into your role because really you actually wanted to, you know, help and ... I mean, you then, sort of meet people on the other hand

F2: That's right

F7: to, you know, ...

several participants talking together

F7: who want to work [where] death is You got in (laughing)

F7: ... bring (F5) in. (F5) comes from an industry.

F5: I am a non-professional in this circle so I speak from a rather unusual standpoint in that I am an outsider, I am a volunteer.

Several participants: Yeah, yes.

F5: I think, you know, some of the questions that Peter has mentioned and and ... to one that should've [you've] been dealing with was, you know, it echoes, you know, my my experience echoes one or two comments from ..., ..., and (name) and the greatest difficulty I as an individual trying to go in to a home as a volunteer to transport a patient, either for treatment or bring into day-care and take home again, the biggest difficulty has always been dealing with the relatives because they're the ones who are usually in my experience showing overtly the greatest concern about un-; I've written down here, uncertainty about the future. And they frequently come up with totally inappropriate questions to me because I am just there from (the hospice) to take the patients in - asking about the future, about this and that and that I find is the most difficult thing to deal with and ... I believe very careful training is needed for people like myself ... going in not really knowing the environment and background in the homes that we have to go into to So that's my greatest aeh, experience with this ... section but also the undying gratitude both from the patient and the family to what the hospice is actually doing and the care that they're giving. But uncertainty of the future, asking questions and asking you to answer, which is, you know, really quite inappropriate, I can't.

M: (interrupts)

F5: I find it rather difficult to deal with

M: ... Yes, yes. But they've chosen to ask you. They could've asked somebody else.

F5: Oh sure.

M: Do, do you think they, do you think it's, it allows them to actually voice those questions, you know, knowing that you're not going to be able to give

F5: Oh, I think they're probably just using me as a con.... to actually voice their concern. And I am sure that others find the same. Probably in the bereavement situation

Several participants: Yeah, yes.

F5: where volunteers are also encounter lots of difficult ahem situations and questions.

F6: It's interesting going back to how people felt coming into (the hospice). We've been interviewing lately ... volunteers and one of the things we do is to show the volunteer round the unit and they immediately come in not knowing what (the hospice) is like at all and by just walking them around and talking about different things and how (the hospice) was set up, etc., we get back to the, the base and I say to them: "Well, how how do you feel about (the hospice)? What are your feelings about (the hospice) now?" And there is always the same: "It's not how I imagined it." And then I go further: "Well, how did you imagine it?" And they say: "Well, not quite sure." They come in with this uncertainty but they go out with a little bit of 'Oh well, it's not how I thought it was going to be' but [even] can't tell you. So there is, you know, when they go, they're thinking 'Oh yes, it is, it's different' and especially if they see the staff sitting having tea, coffee, whatever, they suddenly realize, 'Oh gosh', you know, this is a place where anybody can be in, anybody who is comfortable in. But it is quite interesting when you take them around that they are ..., you know, when they come in they are feeling not known but yet it's so different when they go in, you know, they know a little bit and it's not what they thought it was going to be like (coughing) ... and they can't really tell me what they thought it was like, it's quite interesting.

(long pause)

F2: If we think about crying in front of the relatives, that sort of thing, I am not very good at crying

laughing from other participants

F2: ... cry [cried], but not, but

F7: not very ... is it?

F2: ... (laughs)

F7: But I should imagine if you cry with the relatives that is rather nice for them in some ways because they know you got feelings with them, ahem, if, if you cry

with a patient but if you cry with the relatives, you know, they are knowing, well, you are taking all, you are empathising with them but you've also got feelings and you are showing that, your feelings.

F2: A lot of the, the relatives say to me after a death, you know, they say: "Oh, so-and-so, he/she was lovely and we are going to miss them terribly. Do you know, everybody loved them, even the staff were crying when he died". And they do appreciate that.

F4: I think it's ... goes so far that they are comforting you.

Other participants: Yeah, exactly.

F2: Do you cease to be of any use to people?

F4: You can't.

F7: You can't.

F7: I mean I, yes, I think there is a difference between the showing, showing that you are up-, upset and you're with them and still being able to cope with the situation and uphold to being such a [saint], that I mean you're absolutely no, no use at all and they, they are having to sort, sort somebody else out. I mean, I think that is difficult. I mean, I don't know, it, it may, it sort of may help them in some family, to think that you know, they're, you know, that they are highly into the ... support you. But I, but they don't know how anybody from the staff point of view would come out a bit afterward feeling that they have been so upset that they, that they couldn't help the situation

F4: Yeah, yeah.

F2: Can I ask a question.

F4: Please do.

F2: In your training, do they frown on crying?

F4: (laughs) It seems such a long time ago.

Several participants talking together

F4: Certainly ... in our day, yes, I mean, you

F7: not show any emotion at all

F2: I find that

F4: You weren't allowed to sit and talk, talk with the patient.

F7: You had to be seen to be 'doing'

Several participants: Yeah, yeah

F4: And if a patient asked a question you had to refer them back to sister; so going back to what (name) was saying how doctors talk to, you know, straight bad news to patients, you know, no You know, if a patients asks questions refer back to, ahem, to ward sister, so you know when I qualified and certainly in ... , on the oncology ward [in a single term] and there is nobody talking to a patient about illness and dying. Ahem, you know, it was quite a shock. You know, I was thrown in the deep end and

F2: I asked really because I find that members of staff seem to be a little bit ashamed when they cry. I, I don't think, I think most of the crying is done privately, so to speak, isn't it, in the loo or in the office or just when the Chaplain happens to walk in

(laughter)

F2: whatever, you know. But ahem, I [kind of] it would be doing their job [if they wouldn't] feel it on the other hand I've seen the importance of whatbring, sort of, tears [volunteer] to crying and is to everybody

F4: You know, at the end you can be desperately upset if somebody dies, and as you say being [knocked], hopefully not in front of the relatives but, that you're not supposed to know, but after they're gone, yes, may [need] other staff

F2: yes

F4: You know, to express your fears

M: And how do you deal with that?

F4: I over my shoulder and somebody ... than use that. But I tend to just go off on my own because I know I've got to go back and be there for another [set] of ... ahem, you know, and also patient. That are not going to want to see me with red at the eyes and ...[well] may known, so, it's at the end of the shift when you get home ahem, that I start thinking about what, what's happened during the day, but ahem, it's ... it tends to ahem [to bottle it up]... anyway, so if there's not a really ... work, especially if I cannot take that time out to actually go out, ... before going back to the next set of relatives and the next patient.

F7: I think sometimes ... what we do to ourselves ... and if the [hope is dashed] ... from patient to patient of the unit, each patient has got different [views] is at a different stage and perhaps you're with somebody who's really accepted

F4: Yeah,

F7: all of it,

F4: Yeah.

F7: and then you go to the next patient and you have to put aside all those feelings and be perhaps bright and talkative for the next patient. And I do wonder what we do to ourselves when we try and change our emotions ...

Several participants talking together

F7: ...[not enough time] between each patient.

F4: Yeah.

Other participants laughing

F7: We are luckier than you in a way because we've got a couple of minutes

F4: Yeah, yeah. (*others laughing*)

F4: It's the other thing, I mean, that people actually ... the time, I mean, how many people would say that they would sit watching a [person] which is not terribly ... but I mean, you know, you're such of there, you know, how [would that feel] something. You know, and I think then everything that has been bottled up comes to the fore. I

mean, I think probably this, this is what happens sort of ... wait and some in a day ... in a death, I mean they don't know, I mean it was a trigger for a whole lot of other things (loud coughing) and I think, that, you know, people do, I mean, you sort of may sit and watch [a fad] in a film, you know, knowing that you dealt with the situation in a similarly, and you dealt with it, but you're sitting in front of this film and feel an absolute mess.

M: I mean it's interesting this afternoon that several people you mentioned died many years ago

Several participants: Oh yes! Oh yes.

M: They didn't die just recently. I mean your experience is a very recent one but the others weren't, were they?

Several participants: No, no.

F2: But there have been recent, ahem, examples of people dying here and relatives, very young relatives, that's what upsets the staff

Several participants: Hmmh, hmmh

F2: I find that amazing and all of us really are all upset when it is a young parent with young children and the young children are visiting the hospital; and because last week we had a young family staying right up to the end and that was very emotional for a lot of staff.

F7: [A lot of people] I mean, I think when you got older people, you know, dying that you as staff can, sort of rushing around [things] and family, where when they don't think, I don't think patients or their relatives take ageing into, you know, account. Ahem, but I mean I think as staff, I mean, if you've got somebody who's seventy very nearly ..., you would rationalise, and say, you know, they have had so many, so many years. But I think when you've got a young patient within a young family, you ... in a way, ... being all lost at that in a family and people have got children who are in a, you know, associate with the children and I think it all then heightens, sort of heightens ones reaction to it.

F2: I wonder whether we really know what this emotional strain does to us because I always remember your husband (name) when he, when this place was first

opened if you remember, told us to come in once a week to

F7: Nobody wanted to see you (*general laughter*)

F2: to deal with staff stress and I ... remember him saying to me on one occasion "I can tell as soon as I come in if the, if the staff is under stress because there is a lot of giggling going on". And I thought, that's the last thing I expected somehow.

F1: That's true because on a Monday morning that I came from ... the unit I'd know exactly what happened the weekend because if you were all standing ... really silly and deeply and ... I'd know that it had been a very, very stressful weekend.

F2: But you wouldn't have expected that, would you?

F1: I think

Several participants: Yes, yes, yes.

F4: Because relatives do, you know, do that, I mean you can, I mean you could, you can sometimes walk past the grave, the little graves and you think they're ... and ... what ... is going on there? But, it's, it's really in many ways reaching on inferior rather than

F2: Hmmh. Yes.

F4: you know, extraordinary sort of, you know, laughter. And I think what ... was saying earlier where you literally got to go from a very [stressing] situation dealing with somebody dying, bereaved relatives and then go back and smile at the patients who are there, you know, give them food, give them tea, you know, carry on that way and perhaps then go back to those relatives who are sitting with somebody who is dying. And you just go back and forth and your emotions get so mixed up ahem that whether you are laughing or crying by the end of it.

M: I wonder what you are experiencing when relatives are laughing?

F4: Ahem, the one that sticks in my mind was, it wasn't long after I came here and which is ... now and ahem you automatically picture somebody, a waiting for

them to say something which I have learned now to do, ..., because I felt that this someone was crying and she was laughing, her husband had just died and she was laughing and I just couldn't take it at all that this someone was laughing because he had died.

F4: But it turns out, you know, eventually, it turns out to be, be effectively all through the marriage the only time he'd been ... actually ill ... and she was just so relieved that he'd, he'd actually died and that's something, I, it's when if somebody then tells me they are laughing when somebody, you know, [alive] but seriously, you know, terminally ill, then it is - you can tell, it's the tension really more than anything. The actual fact is if somebody dies ... laughing, their loved one has died, luckily I don't see it very often.

F7: You don't know how to react because you weren't taught, you don't want to seem callous and say, 'Well, you know, that's the way it feels dying', because it's they've lost somebody that initially they left a matter of and, you know, it got to be that, or the tears and the fears are not actually trying to agree with them while they are laughing is a very strange situation ... very often. Ahem, it's not what one experiences an awful lot, yes, hearing relatives laughing when a patient dies, is dying. You ... accept that because you know, you ... in a situation which is very very strange, and you ... there, and, ... strange and you often get, well, you know, laughing about that, when ... dying It's just a way they're coping, the relatives.

F4: Yes, I mean, it's, it's

F4: he said to me, not to, not putting even television into my little room, because, in her wisdom he thought that she, nobody would, you know want to be [dying] ... certainly not watching the news or what's happening and going on.

F7: But I mean it's amazing seeing the actual number of people that were coming, going, you know, lounge just to, you know, I mean, people sort of need it to be doing something that is sort of normal and

F2: ... sort of distraction

F7: Yeah, yes. I mean, a bit of normality in a situation which is anything but.

The participants discuss the late Princess of Wales' death

M: So to come back to the relationship issue, ahem, what happened do you think helping your relationship?

F2: Team

M: Tea?

Several participants laughing

F2: I, I think what, you know, team spirit amongst the staff is very important and, ahem, immensely in ... patient ... strength ... and, you know, nobody is sufficient for everybody and there is going to be a patient here and I want to do something with but I haven't got the rapport with that patient that you have. So I got to get out of the way and let you do it and you're only going to do what I wanted to do but I must be happy to let you do it because you got a better rapport with the person than I have and, (loud noise) then to be able to talk about it with ... within a sort of confidentiality is enormously strengthening ...

M: because?

F2: because you are feeling you are not alone, I suppose. Very often you find yourselves saying something and you need somebody else to support you in doing it, ahem, and ... really to talk to somebody about dying, shall we say, a vast question and, ah, and I am not a medical person, of course, and I simply say "Well, you are just going to sleep" and, ah, they are not sure because I am not medical, so, you perhaps need somebody else to come in to support that; not that any of us can be quite certain, but I mean, that's the sort of thing that we do expect in many cases [isn't it?]. And, ah, in that sort of way I think that we can be enormously strengthened and helped by each other emotion we've been talking about to have somebody to offload, to ... supportive. And I guess that, team, team spirit call it that, can change a place dramatically for the better, if it's good.

F1: Yes, I mean, I think people need to see that they've and I mean, I think we sort of go different, I mean, we, I think maybe ... sort of changed over the years

because of people who were here right at the start had a very definitive ownership of the I mean, when it, you know, started, I mean, we didn't have anything and it was what people sort of made it and I think that the cause of that is mainly people joining the actual staff you know, later on, perhaps you know, harder, because people who've been here from the word 'go' their expectations of everybody coming in were, their expectations were high. I mean, they, they expected exactly the things sort of commitment from people coming in and the people who had actually started off had, you know, higher. I mean, that really was in a totally, totally unrealistic and I think, at times it probably made it very hard for people to come in because in one sense they really had to prove themselves to, you know, everybody else and I think ownership of the service has actually, I mean, it's, it's, it's changed. But I think people do sort of need to feel that, that what what they say is important and will be, it will be listened to, and it will be, you know, noted and if possible it will actually take, it will be taken on board because I think that the service runs very much, very much much better if everybody feels a part of what is going on and that their, that their contribution is, you know, is, is worthwhile and is, and is acknowledged. I mean I think half of the problems of the hospitals at the moment is that people feel that nobody really really cares about their, the contribution.

F4: That's really about communication between one another. ... communication with patients that we ... and

F7: I think it

F4: I find it very difficult to

F1: I think also that staff that actually work here, ahem, actually applied to work here - it was what they wanted and obviously if it gets to the stage where, you know, enough is enough, people leave, but people ... here because they want to be here. They want to know [hand to hand] and in, you know, in a small way have a and, and they go through their training with very little contact with people dying especially terminally ill patients and, you know, because either [they are] at home or due to the stress on hospital beds they have just not been admitted into hospital home ... the patient comes here or at home and they got to deal with the, you know, stresses of people dying through a long illness and so, you know, I think people that come here they want

to learn, they want to find out about the patients and they want to find out about the patient-family and family dynamic. And I think that then [has/happens] when relatives come back and ask questions because they feel a bit more confident, they've got the confidence, they've got the knowledge base there that ... got a ninety-year-old, you know, the family dynamics and ... to the patient the most important. And we quite often find that within a few hours of a patient being admitted we know what their family difficulties ... because we are told about them, well, perhaps on a general, you know, medical ... you may not find out that on the whole time the patient is in with you. So I think, we, we actually ... person themselves with the patient ... relatives ... finding out about them and their illnesses and family dynamics at lot (coughing) ... patients, you know, home care, the home care sisters will, you know liaise with ... and the patients and I think because they got that knowledge base then the con-, you can talk to relatives of patients with more confidence. And knowing that what you are saying is the truth and you are not guessing or anything.

F7: I think the other thing to that, everybody sort of knows that it, you know, that it is acceptable to be preparing patients.

F4: Yeah.

F7: You know, I mean, I mean, ... hard and fast you know, lying. Everybody here knows that that is what somebody else is going to be doing as well. But I mean, you know, it's not a question of one individual is going to be telling you've got the confidence that anybody on these staff are also going to be playing they, you know, their part in it. So it's, it's very much sort of shared shared role.

F4: It happens quite a lot that either a patient or a relative will ask a question of various members of staff on the ward that they find. And ... you know, you don't discuss everything that goes on between, you know rela-, when you talk to relatives or talk to patients. When it comes to hand-over, ahem, you say: "Well, I spoke to so-and-so, so-and-so and ... sort it out" by the time you're gone, everybody they ask the same question and practically word-for-word they get the same answer. Because of ... people are on a, they, ah, there's lots of

M: Yeah

F4: ahem, where they're not to know and we can't say that ... cancer ...

F2: Do you think by the time they've gone round everybody, they believe it?

F4: I think they believe it before they ask the question, and, they just want somebody to confirm what they're feeling themselves. I think the first time the question is answered, they don't believe it. Ahem, and they just need a reassure- answer. Sometimes the reassurance is, they know that they come across certain things that we know what we are doing and because they are, if it's a relative they're actually, you know, interested in their loved one receiving care, ahem, if it's a patient it can be a test as well. Shall they know what they are talking about? ahem, and 'I'm a bit happier ... they're looking after me'. And, ... a difficult question, all very difficult to ask the question and I've never known somebody to come back and say: "No, you told me that and you just told me that, what's going on?"

M: And that helps you to

F4: Yeah, yeah

M: form a relationship. Is there anything in that, that hinders you sometimes or makes it difficult sometimes?

F2: Well, I know what hinders me but I don't want to monopolise things. What I call heavily and I don't quite know what I mean but, ahem, I have had a few examples of people who have leaned on me so heavily that you just feel crumpled by it. If I can just give you one example and it's not from here, it's from the parish but I was called to a house where somebody had died, and I was ... and when I [walked in] the coffin was in the house, no lid on it and there were three daughters there and they were all very upset, of course, and, ah, it was a very closely-knit family, but I remember to this day the impression that I had at that time of all these girls like so many baby-birds in a nest when the mother comes to feed them, you know, sort of waiting to be fed, and I didn't know what to feed them with. I didn't know how to feed them. I know, of course, as a, as a priest the sort of things that I should say but I just felt that that wasn't enough for them. And it was more than saying that was needed. And you get that sort of impression sometimes

from people who seem to almost hand over to you and, and say: "Well, you make all the decisions and you", almost "you feel for me" instead of me doing it, you do it, sort of attitude. And, just occasionally you get that sort of thing and I find that very, very difficult to deal with and I thought why this ... inadequacy.

Several participants talking together (much background noise)

F4: ... there are certain practical things that you do, ahem, I mean I think it's very much, I think it's very much harder if you are in a situation where there is, you know, nothing actually practical that you can do and the feeling that you're fumbling around in the dark, knowing, knowing where to go, you know, next. I mean ahem, I mean the sort of patients, you know, you are doing things with the relatives you are sort of giving, you know, comfort, you are - in many ways there is something structured about it. I mean a lot is not structured. There are half-ways that you, you know, that you actually follow, where I would think that in that situation you were, I mean, really what, I mean other than go through the actual emotion, you know, what you were going through, go through [within a single day], you are sort of left with, you know, not anything else really that you can do.

F2: Those sort of practical

F4: No.

F2: but you are ... and ... even that sometimes can be difficult to ah, you don't know the family very well, sort of know the situation very well and ... one times there is a ... closeness which you have to be very watchable ... because ... go sexy or something of that sort but you see that just might be me, sort of, feeling that that is another person's attitude I don't know

F2: Sometimes they're particularly clingy, they won't let go and the arm around you

M: And that [you] find very difficult

F2: (laughingly) Yes, yes.

F6: ... other difficult issues. I mean, I had an incident yesterday when I rang, telephoned a patient to see how

she was doing and she had an operation on her mouth and I couldn't understand a word about what she was saying on the telephone. And I felt I made the situation much worse because, because she and I couldn't ahem ahem, I didn't understand what she was saying so didn't know how she was and when she was asking me something I didn't know how to answer her.

F4: I mean you get physical situations that hinder your relationship ...

F2: I think that's probably one of the most difficult things

F4: ... face to face ...

F2: Yeah, yeah,

F4: because you can resort to, to other things but I mean on the end ..., I mean you are, you are pretty helpless

F6: I find the hardest thing ... is the silences because if you have silences and you can see someone, your body language will help. But if if you have silences on the phone it's very very difficult, what are they thinking, what are they doing? Because you, you don't know and ahem I think that's very difficult on the phone and and this ahem in that situation it's just totally and very ... quietly to them and and that is quite difficult. And when ... very upset you are aware that they can't talk to you anymore and then the tears come and I just want to leap through the phone sometimes just to be there because I think when you see someone it is totally different because you can act ... If it's on the telephone it is quite difficult because you you do not know when, if ... you've gone away having all their worries on your shoulders because you are not quite sure what they are doing and you're thinking "Oh, my goodness" you know, ahem, "what have I done?" and this is sometimes, it's as being perhaps you made the situation worse because they, they've come on the phone, perhaps you know, you are thinking, "Oh, I've got this letter I've got to type", this this person is on the phone and he is my patient and ...

M: Any final thought or comments or anything from you or?

F6: Just to say what you were saying that we have to ... with relatives and patients constantly by telephone, it is

very difficult, it is very very difficult ahem, but then again, it's something that is necessary sometimes.

F1: But I think that's difficult as well, when he dies on the unit and you've got to tell the relatives over the telephone, ahem, because they know what you're phoning for. Quite often, you know, you start with 'Is somebody with them' and when they hear that [they'll say] "Oh, I'll be fine, I'll be fine" and you are thinking ... it's the only phone that they've got, you know, that person has got a husband who is [no longer] alive, it's frightening if you ... that they are on their own and you know, trying to assess that their loved one has died and that's actually feared what happened.

F2: It's very difficult to break up relationships ... somebody has died and is no longer, you know, sort of [...ting] to the home because you can't go on, and on, maintaining relationships without [any assistance] ... they can't do it. Can they?

F4: I think this is the problem in part if you have

F1: When we were trying to do bereavement evenings, I mean you were inundated, you, I mean, you ended up not feeling that you've done, you know, justice to anybody. So you, so you accept that you have, that you have to move away from it, that you have to move on and you have to be prepared to let somebody else take over ... (tape ends)

APPENDIX 4

Interview Transcript A 1

R: Participant A 1

PS: Interviewer

PS: Start wherever you like to, whichever way you want to take it.

R: Just, just to clarify what you want me to talk about is the essence of my involvement with a Well I'd like to talk about, wonder which one to start with really, maybe (name ---), maybe --- would be a better one to start with. He is a man with carcinoma of the esophagus which is not amenable to resection and ahem it was causing him increasing difficulties because of ... obstruction so he couldn't swallow in other words. And he had a [peck] tube inserted out (several medical terms follow), a feeding tube into the stomach. I am sorry he wasn't fifty-eight, he was sixty-seven but he was quite a young sixty-seven. And I first met him when I was asked to go and see him at his home by one of the home support teams who are nursing teams and the reason for my involvement at that stage or the reason why I was asked to see him was partly for psychological support, partly for an assessment of his symptoms and I found a very ill man indeed who obviously was very intelligent and ahem he had a ... malignancy. But to some extent his condition was maintained by his feeding tube. Well, I mean obviously it was totally maintained by his feeding tube and without it he would have died, but what I mean is his malignancy was probably more advanced than it would have been ... not for the fact that he was getting excellent nutrition via his (medical term) tube. Most patients, when they become ill they don't have appetite and they don't eat, so their condition declines, it's it's sort of natural phenomenon really. This man was ahem probably bearing in mind the degree of malignancy the amount of malignant cells that he had was in a better state than you might expect, but he still had great problems as far as this, as far as this lesion of his esophagus and also it was causing external pressure on the trachea, so breathing was difficult too, so there was a dual problem. Ahem, I saw him and made various recommendations with regard to treatment and talked to him about what we try to do in palliative care in terms of improving quality of life, not seeking to prolong that which for him was something which was very important, ahem, and I think it was from my point of view a fairly successful interview, we were able to; I didn't think that admission was appropriate at that stage and in fact neither did he. So I anticipated that I wouldn't be seeing him

again until such time as further problems crop up because the ... foundation the homecare team are well able to provide psychosocial support themselves. And there was no ... need in my opinion for intervention with drugs. I saw him again, I was asked to see him again at home a little while after that, about three months after that. He was much, when I say much less well, he was less well and bearing in mind the fact that he was not well when I first saw him, he was worse and at that stage he started to talk about sort of what one might term life and death issues and ahem the time would come when he wanted to stop this input via the gastrostomy. His wife wasn't there at the time and he talked quite openly about this and I reassured him that when the time came when he was obviously declining we would stop his gastrostomy feeding, in other words, you know, when he was obviously dying, we wouldn't we wouldn't continue to push that down the gastrostomy tube, and he seemed to be relieved about that. The next time I saw him was for a respite admission and at that stage he was much more direct about his wishes with regard to the gastrostomy feeding and he needed a lot of reassurance with regard to whether we were going to flow with his perceptions of what he wanted to do. I mean it's very difficult, because we wouldn't want to actually do anything which would hasten the demise of a patient if I don't want to prolong a patient's life but actually deciding when you're going to stop gastrostomy feeding is not something that we would do. At that point it became apparent that his wife was very much opposed to his stopping his feeding, even opposed to the idea of him taking the decision into his own hands and not feeding himself, ahem, the reason was because she herself had already lost her first husband with not malignant disease but with a progressive disease, malignant [hypertension] and, aeh, she didn't feel for him to hasten his demise was right, ethically or personally, you know, she felt that he would suffer more by stopping his gastrostomy feeding and which actually is not the case, we could have put just ordinary fluids in there instead. He, he much to his surprise and perhaps to ours as well improved sufficiently on that admission to be able to go home again and he did, rather reluctantly because he felt he wondered whether he was well enough but he stayed at home then for a further, about six weeks and then came in for the last time about six weeks ago, ahem, that's four weeks ago. At that stage he was obviously less well again as one might expect, ahem, his ability to make decisions was fully preserved ... and again, you know, really the very next day after the admission he started to talk very seriously about what we were going to do as far as his feeding was concerned. I think the difficulty here was a) the ethical issue

of what we should do as far as his feeding and b) how we should try and resolve the apparent conflict between him and his wife. Ahem, we did in fact in the end talk to the wife separately and say that we felt that because he wasn't doing anything it was entirely appropriate to reduce the amount of feed by 50 percent and make up the volume with water. Ahem, and we also talked her through the issue of how he could have autonomy in terms of his decisions, you know, we pointed out for example, that if he was eating in a normal way and he could either accept his food or totally reject it. So we came to a decision after some time really talking to the wife and the patient that what we would actually do is take him his feeds and leave them with him for an hour because he was well capable of giving them himself. And if at the end of the hour he hadn't actually used them, then we'd simply take them away just as though it was food on a tray. Which I think actually is ethically the right, you know, the right standpoint. His wife was obviously unhappy about this but agreed that she wouldn't interfere with it and understood the situation that we were in. I think the main difficulty was, just to complete the story, he actually died the next morning after ahem a sudden episode when he was using the toilet, dangerous places for very very seriously ill patients and they often they seem to have some sort of funny turn when they are on the commode, well he had his funny turn on the commode at 5.30 the following morning, declined remarkably and died by 9.00 AM.

PS: Was he at home?

R: No, he was in the hospice, hmmh. I think the difficulty issue here was he, he was an intelligent man who was an able communicator and ahem, one formed a relationship with him, it was difficult not to because because of his ability to communicate. People can communicate in different ways. Sometimes they communicate by by their personality like the other patient that I got pencilled in here; sometimes they communicate because they're intelligent and they can put concepts into words in a very clear way and ahem, this chap was the last one really, and ahem, but he then wanted us to participate in something which we felt we we couldn't do, no in fact put us under a lot of duress. And once we worked out the way through this, I think it resolved the problem, you know, what we really did was knock the ball back into his court.

PS: But it must have been extremely important for him because he kept it in mind and asked again and again

R: Yes I think so, yes I think it was extremely important. I mean I think that, I mean if, if there was the option of euthanasia he probably would have wanted it, you know, and we we, you, I am sure, are aware of the euthanasia debate, in common with most other people in the hospice we feel that that's actually not the right way to go and certainly I wouldn't find it possible to take active means to bring a patient's life to an end, although, you know, as you know we do relieve symptoms, recognizing that sometimes to do so can result in an alteration in life expectancy. But that's a different things. We had a man down on the ward at the moment who was extremely agitated and we had to sedate him because we know that this is not something which is reversible and his agitation and paranoia and fear is such [real] symptoms we must do something about it. So we do do that, but this man was actually asking me to do something else, he was asking me to, well first of all as I say he would have wanted euthanasia if it was possible but he realized it wasn't, but he wanted an accessory in in, and an ally really in actually actively stopping his feeding. Actually we passively stopped his feeding, we simply gave the responsibility or a quart of the responsibility to him and him alone. And, and took his wife out of the situation. But I think the difficulty is when you're making decisions like this or when you are trying to work through decisions like this with people who you have a relationship with, you're aware of the fact that there is a relationship there.

PS: When you say there is a relationship there, the question for me is, there is not always a relationship there?

R: No!

PS: But sometimes there

R: Sometimes there is.

PS: How would a non-relationship with one person and a relationship with another person, is it the people, the personality or the match between you and the particular person or what?

R: I, I think it's both of those, I think sometimes situations too. You know, for example, I mean most of us find that it's more likely that we will build a relationship with somebody who is young, as when I say young I mean our sort of age, rather rather than seventy or eighty, ahem, and has dependants particularly children, because we could feel, you do feel that people who are in situations that you could

identify with, whereas one's capacity to be able to feel, I mean it's not that one doesn't want to, it's just that ahem to some extent the ability to be able to emphasize with somebody depends to having been there or being close enough to their actual, to actually be able to feel what they feel. I mean certainly I think with regard to an eighty-year-old patient who has had a long and full life and is dying of a terminal disease, I mean some of them are wonderful, they are lovely people, but you do [keep] get this feeling that life is drawing to it's close, you know, the relatives coming in, everything is accepted by the family, by friends, you know, it's a natural close, they are grateful for the care that the hospice give, you know, and it's all natural. With people like ahem, actually this man was in fact sixty-seven but you wouldn't have thought of him as being that, to me he came across as somebody maybe in this late fifties which is close enough to where I am to be able to identify with. And certainly younger people like we, we just lost a forty-one-year old with a husband of my age and and no children. Now that you can, you feel very deeply. That, that precipitates a relationship. And I suppose really because you understand. And and maybe also if one is honest because you, you perhaps make a little bit more effort, you know, because you're feeling, you're feeling (both talking together), ahem, as you rightly say you can't make a relationship with every patient even be pleasant to every patient ... But when you look back there are particular ones, there is another one that I saw, I don't want to flit about too much, I am aware of the tape, but just to illustrate the point, a lady of fifty-four, somewhere around there, --- was her name, now she was one of these very extrovert people, I mean for instance, we did a questionnaire ahem asking we always do routinely, asking patients how they find their care and --- was a lovely lady who was very very grateful for what she'd got but she was very open about what she felt our week points were, so she told us, ahem, but it was part of her personality. She was one of those very outgoing people, I mean she is the sort of person who when she was dying asked me how I was! And that does something, it makes you feel more involved with the patient when they actually reach out to you, which is actually a key key area if patients reach out to you, then a relationship is much more likely to develop. And she actually died and as she died or as she was dying spiritually she was cropt up as well and I remember we talked about this at (name) what I really that ahem, very often these times come when you sort of seem to touch patients very closely or you are given permission to touch a patient, ahem, I don't mean in a physical sense, I mean in in this deeper, what one might term, in the wider use of the

term, spiritual way, and that happened with this lady. I, I must confess I do miss her. I remember her well although she died about five months ago, I shan't forget ---. I forget most people who die here but I shan't forget --- and I shan't forget --- because there was that, there was that touching somehow.

PS: I heard about this before from other interviewees and it seems to be hard to explain; it isn't in the words themselves, it's something very fleeting

R: Hmmh, hmmh!

PS: but they do seem to stick, because possibly they go beneath the surface

R: Yes! And I think with people generally, I mean, if you meet somebody and there is a point of contact, you ..., I mean it happens with people at a bus stop doesn't it; sometimes you just sort of suddenly there is, something clicks between people and in in a normal relationship you then determine whether or not you're going to take that forward into anything more if you want to, then obviously you follow the normal ways of doing it, you know, but at the end of the day the relationship is built up or [sensibly] founded on ahem common interest, on the ability to be able to sustain communication on an ongoing basis, it's not like that with our patients. You know, with our patients, they're actually dying, and and anyway there is a common interest, it's their well-being in terms of the care that you are giving. So it's almost as though you can, you can touch somebody at a deeper level almost because you're talking about [their] life and death issues and be, you don't actually have to follow up building the relationship with with the normal things that we build relationships with, you know it's almost redundant. So, so the relationship can be quite deep, at least it seems that way with only only just a short amount of contact.

PS: If a relationship is built with a patient, is it quicker than a relationship with another person that is not a patient?

R: Yes! Yes.

PS: Partially due to the dilemma of time?

R: Hmmh, hmmh.

PS: I wonder if that has some kind of input on the relationship formation, and also on being able to go deeper?

R: Yes. Yes, I think so. I think so, although in some ways I think it doesn't depend upon a sort of breadth. I mean it isn't, it isn't the breadth of the relationship, it isn't even a breadth at a certain depth, you know, it's it's the fact, at least this is the way I see it, at a certain point, you know, the opportunity opened up for you to actually reach deeply into that person's life and you haven't got the breadth there! I mean if that person suddenly gets well and goes out, the chances are that it wouldn't actually develop into a relationship. It wouldn't develop into that sort of deep friendship but it seems to because of the depth of the contact. People are very vulnerable, you know, they are enormously vulnerable and sometimes they sort of open up.

PS: Yes, and I imagine a lot of other things fall away, don't they? When you are well, they seem important but when you get ill, very ill, they don't seem as important any more, taking second or third place or no place at all.

R: Yes, yes, that's right, whether your kitchen units need replacing, yes that's right (laughs), so what! Yes, that's quite right.

PS: So, I imagine, the value structure and system changes.

R: Hmmh, hmmh.

PS: I have been told that when people unexpectedly get well again, after having been very ill, confront the same problem in intensity they had when they were getting ill, because the new set of rules that need to get back to the old life somehow.

R: Some people don't, do they? They do specifically retain their perspective of having had a brush with death, you know, or maybe they drift back but it is more slowly, they come out and they think 'Well, I've learned what's important in life', you know, they live in a different way, they may be not so materialistic, not so worried about minor things which tend to we worry about little things.

PS: I wonder. I have a parallel example from my therapy work. If it's a good session, both my client and I are on a different plane, so to speak, but we both go back to our respective lives and both of us, and I am sure, find it difficult to hold this particular being in a session and I've heard some

counsellor who also talked about that; that in particular times they want to stay at that level but somehow or other

R: you can't, go back. Yes, I don't know what it is, I don't know what that sort of essence is, but it's there, you know it's tangible and we, I think we all recognize it.

PS: I imagine it's felt by the caregiver as a highly rewarding part of caring.

R: Yes I think it is! I think it has to be balanced with normal healthy relationships, you know, I mean otherwise you're effectively investing your life into the transitory and it's good to invest your life in people who need you and that provides a lot of fulfilment ahem, you know, personal fulfilment, as well, but, obviously you have to have a solid base of normal stable relationships to back that up. Otherwise, all of a sudden you find your life is full of

PS: losses

R: yes losses, that is exactly, that's right! I often wonder how people can be in in this sort of field if they don't have some key relationship being married or whatever it might be, ... very difficult, very difficult.

R: And it's not ahem the fact that you can actually go and talk to somebody else, it's not the talking, it's the being. So, I am certainly, as far as I am concerned, I think, ahem, feeling that there is a supportive mutual relationship as far as my wife is concerned, ahem, as I say it's not that she can listen and that she can actually with her mind understand, it's it's in the very nature of the relationship itself. Its ongoing nature, its stability. It sort of counterbalances these ahem

PS: It may be interesting to compare such a close relationship with another person to the sort of relationship you experience as a carer in a setting like this. It is very different, obviously, but these words and phrases always came back in the other interviews: "It's a different relationship", "it's a special relationship", "it cannot be compared with any other relationship". But I wonder, I think most things can at least superficially at the surface level be compared.

R: Yes. Yeah. Yes. When I, I would, I wonder whether it's not in terms of depth, no, I am sorry, I am sorry, not depths, breadth! I mean as far as the depth is concerned, I mean the depth that you, you find people will allow you to to

intervene really in their lives, is probably almost as great within this caring setting as it is within a sort of marriage relationship. Ahem, but, no I think that's probably overstating the case. But, but there is a sort of similarity in terms of feeling, not in terms of affecting people's lives, or you can do that too, but in terms of the way in which people would open up and communicate, ahem, but what is lacking as I said before, is there is not the breadth, it's not a sustainable thing, no, except in a very few instances where you actually do have an awful lot of things in common, under those circumstances, maybe then that's different.

PS: So you don't touch as many point in

R: No, you don't! No, no, I mean you probably only touch a point or two points! Whereas I mean, you know, sort of marriage, really, it's as almost like, well I mean like a piece of Velcro as supposed to two hooks. You know, I mean two hooks what we are talking about in terms of relationship with somebody who is, is dying, but marriage is Velcro, you know, it's it's aeh something that hold two people together, many many different points in my experience. It's interesting, isn't it?

R: So to some extent I mean, I can actually take on, as long as I got the emotional resilience and resources to be able to deal with it, I can take on the concept of friendship with a patient here in, in a much more full way because I know that the relationship is not going to be something that endures because the patient is at the end of the day terminally ill. I don't think that really happens. I mean ahem I think the point at which we contact most patients is ahem, empathy or at least strong sympathy and ability to identify with where they are and sudden demonstration of need of vulnerability; I, I think that's another key word, vulnerability. When a patient demonstrates vulnerability, then something inside most of us wants to be able to help, you know, to sort of meet that vulnerability. We can't always do it. Sometimes [it's] not right to try, sometimes it's that it's actually for somebody else to do that and you can, your role is merely indicating that point of vulnerability to somebody else and say: "I think now is the time to" whatever it might be, to swap the side to talk about it together or whatever it might be. But, but there is a demonstration of vulnerability all of a sudden, and that's normally the point at which the depth of touching a patient seems to be, it's when they demonstrate that. Sometimes there are other factors as well, common interests as well, it's not very common.

PS: Regardless of how long or short such a relationship may be because of death, is there a sort of movement a development a process that changes? Sometimes it goes forward, sometimes it stays, sometimes it reverses?

R: I, I think if it's just the point of touching somebody at a vulnerable point, then probably it goes deep to that depth straight away and doesn't deepen further. I suspect. I think with ---, it was a little bit different, the man with the (medical term) tumour, because I saw him on successive occasions some little distance apart, one from the other. And, you notice things like the fact that he has got a picture of him standing on the deck of a small boat, you know, these other facets to their lives that are, unless somebody mentions them is unimportant to them because they are not relevant any longer. It's past as you say, it's something which is in the past. But I'm not sure that there is the facility to deepen, to deepen that point of contact, you know, unless there is something else, something else in common occurs, unless of course, no, you start to actually deal

PS: and very careful way to basically giving back what they are getting in a different way

R: Yes, yes.

PS: It's not as in counselling where there is intervention

R: Yes. Hmmh.

PS: Maybe we should talk about your lady, your second

R: Well she was, she was intriguing, you know, there was no, with --- there is a possibility you could say, well similar personality type, ahem, ability to be able to make deductions from which he separates himself from emotion, which I, which are all things, of course, that doctors do all the time, you know, so you could say, well there was a certain amount of in common there, sort of problem solving approach, most scientists have this problem solving approach which is all very well as long as it is not all they do. But that is the case. --- was very different. She was hum (laughs) she was devoid of that.

PS: I don't know.

R: She was aeh, aeh, just a bubbly effusive lady, you know, she is the sort of person who I suppose in many ways, people either loved or loathed, according to whether they

could actually cope with her. And I think her family found her quite difficult because they had to cope with her all the time, whereas most people she came into contact with over a shorter duration of time absolutely loved her, you know, because she was so, so easy to get on with. Sometimes I think that different people have these characteristics that make them very easy, you don't have to work hard, you know, they make it easy, that's right. And I always think that many Americans are a bit like that, they have the gift to the [gun] they're very welcoming. Anyway --- was like that, but she wasn't American. And ahem, she had had some major problems and her condition declined over about a year, I suppose we knew her for about a year or thereabouts. But she had intra-abdominal malignancy and and it was just rapid, quite rapidly growing, ahem, and she was, she was very aware of the fact that there was only a certain amount that we could actually do, she was aware of the fact that we tried some things and they didn't work like, for example, we thought that there was some fluid in her tummy so we tried to drain some off, but actually, I mean if there was any sort as opposed to just sort of tumour, there was too little for us to be able to actually get. That was uncomfortable for her, but she recognized that we needed to do it and she sort of participated if you like, you know, she was a part of what was going on. But that certainly is an interesting point too because, you know, when you get involved in sort of procedures with patients the very fact that you are doing a procedure designed to help them, ahem, is a factor in the relationship. Quite possibly this is, for nurses, this is, they may well, I don't know whether they talk about this, but certainly for doctors if you do something like trying to tap fluid from them, you know, then they are very much vulnerable, again they are enormously vulnerable, but you are putting them in that position of vulnerability. I mean, obviously our aim when we do things like that is to get the best result with the minimum of discomfort to the patient, but nonetheless, I think the patient is, they are making themselves vulnerable, you know, I mean they don't know whether we are going to make a mess of it or whether we are going to hurt them or anything. No, that, if in a way they sort of trusting, they are opening themselves up to, they got reason to doing, so somewhere you got a certificate [on the wall] saying doing these things. But it's still a matter of trust. Anyway with lady we did quite a lot with to try to alleviate her symptoms and, but she had a progressive illness, and, ahem, she was always enormously interested in, in, in the people who she talked to. So, for example, I mean at that stage, my wife wasn't living here, or were just in the process of moving when she died, in fact. And aeh, but she

was very interested to know about my family, you know, even though she herself was very ill. As I said to you before, she was always solicitous of one's well-being: "Oh hello ---, how are you?" First name terms, of course, most patients here, I don't think that it's right for me to call patients by their Christian name, they don't call me by mine. If they want to do that, so we ask patients what they want us to call them and then I respond in kind if they say: "Call me so-and-so", well, I am Doctor --- but feel free to call me ---, you know, because it seems right sometimes. And aeh, so she would always be solicitous. I think the thing that really made this relationship sort of something which as I say I shall remember, is the combination of that and then sort of [nattily] with how she coped with the end, you know. Aehm, I feel that spirituality is very important in the care of dying people. I have my own, my own sort of spirituality as we all do, and I am well aware of the fact that one cannot bring one's own spirituality to bear on another patient. But sometimes a situation opens up to the point where you realize that it's actually your own spirituality which this patient is in need of to encourage them in theirs, because there is sufficient similarity between the two. And I think, I think that's the crucial issue. I mean, I couldn't help somebody at a specific spiritual, in other words a religious level, unless unless there was common ground, say, for example, if there was a Sikh or a Hindu here then I could be aware of their need for their spiritual harmony, I could facilitate that, I could ahem, indicate the openness of the unit to their spiritual adviser, we could talk about the broad spiritual issues too, but the religious issues would not be my domain. This particular lady, I never talked to her about religious issues at all for, until really the day before she died. But then when she was dying all of a sudden, ahem, a crucifix appeared on her locker and aeh, I don't know why she put it there, you know, why

PS: Well she must have had it with her

R: well, she must have had it with her but it wasn't there before, you know, so, for some reason she obviously decided that this is the time to put it out (laughs), now is the time. And, aeh, you know, I saw it and I was aware of the fact that she was dying, I went in there and she was terribly short of breath and she did her usual "Hello ---, I hoped you'd come and see me, how are you?", you know, that kind of thing and ahem, she tried to talk a lot and she couldn't, she was just too breathless, and I said: "--- I don't want you to talk, it's tiring you out too much, unless there is anything particularly that you want to communicate with me", small

talk really, I didn't put it quite like that. And then I saw this and then I said words to the effects of: "How are you doing?" And she said: "Oh, I don't feel very well". And I said: "I mean on the inside" and she said: "Not very well". And we talked about religious matters, ahem, and prayed which she deeply appreciated, and where there is an affinity of of religious conviction, even if people don't have a strong religious faith, you know, but they don't have an antipathy, this is the crucial thing, then they appreciate the offer of prayer greatly. I don't have any particular qualifications for praying a priest or a minister, I just have the faith, and I perceived that that was the level where she desperately needed help at that point, so I was able to plug in to what appeared to me to be her point of need. I think that brings people close, because again, this is the very deep level. I think an expression of spiritual need in terms of identity is ahem a very important factor, but also an expression of spiritual [out] working in terms of religious faith, is another. And certainly as far as I was concerned when I left her, she wept, you know, she wept with gratitude that somebody would actually pray with her. I think most people deep down have a sense of unworthiness and she'd had a lot of problems with her family, you know, her daughter's, there were some problems there, and she'd had a great deal of difficulty with her husband. I don't know, I mean it wasn't the time to talk about that because she was actually dying, but I sensed, I sense in retrospect looking back, I didn't think about it at the time that that there was probably a lot of need there and a need for her to feel at peace with her perception of God, which happened to correlate with mine. And also, I think perhaps to some extent her need to get her, to do her business with God at that time, because time was running short, as you said, there must have been some reason why she decided that that that was the moment to pull out that crucifix. So that was a different, a different sort of incident where where the common ground if you like was, well the initial sense that there was more than just a very bold doctor-patient clinical relationship was there there, was her character and her concern about you as a person, about me as a person. And then went on into a more abstract, if you call spiritual abstract, ahem, a less well defined area of com- of, I don't really whether there was common ground, I don't even know really whether she would call herself a Christian. But nonetheless there was something there which caused there to be a contact.

PS: And you mentioned before is a moment of perceived vulnerability in a patient

R: Yes, that's it. Yes, I think that's it.

PS: But to what does this link in the carer, what is the other pole?

R: Vulnerability perhaps, maybe it does.

PS: You very strongly said, most people would respond to this perceived vulnerability

R: Yes, oh yes, well I think so. I mean, you know, certainly, I mean it's, it won't, I think that's right isn't it? I mean you see, I mean how do people persuade you to give money to children's charities? What they portray vulnerability. How would people persuade you to give money to people who are living on the street? They portray vulnerability. They take away the negative aspects, like the fact that they might be small... .. to ... at the time (laughs), you know, they portray vulnerability, almost what you might term innocent vulnerability

PS: But it isn't innocent

R: Well it doesn't even have to be that! No, because you know, sort of vulnerability allied to perception of role. I mean I am not talking about, you know, like for example you got a youngster and they are off the rails and they do things that are actually damaging to you but they come back and they say: "I don't know what I was doing", you know, "will you forgive me?" Well what do you do? I mean, the natural reaction is to respond to vulnerability, at least I think it is. I think it's almost, I am talking off the top of my head and this might be absolute nonsense, but it's almost as though you have to have a bit of a pathological personality not to respond to vulnerability, you know the people who can [ward] off and ignore vulnerability, no they are dangerous people actually. So I think this lady, she was very vulnerable physically, she was solicitous and she was vulnerable at a spiritual level but also ahem, I mean there are some people who are vulnerable at a spiritual level but you can't actually help them, so that almost acts as a block. It's not that, there isn't a block I mean it just means that the patient, the relationship stays at a more formal doctor-patient level. There is no reason why people should accept anybody's help or intervention or sharing in any way at all, they don't have to do that. But when they do, there is no doubt that it, it ahem, it increases the sense of relating or relationship with that particular person. So this lady, I mean, she opened up, she demonstrated I think gratitude is the

wrong term because it makes it sound as though, you know one does something oneself, actually what I contributed was extremely small; maybe it contributed concern, I mean at the very least in contributed concern, you know, because of your concerned [love] with somebody to actually say: "Shall we pray", you know, then it demonstrates concern. I don't know what it is, but it caused her to weep.

PS: And yet some patients don't show any sort of spiritual need

R: No they don't, no, no. So, I suppose with those patients, you're really looking at your relationship on a level of, I don't know how you subdivide people, I tend to subdivide them in terms of the physical ahem, the soul by which I mean sort of mind and emotion and will, that sort of area and the spirit. And if they have no particular spiritual conviction or need, then you're you're on necessity dealing with them at the level of mind, oh sorry, body and mind emotion and will, you know there is not that

PS: There is a dimension that is not there

R: Yes, exactly, there is a dimension that is not there. It doesn't make any difference, I don't feel I have to deal with people at a spiritual level, ahem, but I do feel that when you do it's a fuller point of contact, we dealt with this lady at every point, I mean we talked to her about her problems with her family, we tried to deal with her from a physical point of view and then there was also this spiritual aspect that opened up at the last. I remember, going back to ---, I mean it was totally different with him, because I mean he, he didn't have any real belief but even he, we always ask people whether they have any particular faith, because it's part of whole person care and he said: "No, I don't have a belief but it's not for want of trying, but if you just don't believe, what can you do? I can't be untrue to myself." And in a way, although he said at that point "I do not", I didn't tell him what my belief was, but what he was saying from my perception because I know what my belief is, what he was really saying was: "I do not share your belief." So you would think really that that would cut off that element. But because he opened himself up and talked about it, it didn't. It is spirituality, absolutely. And even demonstrating his sort of [fullawkness], his his wholeness as a person.

PS: We talked about this before, we are not living in spiritual times as compared to other times, so somehow I have this vision of hospices as the frontier where spirituality

can somehow say: "I am here, I am not totally gone". You might not acknowledge me in the world, in your scientific, materialistic world but I am still somewhere in life.

R: Yes, yes, that's right. Well, we're all thinking and this interested me, again, this is not borne out of common belief but there is somebody involved in this hospice at a senior level who very much like us to incorporate into our day hospice opportunities for deeper discussion. And what he would like to do is to see ahem, representation from different religious backgrounds, different ministers of religion to share their, what their perception of spirituality is and how they have it organized in terms of the religious form. I am not quite sure how I feel about that because I mean, you know, the reality is that, I suppose the answer is, is you know, you go at a person's pace and as long as it's something which they are aware that this is what's actually going to be on offer and they choose to take it or not, which is the crucial issue, then fine. And then we do have an excellent discussion group amongst ahem, what we term, the young, younger patient group which is fifty-five and under, they meet together on a weekly basis and they talk about a great deal altogether, with regard to perceptions, not just spiritual but it encompasses that as well. So I think all right, I think I can, I think it's at times when people come up against something they know they can't win against, that they need to know that there is another dimension which many of them have never even given a thought to, or they have, but they have always been too busy.

PS: It seems to be part of our times

R: Yes, I think you're right.

PS: And yet it seems to me that some people at their perceived or anticipated end of their lives raise this issue, seems to be an indication that it is an issue, that it is an element that should maybe taken

R: Yes, I agree with you, I agree, I agree, but it has to be introduced to those people who can actually absorb it; actually Wales is very different from here, you know. I noticed when I came here, in Wales when you asked people what their faith was, ninety-five or more percent would give you an answer, they would say "Oh, I'm Welsh-Baptist, or I'm Methodist, or I'm C of E" or [whatever] it might be. Here, I would say, fully thirty percent, if not more, actually ahem, disclaim any religious affiliation at all.

PS: This is true of the carers as well, incidentally

R: True what, you said

PS: of the caregivers

R: Yes, I wouldn't be at all surprised! Yes.

PS: Well, I think we've covered (tape ends here).

Transcript Interview A 4

R: Participant A 4

PS: Interviewer

PS: The focus of the interview is on the interaction itself, on the communication with patients and relatives. What is going on in these situations?

R: I think when I started, twelve, thirteen years ago now, I hadn't trained as a counsellor / psychotherapist, middle, middle road, you know, and I ... supervised by ... psychotherapy ... so I had a very, sort of strict model, if you like, in my training, which dictated fifty minutes ... blah, blah, blah, you know, and I think when I first came into palliative care it was a real shock to my system because I couldn't make my model fit with what I was doing or what I was doing but didn't think you should be doing, if you like, and I went to work in a big oncology unit and I, I don't know, if it was my personal preference or just because there were so many people there but I ended up picking ... a lot of the young people. And I worked, I think in two or three instances, I worked intensively with, and maybe that was a reflection of my need at that junction, to do good if you like, or, you know, do a good job and I think that with a lot of hindsight that that's something people go through with when they first go into palliative care. They need to have this very intensive relationship if you like with patients, it's something as a supervisor now I watch out for. It's interesting if for oneself there is a real, there is a gift in it, but for the patient, I don't know. You know, and I found the work of Elisabeth Kubler-Ross and people like that, which I was quite sort of overwhelmed by at the time, sort of thing and I no longer support any of those things, I don't know, very damaging actually. Ahem, I [don't] think that the people that are ... there are on trips, ... and I

PS: It does seem that way sometimes.

R: That's everyone ... these things otherwise. And I feel much more at peace with that now, but at that time I was about twenty-six or so, and, I remember starting to work two or three years ... and I found that quite difficult to manage because work could not take place in fifty minute-blocks, it just couldn't but he was coming into chemo, he was too sick some days and things move on so quickly in palliative care. You know, ... my supervisor, he

was from outside the hospital ... would make an appointment every week you know, blah, blah, blah and it just wasn't working, just didn't work. And I felt hideously guilty about that it wasn't working and I thought that I wasn't behaving properly cause I had this model in my mind which kept suggesting to me that I wasn't practising as I ought to be and I had had a lot of practice previously in other worlds, you see, so I knew I ought to be different but I just wasn't doing it. Ahem, and I developed, so I had a quasi-counselling relationship with this ... and probably a quasi-friendship and a quasi-all sorts of things, which now I'm quite comfortable with, it's part of my practice I can manage that type of relationship very adequately without ... upset. But at that time I was trying to integrate meeting someone of my own age in a hideous situation, facing up to their own death, facing up to my own death, facing up to their, their unconscious anger towards me, despite the fact I wasn't ... staff, ahem, facing up to my anxiety ..., the fact I might die if I got something like this, cause they seemed perfectly all right people they got it ahem, this chaps ... limp ... was a poet which is probably why I got friendly with him [nearly] because he was, the sort of intellectual really, and I found it more difficult to give him any counselling ... he, he used to take the Mickey out of me really, say to me: "Hmhm, sort of chatter", you know, can't use talk to him as a human being, 'cause I did attempt to talk to him as a human being and usually lost my safety of my, what I would now call, my sort of 'professional overcoat', if you like, which actually wasn't, probably was a gift for me, it was a very painful learning curve for me. I think I needed to loose this sort of pseudo-professional counselling stance that I had adopted because I didn't really understand that, and actually believed that perhaps counselling, psychotherapy is not the same as whatever the Americans call it [panatology], you know, it's different, it's totally different, and I no longer would say, I could work as counsellor outside but what I do here is not counselling ... a lot of ... understanding. Ahem, anyway, this guy seemed to be getting better and we used to have a lot ... conversations perhaps; spirituality I suppose [if] he came from a very strong ... family and believed, strict believe in God, very strict people from the valleys, parents ... and they were terribly proud of this chap and come to London, and he was going to be, and he was merely getting his ... you know, and he seemed to be getting better and I right quite a lot now, I've written quite a lot about this experience which has taken a long time to process it really and aeh I remember thinking he was getting better and [would see him] every now and [then] he'd pop in and have a coffee. There was nothing you know, I don't know, if

perhaps he hadn't been sick and I hadn't relationship but we didn't have a relationship and it was never on the card, it was never spoken of really but I think it was probably somewhere in the background, a lot of transference and all the things that my supervisor might have mentioned to me if I had been more honest with her but I wasn't. You know, I felt quite comfortable with this relationship and aeh, I was running, you know, I was not only seeing this guy I was seeing ten or fifteen other people, you know, aehm, but on a very sort of come-and-go basis, these folk would come in for chemotherapy. They'd come in aehm, then they'd disappear for two or three weeks, we were a big centre so we wouldn't see them, ahem, but options ... what one like, you just couldn't run any of the things that you understood, you had to break boundaries by phoning these folk up all the time and do all sorts of things which didn't seem quite right. So I was doing all this all the time and I, and I was really unnerved by it, I suppose, but on ... I thought, I really found this very interesting, aehm, and what [he] does seemed to make a difference, you know what I did see to be making a difference and I counselled in other settings which really didn't seem to make an awful lot of difference to anybody and I think that's my personality, I need to be able to make a difference to people. I don't like, I am very practical ... in a sort of aesthetic sense, perhaps, anyway, this guy eventually came back and I remember one of the doctors saying to me ... just ... weird and aeh, they something about him not lasting 'till Christmas. And I just couldn't believe my ears. ... perfectly all right ... talking about it. And I was just beginning to develop a relationship with these consultants, you know, I was the sort of baby counsellor and they weren't really sure about what I was doing and they were getting a bit ... with me and just saying why he had come back and I was absolutely flabbergasted, I didn't know, should I tell this guy[s], nobody else seemed to be telling him, you know, and he well within the next week he was admitted and he was dying, it was quite clear he was dying, and he was in an awful lot of pain, nobody really knew how to deal with him, you know, they left him to me, really, and didn't know much, you know, I mean, I fell ... on ... hold his hands 'cause he was in so much pain, 'cause he, he got this very generalized pain when ... could[n't] touch his skin, you know, he was startling and there wasn't time to talk about what did he think, he was, you know, facing and all the rest of it, he was coming up to Christmas ... and it sort of run out I think it run out at the beginning or middle of December ... Christmas and his parents came up like ... I did quite a lot of work ... was there. The mother's brother had just died of leukaemia and ... hadn't been there and he

hadn't been home and the mother ... the slightest ... she kept running out of hospital screaming, you know, it was a desperate hospital really, was no, nowhere to see anybody, I mean that was the other thing, you know, you had to do your counselling at the bedside with the curtain round you if you were lucky spring through, interrupt you, you'd think, I've just got a really important point here, how am I going to manage this? you know. And certainly over a range of years I have learned to manage that very well but at the time I was totally flabbergasted, I was used to sitting in a quiet room listening to somebody, making my interpretation or not, as the case ... be, not dealing with some stupid nurses "Oh hi, cup of tea" you know. I don't know how many times I individual time all that rubbish, it's very interesting, and it never will be, you know, it's like I am adapted to the circumstances. But then I was trying to adapt the circumstance to the model I had in my head. And I am talking with him at about Christmas, going up to the ward, I came in on Christmas Day, very unusual, that wasn't ... and I went up and ... all his family around the bedside his family. You know, one of the things I teach now, about joining the family at the bedside, don't do it, you know, or do it with cognisance really, but then I didn't do cognisance. I thought I, you know, a pseudo-daughter-in-law, that sort of way, and I remember talking about a [theatre] I'd been to before Christmas Eve and he talked about this [concert] he'd been to in Wales and normally they all went there and I remember him saying: "You have to go ... ". And that was probably the only time that I knew, he knew, that this [wasn't] there, you know. And about two days later he just became unconscious, he was sort of half-conscious with an awful lot of pain and the guy who was looking after him, the consultant, who I, ... later married, didn't get on with very well at the time. It was, he was a very kind sort of caring bloke but he just couldn't deal with that whole situation ... These poor Welsh folk kept saying: "Why can't We are in London." And what I had in my head really was that, you know, he was now really unconscious and his mother did not want him to die there. So I begged and pleaded with everybody concerned with me getting an ambulance and sending [him] home. And they were absolutely horrified, this idea you know, he's die in the ambulance what's he going to be like, blah, blah, blah. And I just got into my head this is what we had to do to make this right. So this is what we did. And he'd got a thousand pounds for a private ambulance from the Midland (bank) and he sent it down. And after he died, one week later, me just going into work, he looked round and he said [Oh]. You know, it's one of those experiences, the sort of seminal experiences

and I find that really hard to put behind me because I hadn't been there at his death, couldn't quite accept he'd died and it, you know, it (loud cough!!) changed also my practising ... it made, I was very aware that I was ... involved ... I don't really have that concept any more. It's a concept that, you know, a supervisor might say or my supervisor might have said. I don't really see it like that now, I think what I understand from that experience is that if you are going to go on the journey with people you're going to have to jump in, jump on the bus and stay there. And you've got to have a lot of personal resources if you want to do that. And you have to do some things in order to, quickly [observe] if you like. And the ... I could never quickly and ... until the last two or three years when I wrote about it. When I had a son I remember thinking at the time that if I have a child, a little boy, I should call him --- and my little boys first name is ---. It was like one of those things that I had to complete the whole ... It's like he gave me things as I gave him I think and perhaps and what I felt at times that I hadn't done it right, hadn't done it right, you know, I'd done it better if [I had] been all right. And I think things I learned from that is that there is no doing it right and that the concept of being involved or uninvolved or over-involved is nonsense and that what we need to be is to be there and being aware of how you are being there in that individual circumstance and that you can actually [luck/lack] people. Sounds a very woolly concept but I think you can do that ... thing and I have done that with, usually people I've been very involved ... did I have that, that I've really deeply cared for. Also knowing that they're going to die. I haven't thought that on working through with some issue of my own that I felt that I got terribly close to this person but equally I think the thing that certainly that I will teach now is the idea that who you are being there for, are you ex[ploiting] the family by being there, you know, like Kuebler-Ross there, holding patients hand, rest of the family outside, you know, ... what. And there are times when you find yourself in that situation and it's a very very seductive trap to fall into, certainly I suppose in terms of individual work I think that individual work is a very limited practice when people are dying because it's about family group and that you just pick-up all sorts of transference unless you are a very skilled operator. And I am now but I wasn't. You isolate the rest of the family group if you pick-up the transference ... you are the only one who can do blah, blah, blah and you pick-up the anger towards them, da, da, da, you know, you get into all this nonsense really that you can easily do without realising what you're doing. So that's was a very sort of important experience for me.

And it contrasts with one I had here two or three years ago. Not longer down the line with a young woman who was twenty-four who, she'd had heart pain and she was one of those ... that you just, I am quite clear in my own mind that people are going to die. I don't know how I know it but I ... I have done so much work it's like people talk about it in palliative care, it's a thing I write about, it fascinates me that once you've worked in the environment for a while some people have a very strong intuition about how and when and not so much but on and off I am one of them. I have this, I just sort of know, I think this girl is not going to be around for very long. And people say it like that, they don't say "The eleventh hour, so-and-so" but I mean, I don't know, it's a range of medical knowledge, it's a range of, I think you can be very intuitive with somebody, you could feel that things are moving on with them really, and she was only around ... And she, it was very odd really, she had heart failure, she appeared to be quite pregnant, the ... accumulated, and she had this mom who was a bit of a disaster area really cause this was a long-term problem really and just could not bear, could not bear to let her go. And she was doing her best, this girl, sort of saying "I won't have any more treatment ... she could have ... I gonna let it go now" and sort of "let it catch up with me" really. But she, I suppose because 'cause I am a mom now it's very, my transference is about being mum and it's about people needing to be mothered ... mothering this girl and I could feel it and it's very hard to sort of hang on to the mothering bit and to hang on to the grown-up bit and I was their scribe. She wanted to write things to people and, so, and she was really, you know, absolutely [put out] her up and saying: "OK, what do you want to say next?" I think one of the struggles for me with her was that she used to write poetry, very bad poetry, it horrified me, you know, poet in another world, and I wanted to change it all the time and [she said] "If you want to change it I'd rather you did so." (laughing). And you know, it's one of those things I used to think 'what is this about?' you know, this is about making better in some way, you know, making what she was leaving better and she left ... [that arrangement] with her family and she left one uncompleted which very very naughty I completed and quite knowingly, only to the extent that I love and care for you ... blah, blah, blah, but I thought I just couldn't get round to that one. And, it's one of those things, ten years ago I'd been scandalised if I'd even thought of it, now I just think in the great scheme of things her intent was to write something special for each person and therefore since this is all they have in bereavement - and I also run bereavement [services] I know that is very

important. And to actually make out one of the members that got forgotten be really bad news. So, of course, basically, I ... really guilt about that, I don't sort of think, I don't even - I suppose I did get very involved with her. I was there right up until the death with her mother beside her and I did find it acutely painful. But I was quite into finish it in a way, I knew she was going to die I said good-bye her, I went in to say good-bye to her, she died. I went in sort of the next day I laid the body out to her mummy, it was sort of fact that we deal here really and I like to involve myself in that way where it's somebody I know quite well. Where it isn't somebody I don't know quite well, I don't. I don't need to ...iously involve myself ... interest ... of it. Ahem, I think as a worker, a professional or whatever it's important to complete circles. Otherwise, otherwise you have an under[lying] grief issue of your own which you, whether or not you came into the work for that, you certainly accrue as you go along. And I think that there is a period of time when you need to have a break from [it/here] really. I mean, I've been here a long time and some people seem to be able to stay in it a long time and I think perhaps if you do, you either learn ... survival skills but I think it's you come to a sort of place ... professional world, you come to a place which is ... all right. And I am very unprofessional in a sense but very professional in another sense. I dispense with a lot what people would conventionally think [I miss] the boundaries, I pop up on someone's bed and I know the issues we need to talk about and we ... quite open. But I won't be [wearing] like that, I won't say 'You've got fifteen minutes now', I won't do any of those things 'cause actually I don't believe in I don't mean to do, I know when I am out of my depth and my colleagues ... work with know when I'm out of my depth too ... (whispers) [back off] ... And I think that's for me one of the blessings working with other professionals too, not all of them, some of them are disasters but some of them, you know, that's where I had my support from. Not my own professional ... 'cause they are just not there! The night nurse who will say to me, one of the nurses here who is health care assistant, real local woman, very sensible women,, "don't believe in any of this counselling mumbo-jumbo" ... telling me that (laughs loudly) ... but she's got all the right qualities: she can stay with it, she can end it, she can do all the stuff we need to do. And we had a young man who had had a stroke, he had a cerebral tumour, he had a stroke, he was completely paraplegic, he couldn't speak, he couldn't do anything. One minute perfectly all right, next minute in this hideous situation with a pregnant wife an two small kids ... did a lot of work with the wife, couldn't do anything with him,

couldn't do anything with him at all, couldn't get him to even, didn't even know he was in there sort of thing, couldn't wink, [he did] nothing, very difficult you know. Very difficult working with her, supporting her, not knowing how long he was going to live whatever, and the day he died, again that's just I knew that the husband died. I was going home and I said "Oh no, ... counselling, somebody pick my kids up" and I stayed here ... feelings, really really strong feeling and sure enough, the alarm goes off, very unusual, and we're rushing there and he's obviously in a big fit, you know, ... I know he's going to die (whispers). So we get this poor woman and she can't bear to come in really, she has to stay outside and --- who is one of these nurses [hopeless women] I go in and we all not know what to do really we're flapping about doing our staff work, flapping about, really. She seemed quite [hit] by him, she, she's holding his hand and she is saying to him: "I've [been out there], it'll be all right, it'll be nice and quite, [you'll] be fine, Absolutely brilliant. And just think 'where has this woman got this from?' You know, me, even me, I was struck with that ... I am staying there with my cup of tea crying and she seemed there doing the stuff and I think I don't need I am not [needed] ... so eventually bring the wife and he dies. And later on, afterwards, I am devastated by this, I was sitting there and weeping [warily] into my cup of tea which I don't have a problem with, ahem, he don't like it, that's the counsellor, it's not really a I do it as a sort of object lesson to ... now and then so to show them I am notsly on the job and --- comes in and she says to me: "Do you want a cup of tea then?" [She goes then] "Yes a cup of tea". And I ... [talked/taughted] with her ... bit about counselling and communication skills and one of the things I teach the staff is the professional overcoat, whether it is your professional overcoat bound up to your neck and made of thick wool or is it a see-through Mac which we're [all aiming for], you know, ..., so after she gives me the cup of tea I had a bit of a weep well, she says: "Now did [I] cope well ... then?" "Shut up!" For me that was perfect support you know she recognized that at that moment I couldn't [get] it all together but she could equally say to me: "I know you're ok now" and we demonstrated we care about you "Shut up and get back to the job" ... you know. And there is a lot of talk about staff support and a lot of the time I think that perhaps the [one feature] of sitting around, I mean facilitating, I've done all that, you know, I've done it myself, those things to me are the things that work and those things that are done by people like --- who are able to stay with it, they get very ... to stick with their own. But it would easily believe, I don't need to know

what I believe really, I am interested sometimes but none of us really need to know what the other one believes about, or what happens or why. I mean, I think the thing about working in a hospice is you need to suspend the 'why' faculty, ... you believe you don't, you can't do it. You spend all your time thinking 'Why?' and that's what you do for the first few years in palliative care and some people get lucky and they just ... Some people get on a, you know, 'be professional' trip, some of the counsellors I know are absolutely overwhelmed with their professional trip, you know, about the whole thing, some people get on the ... better than everybody else trip, you know, it's such a range of options that we all need to go on one description or another but I think it would be quite interesting to study what makes people manage a long time in palliative care. And I suppose I am a lot more a religious person than I was, I was quite a sort of [makes noise ahrrgh] defend this, I am not any less than that thing, I have a great deal more respect for that which we don't know about, 'cause I've seen so much of it now. And I think at one stage it really sort of quite scared me really ... a number of years, what what [does all this mean]. I had some sort of spiritual crisis ...what does all this mean, how does one wrap this up into something that makes sense. And I think what I've unlearned is I don't need it [here]. It makes a certain amount of sense and although I stick with my intuitive, my gut, about sense, I am ...ft and that's interesting in a way for me. I [do my time].

(Both laugh)

PS: I think it's very interesting how you started and it is of relevance to all of us who work with people, boundaries, the supervision bit and the transference bit. I can very much empathise with this because I think we all go through a phase that whatever model we have in our head does not match the work we do.

But how do you work now?

R: Well, I did [n't] funnily enough do hang about the fifty-minute-level if I can. I think there are certain, I think the agenda in, there is an agenda, I think it's wrong to think that one can work, I think one can work at a very deep psychotherapeutic level with people ... I don't think one can't, I think one does one is doing anything of any use, and therefore I think, you know, I call myself a counsellor ... call whatever they like - [therapist] I would outside call that myself that but here I think it's frightening, and I just call

myself ---, you know, less scary. But I think it's probably a political thing as well that you have to make your skill relevant to those you are delivering to. So I think it is important to, and I have thought it is very important to think about our language and I do I moderate my language quite markedly to be very simple really not to use difficult concepts 'cause a lot of people I am working with are using and without captualizing people to, not over-interpret what they say or the level, I tend not to use interpretation, I probably use it without realising any more, so much part of my world. But I don't practically interpret but I work with the sort of themes that people would talk about and if we talking about, one woman I have worked [suitably] to talk about in the context of someone I have done something with, one young woman I was working with really couldn't talk about dying ... She could talk about the possibility of it in the future, she couldn't talk about it like right now and right now was pretty much on the agenda. And with young people that tends to be more ...ious. So you tend to work in quite a themed way. It's rare to talk straight about death, it's much easier to talk about it in a metaphorical way and I remember the last time I went to see her she had been making me gifts. And they were around 'good-byes' but she didn't say that. They were about things she was doing in the day centre, lovely, you know, a bit of knitting in her way and we had two or three, she knitted me this little cushion-thing. Again, I thought absolutely horrified, 'what do I do with the cushion?', 'why?', 'what does it say about me if I am ... a gift?' you know, and in answer to all that I sort of "Thank you very much". It was very very simple and a lot of the contact we had with each other was very simple, we were the same age, we looked quite similar and there was this symbolic thing that for her.

R: I do a lot of work with kids and for her she needed to, in order to hang on to being here she needed to feel that she was into some degree on the same par with me really and she made me this thing, and I thought ' ... accept any more gifts', you know, until we talked about gifts, we talked a lot about gifts and about the gifts she had given her children, how she brought them up, and all sorts of, really a lot of our conversations were about spirituality, they were for her about forgiveness really. She was grateful with the dogs, and she'd had an abortion, and she had two abortions actually, because she'd been having treatment, ... for a long time and you know, they were contra-indicating (loud hammering), they contra-indicated but because of her treatment. She had a lot of problems about [paying/praying ...] her abortions and she knew she was dying and she could

not speak to the Greek-Orthodox minister about these things and this was quite a big problem for me because I do talk a lot to people about spirituality but I really felt, what she actually wants is absolution. You know, and 'what do we do about this?' sort of thing. And she was at another hospice, she was at St Christopher's which, you know, is much bigger sort of [we] deal with here, and we talked about the gifts she had given the world and herself, you know, a lot of symbolic stuff and she kept coming back to this issue of abortions and we talked about it and how could she, what did she feel about it and I did all the counselling stuff and I just didn't feel all right 'cause I'd given ... and I had these (shows something) I still had them, I was wearing these. When I get twitchy as a counsellor I pull them and I remember bending over her one day and ... 'cause she had to lie in the bed and I'm doing this and it broke. (laughs) and she sort of laughed about really, she said: "Give me those", you know, she is absolutely insistent she'd give me those and I'll get them sorted it out for you. And I came back two days later and in the interim I had gone and talked to the chaplain and said to him: "This lady really needs absolution, that's what she is looking for, she means she is being condemned and she finds it quite hard to talk about it in absolution terms but she feels that when she get to where she is going that people who do such things ". And it was all quite a big turning point for me 'cause this guy he is a very sort of astute fellow and he said: "You can give her absolution. She won't see me, you can do it". I said: "I can't do it, I am not" and he said to me: "You're working on that level with her" he said "what's your problem? Get back in there and sort it out." Oh God, (laughs) so I had to sort of had to listen to him carefully and I went away and thought about it and thought of 'Well, ... didn't give it a go really'. And I went back and she produced this necklace for me and she said: "Look, I sorted it out for you." And I thought, I said: "How did you do that?" And she said: "Oh, I know somebody who ... necklace[s]." She said: "I can see it's important to you so I put a very thick piece of cord through it, so it won't broke again. And I felt that really strong symbolic message in there, you know, and I said to her, you know, I can't remember what I said to her but we talked about the [fact] that she'd given me something and how important that was for me to receive it and how in some senses I was vulnerable in the phases what was happening to her and that she was giving me something back if you like and an acknowledgement what I had done for her [70]. 'Cause every now and then she would say to me: "I couldn't have done this without you." And the other thing she said to me was: "You must promise not to leave me. You must

promise 'till the end of this that you will be here". Not being with her all the time, but "you won't leave me". And at one stage that did give me a big problem, but I don't have a problem with that now, and I said to her: "Whatever, I will stick this out with you", symbolically stick it out with you, you know, I'm going to ... the rest of Anyway, I know we talked about this issue of the abortion and I just came up with, like I do now, at the time I used to say a simple metaphor wonderful this little girl and this had happened and she had no choice what to say to her and she said: "Well, 'cause I'd say to her 'It doesn't matter' " and I said you'd really think that God would feel that you did something in order to be here for the children and that you [would/were] rushing about. And this sort of metaphor of father ... care ... And that just found her, it talked about it ... and that was a very short quite simple conversation and yet to me that was like a, you know, a big day sort of thing. And I think about a week or two later, she's a very symbolic woman actually when I think about it [almost everything] we did was symbolic, 'cause some of the rest of the time she just wanted to chat and have a [tea with me], she just [seemed] to have some very deeply symbolic conversation about something but this week we both knew exactly what it's about and she said: "Oh,he ... half an hour. At one stage my boundaries would have said 'He [sent us]' (laughs). That was fun, you know, yeah, I[our] women, yeah that's funny, that's interesting, ... about your kids, whatever, you know, let's do something else. And she said: "I want you to take me outside", this was the day before she died, "I want you to take me outside", so I took her outside in her wheelchair and I just knew, this was, she had something sort of planned for me and she had liver-secondary, so her [focus] was going nearly and she said to me: "I want you to go over there, I want you to pick a piece of each like a herb garden". So I picked one of each of these herbs gave it her and she had them and she snapped [smelled] each one and she said: "This is so-and-so" 'cause her sinus' [going] and she gave it back to me and it was like, it was like this symbolic 'Hello and Good-bye' to the world, it was a really, even now 'ugh', you know, it was one of those things, one of those memories that I shall never forget and very beautiful really. And I took off and back up to her bedroom and the next ... is unconscious and she died. And I remember going to see her after she died, I went back to the hospice as I wasn't working in the hospice but I've been in a hospital and just followed her through and the hospice staff were brilliant actually, they knew this was a big deal for me and the old vicar pops up and he says to me: "Want me to come with you?" and the nursing comes in, sister, "Do you

want me to come with you?" And I said: "No. I just want ... leave me alone", you know, and I went in so see, and I sort of sat to and there was such a strange difference in being someone who is alive and being [with] someone who is dead because their spirit is absent in every sense, it is absent from her body and that was something, whatever I believe in I don't think I, I mean I've seen plenty of dead before her, but the first person I saw [who] was dead it was such an important experience for me to know that they are not there, after people ... quite comforting, they are not there, you know, and she wasn't there either. And it's sort of OK if you know that they it's OK to let them be. And then I did some work with the children, go and see her body and that was me and my professional 'help the children' work, first it was me and me. So, I suppose I don't keep, I mean with the bereavement service, for instance, I keep them to the hour, I keep to a fairly strict counselling model, I don't do much group work myself, I just don't say much about it, [don't want to do it] (whispers) ... You could endlessly re-visit the cycle of grief, sort of I don't, well right now I don't want to do this, and that is a much more clear counselling model timed intervention. And I suppose psychodynamic, I still do work psychodynamically but a modified form of psychodynamic work, I don't really like (whispers) the person-centred approach, which most of my counsellors, ghastly. Most of my counsellors arrive, counselling courses are full of this nonsense and I try not to (laughs)... because obviously they're going to work that for themselves; I do say to them, you know, this work needs to happen quickly and, and this folk don't want to be messing about. You got [to think] these folk might be paying you, and if they pay, they don't, they want results but they don't want to be dawdling about having you listen to them, you know, your third ear... (laughing). So I have a much more pro-active approach, and I, I am quite pro-active in teaching and in my own practice because there, certainly with people who are dying, there is an agenda and the agenda is about working out where they are in assessment terms, for instance, where are they at the moment, where are they spiritually, where are they sexually, where are they emotionally, what do they want to know from you, do they need to know anything?, you know, what's going on?, you got to get the picture and you got to get it pretty quickly. So you need to ask in a very skilful way, 'cause ... all illuminate your experience, your previous experience as [pro], so that's very much ... I mean, I can do quite classic - I have done quite classic counselling with folk where you're listening, you're friend, what interpretation, the symbolic stuff is the most important to me, but I am always

very conscious that this might be the last interview, so the symbolism within each interview to me needs to be as it is, it needs to be a piece of work in itself, 'cause you might not do any more. And also that that person will be doing that sort of deep work on different levels at different times with different people and I may just [happen] to be one of them. So they might do it with another nurse and another ... they might do it with the cleaner, you know, does it matter? We have a pink sheet here where we record significant conversations so you get a bit of an idea where folk are, but it's not a place for primadonnas even counselling, you know, if you want to hug this client in bosom, not a good option. Having said that, you know, there are some situations where I understand the nature of symbolism probably in a more overash.... than a lot of my colleagues, you know, why I can relax ... with people. That girl, I mentioned, the young one, she liked to grow a plant, so actually she used, she realized [she/we] had a garden, so we got climbing [plant] and this was, we used symbolic, to discuss the whole issue about seeing growing plants, growing, the whole cycle of the world, that was just find for her, that's what she needed to symbolically understand her life and to understand in a sense the un...ables, 'cause for me working mostly with young people, the unknown of all the 'why?' is their biggest issue. And it has to be almost absent for me which is quite a strain after a while. I think probably for some people, it's quite interesting to watch them even like to have a baby and they get there [midway] do something, create, [prophetically] creating in order to something, the recreation need, I don't know what it is but it's sort of there, to go on, do that.

PS: I suppose you rely a lot on intuition?

R: I think I probably do which I am rather ashamed to admit in a way, at one stage I lot of things. I think I have a much greater sense of my tuition, whatever measurable quality intuition is and I ... cognitive therapists who tell me that there is no such thing, ... of nonsense, but I know it's not, I know it's what I know. Nurses have it, you know, other people who do it, it's not just to me

PS: Yes I know that from the other interviews. It's a highly developed area

R: highly developed area and it really interests me, as an interested mind as to what exactly it is (loud coughing) ['cause] it's blend of the spiritual (loud coughing) and another part of ourselves that's sensing things about people's

emotional state but also about their physiological state and maybe about their spiritual state, I don't know. I think somebody who is a good caregiver and has done it for a while, one or two of the nurses, they are like me, you know, if they say someone is about to die, there are about to die. You know, it's absolutely intrigue[ing], you get some of the new doctors ... you could hear him telling the words (whispers) and I just thought 'Let's get rid of that doctor'. And have a conversation about wills or last words, or, that's what I mean about being interventionist, if you live with your intuition you got to get on with it, otherwise, you know, problems [station] about how long someone is gonna live. You generally have a good idea what someone else does. It sort of fascinates and scares me at the same time 'cause it gives a sort of substance to, you know, there is a lot of nonsense talked about certainly in bereavement; most folk will come to our bereavement service about to see ... and all sorts of [blah, blah] which I don't go along with at all, you know, my strict... .. fashion ... (laughs) but on the other hand it's everything you after them and it's quite hard to know what to do about that and what for you to take on, because of a lot of things have happened here and certainly in my, my sort of career that would make me wonder about ...

PS: I didn't realized how much of the communication and interaction is on a non-verbal level and even deeper.

R: I know what you mean. Absolutely, deeper than the non-verbal.

PS: It seems to be one level deeper and totally unexplored territory?

R: It's funny 'cause it's what I write about. I spent a long time with a writer - he publishes a lot of things about bereavement really, personal experiences, not you know. Talking about this he is exactly [wacky] but he knows I am not, if you know what I mean, it's almost like wanting to do scientific study. Just think, I know I am not at the [wacky] end of practising in this area, you know, I am pretty sort of more of middle of the road really, but I know it happens, it happens to me, it's happened; it's like the more you tune up the sense the sort of worse it gets. And I remember going round talking to other people about it here and sort of saying: "Does that happen to you?" "Oh, yes, that happens to me". Not everyone, not everyone. There are some people that are definitely more tuned up for and the nurses, I remember me saying to them at one stage: "It ". One

guy I knew exactly he was going to die he came of my office and popped down the corridor and I knew he was about to die, no rea-, no no nothing that would indicate to me. I've written down my pad - I thought: '[Let's] test this one out.' And I said to them, one of them is called Lynn: "Why, you know, why does this happen? What is it?" and she said to me: "Well" she said to me "you see death but are not aware that you can see him or it", you know, and I was sort of flabbergasted concept.

PS: This is not a thought when you

R: I talked a lot about this. It's not a thought what it is, it's like, the best way I can explain it is, if I say to you "What is two and two?" You know what two and two is, well it's exactly like that. It's, you just sort of look up from whatever you are doing and are absolute certain you know, that's the best way of describing it, you know. You don't know how you know, you don't know why you know, you just know. And it doesn't matter [whether you stay at your desk or you go down or whatever, and I often say to people: "Did so-and-so happen ... ?" just to test out my ...rum and inevitably that the case. And it comes and goes, it comes and goes. Sometimes it's awful, absolutely awful, everything. It's not just like 'people die', it sort of bleeds into lots of things like, you see a pink car at the end of the road and it sort of gets completely out of hand and then I think I just keep [whatever] ... die

PS: Is there some level in us that works differently, where this belongs to?

R: Yeah, I do. I think there is some very rudimentary developed sense that we all have that has just accidentally developed in your circumstance and it may be about energy, I don't know what it is about, I really don't know what it's about, but undoubtedly, the proof is in the eating of the pudding you see it, and you see it [in] all sorts of folk and therefore it's not about one person on a whacky trip, it's

PS: It's equally not anything that can be taught?

R: Oh, absolutely not, I don't think so. I mean, I know a lot of people do meditations and they try to heighten their awareness. I would never do that, I don't want my awareness any more heightened that it [already] is (laughs). Sometimes, in fact, my other counsellor who is much more into stuff like that than I am, who works here, who I manage, she knows I don't like [using] stuff like that but

occasionally she will say to me: "I think it's time you sat down and grounded yourself." She believes in this grounding what I think is a lot of rubbish but I'll do it. When it, it got particular bad about about three or four months ago and you know, every ten ... (clicks her fingers) I knew something was happening and I [said] "She's ... bonkers, is she? Sit down and" you know "take a deep breath" and I imagine this white light with a and it did go away actually, so I do use that now actually without actually paying ... lip service (laughs). But it is very interesting 'cause it's a sort of, it's one of those things it's quite hard to talk about I think without being labelled a poop.

PS: But it's something very different from what it's in the textbooks about non-verbal communication with all the ramifications that they put into this field, getting more and more smaller segments to analyse?

R: Totally different. I mean if I, you might use infra-red camera or something you might see changes in people's energy fields, I don't know.

PS: The healer I spoke to earlier talked about energy fields.

R: They do talk about this. This is funny actually. I am, the first hospital I worked in was the --- and the guy there was very keen on getting a lot of alternative folk in, this was ages ago, so it was a very radical idea at the time and after about working there three or four years I got married and I got pregnant and my first child died, she was stillborn, big trauma, you know, couldn't work, couldn't work in bereavement. And I went along to one of these whacky conferences they were having, cause I was off work, and I thought 'This is whacky' and the guy said to me: "This is a whacky ..." and you know, every bit twitchy about me because I was newly bereaved, it's about s...ngs and stuff. And they had this healer there from the Bristol Centre and this professor said to me: "You gonna have [to forget] her 'cause she is really mad and I don't want to have anything to do with [them]. You can deal with these folk" ... you know. So that evening we all had to go out to a meal to entertain these folks and we're all sitting at the table and I end up sitting next to her and she is dressed out with some straight garment and she just [garbs] and everything, and I am thinking 'Oh, there are all these doctors slivering and ugh, look at her', you know, 'what is she like, we don't want something like this in our own environment' etc. etc. Anyway I am sitting next to [her] and we are having our [slimed] in supper order and she said to me, she just turned

to me and she said: "You've had a terrible loss, haven't you." And, of course, everyone on the table sort of absolutely horrified and I said to her: "I suppose I have in a way", you know, I was being very difficult about the whole thing and she said, she put her hand on my back and, you know, as they say with [healers/healers] I had this huge sensation of heat on my back, she, she was going through my body, and it was her, you know, and everybody else had stopped really paying attention to us and she said to me: "It will all be all right and you are going to [have] another baby." And the next day I found out I was pregnant. And it was weird, it totally changed my view of healers. I've never been to a healer since, I don't want to go anywhere near healers but, undoubtedly and I remember saying to my husband at home, "she [branded me] real hot", really weird, and I am a terrible sceptic, you know, so it's, but I totally changed my view and I now just sit on the sidelines and say "I don't know, I don't know." How did she know that? in ... circle, how could she know that? Unless I was giving off some sort of pregnant energy, I can't really go into this sort of whispering angels stuff

PS: There seems to be something going on between people

R: Yes, and I think if you can be in touch with that bit, whether you're conscious or unconscious of it in a way and I think you must be unconscious in a lot of it when it pokes its head up, forces you to take notice of it, then I think in some way that's where you get your resorts, that's ...where I get my resorts and I get a lot of my authority in what I do from. I am quite authoritative now about certain things and I just go along: 'So we're gonna do this', you know, (whispers) ...["How did she] work that one out?" I just sort of know that that's the right thing to do and there are other people I will hear the same thing from and there are other people who think '...[Oh,] go for a long walk while we sort this out'.

PS: Do you think it may be all connected at some level, a manifestation of a third force that acts somehow in human beings [who are] together?

R: I think that's right, I think that that's probably what you know traditional psychotherapy stumbled on when they talked about intuition and some of those things. I think that part of it is probably the intensity of the sort of work we do here, you know, it's just volume is jacked up a bit. It is also a bit like ahem, you know, Sartre had these three ages, the political, the spiritual, and I just think that you become

spiritually a lot more self-actualised a lot earlier in this world and for some people, that's why they are there; I am sure that's one of the reasons I am here, as a for...ay in some sort of way, ... into sort of spiritual world, a spiritual ... you know, the things you can't quite get a grip on, and it's probably the thing that keeps me here really although in a way I am probably, it's probably time I left. I sort of quite like to do something else now.

I have stopped doing an awful lot of face-to-face work in the last year and a bit and the more I write the less face-to-face work I want to do, funnily enough. I am not quite sure what that's about but, you know, I mean if the golden finger came through the window for me I'd give up and just be writing now, just stop. But actually I feel I've sort of done what I need to do if, I don't need to do it anymore; I can do it very competently it's more of the same, you know, that you lose your edge in a way if it's more of the same and I see a lot of my new counsellors, you know, they're all (makes a gesture), they are all there, you know, they are on the road and I think 'fabulous, off you go', you know, (coughing).

PS: Thank you very much. (interview ends)

Transcript Interview C 1

R: Participant C 1

PS: Interviewer

R: So, do you want me to relate, I am just thinking of just certain instances related to patients' death perhaps that I ... speak to you really and their families and just kind of go over some of the things that stand out in my mind and perhaps instances that I highlighted and kept with myself

PS: Yes, exactly.

R: Right, ahem, I mean, I kind of, I've been working in palliative care mh, mh, two breaks and I've done about seven-and-a-half years really; so obviously during that time I've experienced a lot of deaths, ahem, not just professional deaths, I have had personal loss as well including a ... my own grandfather at the hospice which I am happy to sort of mention and relate to a little bit, ahem, because obviously that's added [to] some empathy for me as well. And, and I think, as with all things it's not the patients' dying doesn't effect me any more because I think it very much does but of course there will always be certain patients that actually affect us individually more than others, and and that obviously can because I've perhaps built up more of a relationship with certain patients and their families or spent more time with them ... perhaps that I've actually related in some way on a personal level to a particular patient more. So I think that's important for me to sort of mention first, that there, there will always be rather than feeling ahem, a sort of sense of loss about perhaps every patient's death, there there will always have been patients that have affected me more, ahem I think that's important to remember. Certainly there have been a couple of patients ahem for a period of two or three years ago now in fact, not very very recent to me but that were very young patients, they were thirty-five, thirty-six and they both had young children. I now have a young son and I think that is something that obviously for me ahem has, has been particularly poignant because I, I'd once spent a long time with both of those patients. One of them was a lady who we've actually nursed through an awful lot of stresses in her life and we actually, if you like, to get to where we wanted to be in the end and that was some acceptance of her own death, took a long time to get there. She actually understandably for many of us felt that first of all she was getting better and then working through that took a long time and she actually not only aeh, lost many of her physical attributes but she was

losing obviously all of the social bases in her, her family and her friends as well. That was very hard because I think sometimes in me there is, you almost know where you would like that patient to be or where you hope that you could help them get to in relation to their own death and sometimes that can be quite clear where you feel other ways [otherwise] that you can help that patient; and that was quite the case with this patient who, perhaps we could talk about the 'Sue' or whatever for a moment. Aehm, it was actually quite clear where we needed to go, the difficulty and some of the frustrations which perhaps is the wrong way to think of it and afterwards it's understandable but at the time it it perhaps could be frustrating because I felt that her time was very precious and it's very hard almost not to be blunt and actually highlight that and sometimes there was, there was an element of me that almost wanted to say 'This is the time we have, this is what we need to achieve and this is what perhaps you would want to do with that time'. And, of course, it's actually being able to stand back and think 'Well, I am on the outside of the [community], she is the one on the inside trying to look out'; and of course it's always trying as much as you can to understand why patients will suddenly just be angry or block off or not want to go any further. And and that I'm, I'm fully aware only can ever be to a certain level because I am not (emphasizes 'not') in that position, you know, 'There but for the grace of God', so I'm not in that position. That was quite hard because she needed to do things for her children. She wanted to make tapes for her children so we actually helped her to make a lot of tapes, things that she wanted to leave as a legacy and that can be very wrenching because, of course, we became very involved with that and that I felt extremely hard, one, because I, I understood how necessary it was but I think it actually is a very, a very hard thing for a patient to try and envisage what their son would be or what they daughter would be at a certain age and try to imagine what they would want to hear about a mother that has perhaps been dead two or three years. So that that was something that has always stood out in my mind perhaps as an example for myself as well. Another odd one was, was very similar: a young lady again but actually there were a lot of cultural influences as well. She was a Romanian lass and that, that was extremely difficult because there was almost a a tug of love battle over a small son and and that was very hard to guide her, because I could see that she was actually rather than wanting to find the right emotional future for her son, there, there was a problem that she actually wanted her son to remain in this country. So, that, that was very difficult and other frustrations linked with that as well and that's

something that stands out in my mind. I think some of, many of the deaths that I've perhaps experienced that have stood out to me more have been young girl patients that I think we've had empathy with, and also because I think on the whole that's when I, I, I sense a new experience a lot more anger in those patients because understandably it's not the right time for them to die, they feel very cross and it's actually moving from that crassness, and sometimes of course, we never do, to if they can, if they have an acceptance of their own death. And often that doesn't happen. Often it's just something that's too awful for them to accept at all, understandably, you know; I don't how I would feel, obviously, at that time. I think, I think that that's quite parallel in a lot of patients and I don't think that because patients are older they accept dying more necessarily, but I think there is a certain fulfilment that when, when patients have perhaps seen their loved ones grow to a certain age and perhaps had grandchildren and perhaps had spent and achieved things with them, there has tended to be more acceptance possibly, so that's something that is quite traumatic. I think the biggest thing for me really is how a patient dies. I presume that's, that's the biggest reason I think I am in hospice care is because it's not, it, there is a certain amount of acceptance whether I like or not of what my own religious or spiritual beliefs are, whether I like it or not that patients die and whether I believe it's fair or not, I, I think probably I don't; a lot of the time I think I, I can be classed as fairly reasonable on that but I probably don't accept it as fair a lot of the time and I certainly question and go home and think to myself 'Why are people still dying like this? Why, why aren't we able to stop that?' But of course, many of these patients have been through the most up-to-date treatment and they've had rigorous battles and that's where I think a lot of my hopes lie in that not that I can actually do anything about the fact that the patient is dying but how the patient dies and that's certainly with the comparison to working in acute oncology, in acute hospital settings and comparing the two is the biggest fact for me. And I would say that that's actually the biggest sustaining factor for me in continuing in palliative care, actually feeling that we can make a difference in how a patient dies. And I think you can do that on an individual basis as well as collectively on a multi-disciplinary basis. Once the obvious with symptoms and control, but in fact the time factor is important and the fact that we feel and I feel strong enough to actually, I think there are very few things that I could say to a patient or a patient could say to me that would shock me or scare me into not feeling I could deal with that with them. I, I think most things, and I hope that now and I think

on the whole I do recognize what a patient is asking me and if they're asking for honesty and if they're asking at about a certain stage I now don't feel, and I think it takes quite a long time particularly for nurses who still tend to feel they need to involve medical staff and, and still are geared towards actually finding a doctor to answer the difficult questions, I think it takes quite a long time to actually feel calm and confident enough to sit down and talk about [those] incidences and episodes through with patients. And that I have done on several occasions and actually two or three of those instances do stand out, but I've actually at the time thought to myself if the patients asked me if they are going to die or if they're going to get better, there is almost a split-second in me sometimes when I realize how easy it would be to be to reassure them and to give false hopes and to make them feel better. And, and that at the time a split second of me actually thinks 'It would be so nice and so much easier and I'd love to be able to just do that; it it would calm you to be able to say'. But of course, that is only a split-second because already in my head it is trying to work through what the patient is asking me, what they want to hear and how we can move on and explore what they are asking for further, and, and several times that has happened. Ahem, and I can think of a couple of patients that that have actually afterwards we've gone through, we've moved along and we've, we've come to the fact that they are dying but obviously we don't know how long ahem, and we've talked about many of the things that we can still look at afterwards and that's not that I believe that you have to end all conversations on a positive note but I do believe very much in hope in palliative care. I think it's essential, I think that, and I do think that there is hope in palliative care and I think as long as you create a hope that's realistic rather than the unrealistic hope; and I've certainly explored that with patients and perhaps used that for my own safeguard in maybe sometimes you feel you have to, to opt for something that is hopeful and and that possibly is the case. But I hope always and I think that it's always been a fairly realistic hope but certainly I've, we've talked through about the fact that a patient isn't getting better, that they're dying and that many of the things that they had hoped won't happen and making realistic goals. And that can feel very hard afterwards and I would say that that does not weigh me down when I go home but I hope and I think that I actually do think through that process still very much and 'Did that go the way it should have gone? Did the patient come to the conclusion that perhaps you would hope and that they want you to at the end? How is that [left] that patient to move forward? Ahem, the next day; 'Have they

got something that they can realistically work around afterwards and do we need to move on?' to the point that I think, I think I can remember once when it backfired dreadfully which wasn't actually in palliative care it was in acute oncology and I think that was almost harder in some ways, because, of course, a lot of patients are still at the active treatment stage then in many ways because we're resigned when we are in palliative care to a degree, not because patients are imminently terminal but because a certain amount of active treatments have been ruled out once we are seeing many of our patients. I think it, it did backfire and it was very horrible and and left me feeling quite shattered afterwards because the patient was very angry that that we talked about the fact and we worked through and the fact that they actually weren't getting better and at that time I did think 'Did we do that right?' They obviously weren't ready even though I felt that we'd led all the way with further questions and actually got to a. The next day it was good and the patient actually approached me and and spoke about it, but but it still left me with that feeling that you really need to be very careful about what you're being asked and I think I do come away with that and I try very carefully to listen to what I am being asked by a patient rather than what I know and think 'Yes it would be easy for me to tell them this but are they actually asking that? Is that what they want to know now?' And I suppose that's still probably the biggest challenge in palliative care in many ways, actually what a patient wants to know and what they're asking to know and how you can move on to do that and and that probably is one of the factors. I think we found this as well, it's many patients that are dying, many of the families are actually asking obviously how long and what sort of death and that that can be some of the hardest things really what they're actually wanting to know and how a patient will die, especially as we are often perhaps trying to arrange for many of our patients to go home to die. So that can be kind of a significant factor really. I'm just trying to think from the point of view of the families that have been traumatic. Can we just pause for a moment Peter?

PS: Yes, of course (tape switched off)

R: What I was just trying to think about for a moment or two is, is perhaps ahem, something else. I, I think often the kind of the personal feelings come into play and I don't think to do a lot of these things, to experience a lot of these things you need to necessarily have been in the same situation yourself. I don't, I don't believe that you do need to to have understanding and empathy with patients and

families. What I would say from my own experience is I do think that that made me look at the place and the environment and a death differently, and, and just briefly what happened was, my grand-father had had cancer for two or three years and actually we found him here as a patient, he ended up coming here as a patient for only a period of three days which I think probably was as well from the point of view that obviously there is a huge difference and I think it highlighted to me the huge difference there is between a loved one and a patient which probably we all know but it actually, I don't think I could have imagined quite how affected I would be in a completely different way. And that's when I probably saw what I hoped hospice care would be for people and what it could be. And what I think I, and truly believe it is for most people, how they see it, because sometimes on a day-to-day basis it's very hard to think 'Did we get that right?' and to actually be reflective afterwards and wandering 'We've actually thought that through and did that work well for that patient? Could that have been improved?' And I think, I think you can be over-critical of yourself and what you try to achieve and what has been achieved because often, often death is the final resolve [result] and in many ways that can seem, that that is a negative factor in many ways, of course it is because somebody has lost somebody they loved very dearly and somebody has perhaps died much sooner than we believe and they believe they should have done. So it's very hard to actually turn that into a positive incident and turn that into something that you can work from and move on and think 'That went well.' But, of course, it does, it does happen like that and it does go well and I think often that is the case, it it goes the best that you would hope that it could do for something as sad. And I think with my granddad I actually realized that. I saw completely differently and funnily enough even just walking along the corridor, the place could have been a different environment. Yet I walk along this corridor so often in a day but it really did seem completely differently and I realized sitting there, ahem, how vulnerable it is to feel that you are sitting with this person that you don't know what to expect, you know that they are dying because of of the fact that you've had conversations and you could see the changes, but how vulnerable it is to feel that other people have total control of this situation and and you rely, communication is so hugely important and it only really took, even as a nurse, somebody to come up, one of the girls and put their hand onto my shoulder or say: "How are you doing and how is your ...?" to actually realize how reassuring that could be. It took very small acts in communication. It really didn't need somebody

to come and have in-depth conversation at the time and talk about what was forthcoming and how things were. It just took somebody to actually be aware that you were sitting there feeling lonely or feeling scared or feeling worried about what things, what would happen, to be aware of you as a person now, that, that was very very important to me. I also, because of I experienced when my granddad died and it was unexpected in that aeh for it to be then and there, it was much sooner than we'd envisaged, although obviously we knew that would probably be the outcome. I think I was aware and and that made me question many things really, I was aware that he seemed to be aware of a third presence before he died, not necessarily a family member because he certainly talked about people that he couldn't see and he appeared not to focus any more. Now, I have known other patients experience that and that that has made me wonder if in fact there is something and if in fact we we do have a presence that that actually guides many of our patients and I, I don't say specifically and for every patient but I think it left a question, more than anything for me, is there other presences that come and are they aware and and I think from the fact that patients have often woken up and said they were aware of an alternative presence in the night. And I think spiritually it's important to kind of look into everybody's individual spiritual needs rather than just family [just need], the two being different [obviously]. I think it is important, but I think it highlighted to me as well at the time, ahem, perhaps that what patients themselves may be experiencing that that it is extremely hard to know and to imagine and impossible really what a patient in the last hours, what's happening through them and what they're seeing and what, what is reassuring them really. I think we all believe how important communication is to patients who appear to be unconscious and at not understand and I now think oh it's of paramount importance but I think we do highlight that with relatives certainly how important it is to talk to them. But I think experiencing it first hand probably did open some fresh avenues to me, things that perhaps I wouldn't necessarily have considered unless I'd experienced them. Certainly the warmth of the environment, the smallest act of communication was very important to me, so I think that was quite important to actually think about.

PS: The way you describe it seems to me if I use a metaphor, like a journey

R: Yes, yeah.

PS: but you as a carer are somehow involved in this journey of this person

R: Yes, yes, yeah. I think that we can be to facilitate with the journey. I think, I do believe that it is but I don't, I wouldn't generalize with patients because I don't know and I suppose I still do keep a very open mind. I do think that most of them are and I certainly believe for some of those patients, before they die, there probably is a lot of something happening to them spiritually and something actually, and I really don't mean that necessarily in a religious context, I mean something's happening to them, it's something that perhaps they're working through. And I wonder if they are aware of [their] presence and if they are, but on a very superficial level and that they're actually working through and it is part of the journey and it is all extra-sensual time. And, of course, patients die very suddenly and whether that, that means that they're actually not as well prepared, that that certainly I think is a possibility. And that period of time can be very distressing for relatives because, of course, it can seem very frustrating, actually sitting by the bed of an unconscious patient and actually feeling that they are talking to somebody who isn't responding back and feeling that they are not, ahem, not serving a useful purpose because they, they perhaps started to lose this person that they love already, but, of course, they're still lying there. And I think what all I can try to reassure them is that it is very important, that I do believe in, and because one, because I do believe it and two, because I do feel it's important that they realize how important their presence is and how reassuring it it probably is to that patient, to be aware of their voices, the familiar voices, the familiar smells, even if they can't anticipate, I think probably it is important for them to be aware of that and I do I do try and I do think patients and relatives need to know that how important that is. But I think probably it is a journey and I, but I wouldn't generalize it with every patient, I think it's it's a very individual thing and I think it's a very specific thing with patients. And in many ways often all I can relate it to is that we do pick up a book at the end of of the book, we may be reading the last chapter, we glean from the first few chapters, ahem, what we've been told and from hospital knows, incidences that relatives have told us but often it is picking up the book and the end of it and, and for a lot of us it's actually trying to imagine and it's not essential and not necessary to do but in some cases it's, you almost want to is actually to glean what's happened before, what's gone on in the book before, what, what has this person been about (I & R briefly talking at the same time).

That's right, and what, what they actually, what is important to them, their values and their principles, not because it may be ... necessarily help their deaths be more peaceful and more sound but I think that it is, it feels quite nice to think that you've known something about that person and that you can then understand some of what the relatives are trying to tell you about this person, that of course, you then don't just see in an unconscious patient. You see somebody that has been very ... and very special and on a daily basis that's hard to do sometimes and I, I wouldn't say that it's essential or that you do it all the times because, of course, you don't. I think there has to be coping mechanisms working with death; I think we develop our own coping mechanisms and it's essential and it certainly isn't for everybody, because although a huge proportion of our patients are going home and they're here for symptom control, various other things we may never even see, their deaths. Obviously a lot of the patients we do and we are still involved an awful lot in the care with patients and families, therefore inside needs to be something that actually not makes it all right but helps you understand and cope with it and that is very for our own spirituality from what our own perception is of death and what we believe in afterwards, ahem, and I think, I think you can only explore that on an individual level. I mean, certainly there are group sessions that are important for support and reassurance and I think they are essential, the support does take place; but ultimately it's what you, how you actually replenish your supplies yourself and what you believe ahem death is perhaps about and what you see afterwards and what, how you believe it should be for patients. I think, ultimately, that's, that's the area that helps you cope on a day-to-day basis and certainly it is for me, certainly for myself I think, as I said before, it doesn't mean that it's always acceptable but I think that it's definitely concerned with how a patient dies. I mean I can think of a lady and a chap who were in at the same time that were middle-aged and were very vibrant people, very very full of life, ahem, and what I would call or class as as 'life's givers', people that are actually very generous in spirit and affection and and have huge admirers because of their personality. That's always very hard because, of course, you you see not just perhaps their immediate family who love them so much, but you're constantly flooded with people that actually idealise and love this person so much so you instantly become more involved and are more aware. And sometimes, these people become almost your friends, they are ill and they are patients but I can certainly think of a couple of patients that that, not that you necessarily would think out of this

environment, they would be a friend, but you actually have many more feelings for them than that other patient. They are very powerful feelings, you actually that, you feel very pleased to be involved in this person's life, even for a very short time; they're very generous and very giving and I think I am thinking and, a lady has come to mind that is really, probably the most recent death that has, that I can think of that has touched me quite significantly and it's a lady who was late thirties who all the way through her admission here, which was for quite a long time, in fact two periods of time, was extremely calm. It's not that I expect to see patients who are angry. Sometimes I am amazed that patients aren't more angry, sometimes I sit there and I think 'Why aren't they more angry? How have they worked through and come to this acceptance?' and it's incredible that, that their realistically thinking about the end of their lives and they are not cross. And that amazes me at times and it still amazes me now, possibly because I think of myself and I think 'Would I ever be in their position without being cross at dying at that age? Would I would, could I ever achieve that?' I don't know, I hope so if I was faced that but I'm, I'm often amazed and in awe of [this] and ahem, this lady was extremely calm throughout her whole of her stay with us and very realistic, very realistic right from the word 'go'; had many things to sort out. She had a very strong faith and I would say that that certainly aided her in her journey but very categorically she wanted to work through all the things that she needed to do. And she had three children, they ranged from 8 and 9 down to 6, two girls and a boy. She quite calmly suggested one evening she wanted to have a very nice candle-lit supper with her husband with a, a bed that attaches to our patients' beds and that he would stay the night and they would share a special evening together. That, that's something we are asked for very often and that's something that is, is, we encourage and is wonderful and is very easy to arrange and very, very ahem positive in my view and in our view. She then asked if we could arrange for each child to stay individually because she needed to go over special things with that child individually and wanted individual special time and that, that was very hard to imagine that anybody could be that brave, for me to think about this. She could actually obviously I am not aware forgiveness of the things she actually went over, that was very special private time with each child; to me that was a huge thing, a huge thing that this patient could achieve. Even now it brings a lump to my throat because I can't imagine that anybody having that much guts to be able to do that. It was incredible really and each child did stay overnight and we became very 'mummyish' to any

of these children, they were very little. We found them night dresses to wear. But it was a very happy time, it ...

R: But I, I was amazed she had the ability to be so calm and how could be so calm, I was in awe of her I think, a little bit, ahem, I truly felt she tackled, it amazed me what and in fact it didn't and I often wondered if we would see an angry spell, if, if she would become angry before she died or cross or could it be that she could deal with it so calmly and so well and and in fact, how was that for her family? Was that hard on them that she was almost so calm? But she was like it to the end and I presume that she had always been like it and that that was purely her personality. And, of course, she was sad to be dying, it wasn't that she wasn't sad to be dying, I think she had, she had certainly a huge amount to give up and, and not die for, but she didn't get cross all the way through and in some ways coping with somebody's anger is easier than not seeing their anger because I think you could almost think 'Well, that's a normal reaction and perhaps we'll deal with it this way or we'll help them talk through'; it's almost unbelievable to see somebody that peaceful, and and somehow harder, perhaps because you wonder what you could offer this person, maybe you feel that you are not being of as much use or, or in some way helping this person as much as perhaps you would like to on their journey or feel is important, but that in itself is a good learning ground because it makes you realize again how individual [it] is, that they don't all need you to help them, that sometimes, creating the space and the environment they can do it themselves and maybe, actually they don't need you to help them on that journey, maybe the time out from their own environment is all that they do need and recognize and that is even more important and not doing something that you don't need to do. You know, it's, it's the doing of things but it isn't always necessary and it wasn't really that necessary there, she could do it and she did and all we gave her was the ability to do that to the ... and to support her through that and we didn't actually need to help her think that that was what she needed to do or perhaps would be good to do. And that was a huge- a big thing for me, a very special thing ahem because I was in awe I think of the women, absolutely in awe of her.

PS: I've heard from other interviewees that they have great difficulty dealing with people that come in and say: "Yes, I am ready."

R: Yes. And all I can relate it to, is maybe, because you start to put yourself in their position and think 'Well I know

I'd be angry if I was that age and I was dying and I had to leave my three children, I'd be angry'. But, of course, it's it's not we would all think about our own mortality and I imagine that working in this environment we will think about our own mortality more so than the average person on the street, I think that that would be fair to say

PS: I think it's inevitable

R: Absolutely. I, I hope that in some ways it's a positive factor ... where it actually makes you utilize what you have and on a day-to-day basis and in a more special way and I think that, I think that there is some significance in that and I think that when I get home I actually do, ahem, on the whole, I mean we, I said on a day-to-day basis I go I think it's huge steps to [be] alive and I must make the most of today, it could be my last, of course, I don't, you can't survive like that, but I do think that something actually prioritises in you and and that something actually makes you think 'Well, that's a possibility' and, of course, we aren't all going to be eighty, you know, that's not necessarily guaranteed; therefore it is important and what is important? And I think there is an element of that in your life as well as, of course, the mundane realities that that we all face on a day-to-day basis. So that will -. The other kind of incident that just probably that as a maybe my last one that stands out and that would have been some, a lady that we lost three or four years ago. It's not that the patient herself or the death itself was particularly significant but more in after... the death. Funnily enough it was a lady who was a French lady and her and her husband were both teachers and in fact I had been at the school where ... taught her. So, part of my childhood came back in that I, I actually that was strange to start with actually working on an almost a role reversal, that, that can feel quite strange in times actually, not the pupil-child, the pupil-teacher relationship, but almost the carer-patient relationship and actually here you are the one, not with the power but the one who they're looking for for support. And that in itself can take some getting used to I think. But in fact, this lady again was really quite prepared for her death, she was very calm, very collect, and she had teenage children and she wrote letters to them, things that were and gave them to them then, but things that she wanted them to read and, and special messages for them, which, which was was excellent. The thing that hit me I think the most is the anger her husband felt after her death. He felt very angry that she died and left him and was cross with her which isn't unnatural, but he actually, it lasted a long, long long time and I used to see

him, he'd come back sort of every three months and we'd spent an hour and he'd go over every detail, every detail leading up to her death which at the time [was/worked] really fairly well but it almost got much worse as time went on. It, he actually, it became parallel and he almost got to the point and I think there are very few families that I've seen, perhaps because not all of the relatives come back that maybe feel like it, he actually resented in, to a strong degree, any time that anybody spent with his wife that he hadn't been part of and he wanted all the information. But he then got crosser every time that somebody else has had a time part of the person when he couldn't. And the sad

PS: It's an amazing luxury, isn't it?

R: That's right, absolutely. And, you know, he, it was almost [borne/worn] of the fact that he loved her so much, he actually almost idealised and worshipped the person. I think, through her death and through it, he actually built this person up into a huge person in his eyes, whereas in fact, I think they'd had a wonderful life and a wonderful time together and obviously not enough, but by the time she died, six months, she was a, a figure way out of [here] which of course she wasn't. She was his wife and his best friend which he talked about at the time and, and I think wonderfully so. But he had supported her very well and I think he stopped seeing that, he just saw that this huge person to him had died and left him and he couldn't manage without. But he actually almost destroyed the relationship he had with his daughters because they didn't feel they wanted to share the letters with him at that time. They were very private and very individual and they wanted to keep them close. And it was something that caused him a lot of anger at them, he wanted to see, exactly that. And, and that was quite difficult actually trying to bring some reality back to the situation for this man because I as I said, he visited, certainly I saw him three or four times over a period of two years after her death and spent quite of lot of time, his daughter was having cancer and he would spend the whole hour here talking and we sit down and go over the things and, and the incidences became bigger as time went on. I've heard only recently funnily enough, which is what makes me think about it again, luckily that he is moved on now and we would actually later and he has actually just started a new relationship, I think, moving on. But it was actually how somebody again who dealt with her own death very calmly was almost detrimental, because I think he felt unneeded at the time of the death, I would [suggest] although he was needed.

PS: That's interesting and I thought about how it might possibly effect the relatives when a person is very accepting and matter-of-fact?

R: She was very organized, but a very sensitive women and very kind, and knew exactly how he was, understood him totally, absolutely totally; she even talked to him about moving certain plants in the garden at the time that she'd started and they'd had more light there and he maybe he wouldn't think to do it afterwards, so she talked to him about very small instances. And he at the time did things but because he loved her and wanted to do them and coped very well, but I think afterwards, looking back on it because she coped so well, I think it almost didn't give him enough to feel he'd done for her at the time of her death and, and then he was, needed to know every small detail afterwards as if he was working it all through in his head. But thankfully as I'd say, it was quite worrying time but it has moved on, and he certainly talked about suicide. And that's very hard, again actually thinking about, if a patient talks to you about suicide and, and, and relatives how, how realistic those fears are that you have. I mean, is there something that you generally, because that's happened several times, patients talking about wanting euthanasia and to finish their lives, but also relatives talking about afterwards, bereaved relatives about how they couldn't see any point going on and truly felt like it in themselves. And that, that a big burden to carry sometimes in if this is a significant ... and if that's something you need to be worried about or if that's purely reaction, and I would say 99.9 percent of the time that is reaction and understood ... as so. But I think that that still is sometimes a burden to take away with you and think 'Does that mean that you've taken this responsibility away with you and have to consider that?' And, of course, we share those types of things, they are not something that are isolated and you take on your own, but I think that's something that you do certainly think about, in is that something that you need to worry about, be scared about for somebody afterwards? And also think justified and it's certainly, I think when euthanasia is mentioned, you certainly feel perhaps a little bit more that you have to justify all sorts of medications that you are putting up and giving patients. I am very perhaps much more aware of, if patients have said: "Oh well, they're here and I know that you, you help them on their way with medicine" and that's not uncommon in ways [that you say]. You, you find, and I find myself actually thinking at the bedside explaining in much more details than I perhaps need to or would do, "this

is the injection we would normally give you since, and I know that you'd ... [that they've been having ... up]" and perhaps justifying your actions because these patients are dying and because certainly although you want and strive for a peaceful death that's not what you want families to go away thinking that you've actually aided death, that, that you purely, that you've been part of the journey as we've said, and that you've hopefully ensured comfort and peace, ahem, as much as possible. But that is different to actually and that feels different to actually, ahem, speeding up death and encouraging death. That still feels to me very different. And I suppose I still do truly believe that with good symptom control that's not necessary to do, communication at it's best to families, it's not essential to do that, one because you can relieve physical symptoms and two because we can support families, either through ... deaths. If, if you are aware of their needs and and take the time to do that, I think it certainly, it can be intimidating at times, it can feel ahem, very on their guard, especially here in the environment like this when some of the most testing things [for dying patients] from families are "We'll [pull] the drips up" and while we consider it ... And that's, of course, it would be easy to say: "Well we were do, we are going to do that", that, that's very easy to do. It's much harder to be able to think 'I need to take this person's life and sit down and explain to them why that is essential and how the process works and why we don't need to do that', that takes much longer and is much more testing at times in you are aware of your own limitations, if you like, at that time. Ahem, because it's still ... and ... that somebody they love and want to hold onto even in that perhaps unconscious state as long as possible, and actually remembering that really.

PS: And as you mentioned before it may be that the patient may need the time, to get things sorted out, to

R: And I believe that the relatives probably do need (both talking together)

R: I think that we do still have patients that die suddenly, perhaps if they'd had an acute haemorrhage, but they are in the minority on the whole as far as They are still in the minority. On the whole, there is a certain preparation time and if utilised properly, that, that is essential, it's essential, and I think for them as much as anything, even though it feels very frustrating, they exhaust it at the time. My experience when dealing with bereaved relatives afterwards and their communications are that, that is time they've also spent with the family together, often going over

instances and telling us about incidences because they come: "Oh I remember when dad did this" or "I remember when mum did that" and that's essential to them as well, that's almost actually reliving the person's life and, as part of the family, that I do believe they need to do. And granted that individual from patient to patient and relative to relative. For some people the thought of sitting by the side of a dying patient is exhausting and too much and I am quite appreciative that that's not, if that's the way they need to cope, if that that's perfectly right for that person; and I think it is right for that person. But it still gives them a time, there is still a time for some acceptance to start and some working through the process to start really. So I do believe it's quite important [for them] and possibly even for us really as well a kind of a peaceful time, possibly for us as well. Sudden death is still quite hard to deal with in a patient that you hoped you'd achieved the maximum with the symptom control, with the family and with patient resolving some of their goals that they have. And many patients may never resolve their goals, may never want to resolve their goals [606] but to me that's still acceptable, there is choice involved.

PS: they have a choice?

R: That's right. It's the fact that they, there has been some time if necessary, and some thinking time for them to go through, even if they feel they can't use that, that's still acceptable, because that that time has been there if they've needed it and there has been something to prepare and and hope something to help and even that's what they needed as well.

PS: How do you think that working in palliative care has influence you, effected you personally?

R: I think, I sometimes think 'Am I too accepting at death?' I sometimes wonder if that's something I, I almost accept and I think when I was first here, I think cancer, because ... most of our patients here understandably have cancer, with the exception of two or three percent, I think I perhaps was too accepting that people died from cancer and that sounds very basic and very blunt but that's how I, I think I probably did perceive it and and that was wrong and incorrect. And I needed to spend time away in acute oncology to see the flip side of the coin; that's been essential so that I can actually think 'Well, hang on, these patients have been through this, have [done] this, some of them quietly down the road'; of course, they are not [all/old]; some of them ... much soon,

some of them are ten years down the road and there is a huge proportion of patients that will never, ever be part of this palliative care that are still, you know, having ten years on and are walking around, fully fit and well. I think that's essential, one, because I think it can touch all of our own lives and I think that's, that's very hard to walk around thinking that everybody here has cancer, will die. I think it was quite a blinkered view to begin with and it was essential for me to go away and, and I think it's done now. So I think it's a more rounded view this time around because I've done quite [of] two spells in palliative care, hospice work. And I think it's a more rounded view now, I think I can realistically look at what's taken place beforehand, realize there is hope, but I think I also, although death is more accepted for me, working in the environment that it should be, or, or, whatever to a thirty-four-year-old person may be, may be it is more accepted. But I still think that there is a certain amount of rounded experience that actually makes me think 'Well, now I believe it's one how we live and two how, the choice involved for patients really, that many patients have been through a lot of traumatic things before they get here and that's almost essential for and this time is a time of rest and peace and working down that they almost do need. So I think I, I think now it's a more rounded view that I have of death really, and, and of cancer, probably predominantly because of it and that's important and I think it would be hard to continue if I didn't feel like that. I think on a long-term basis it would be hard for me to, to go on and to see it as a positive environment and I do see it as a positive environment very much so, ahem and I also see the role for myself as a positive one as well. I think that there is many things that we can actually initiate and help and comforting a patient, ... their family with, that, that's essential to me that you do find that and you do have that because I think it's, it's essential for patients really. I think that patients do have to, I truly think that it is quality of life and that that is of paramount importance, not quantity. I have no control of the quantity, none of us do, but obviously this [shorten] of quality that a patient has left of their life, you know, is significantly, but the quality is something that I can be involved in and is of paramount importance. And it is almost, ahem, possible to help a patient understand [and the] quality, apart from the obvious things that we do in the environment and that I ... quality. I, I think there is the other things that you could talk to

PS: Do you have to introduce patients to this concept of quality or

R: Sometimes, sometimes, not always. I think, I think sometimes a patient's own philosophy is being that they know exactly what's important to them and they know aeh, the types, some of the people we've talked about, they perhaps know that their life is, is imminently shortened and they don't know how long they've got but they are very aware of what they want to use that time for, quality [simply]. They're actually not so concerned with time, more the things they will [...ching], nothing certainly; I certainly talk about small goal to the patients, you know, what what could we do, what; but I think that certainly, often it's important. The biggest thing I think is from a quality point of view is actually helping a patient utilise to die here and now rather than next year, because that's the bargaining. It's not that you want to rule out that they'll be here next year, even in the most obvious cases when they won't be, that's not necessarily fair to do that, but it's helping them come back to today rather than using all of their energy and preparing for what they want to do next year, hope pathetically like the patient that says: "I booked a cruise for next June that's essential to me that I get on that cruise, absolutely I must do that", or the patients that's daughter is getting married next year, next June: "I want still be alive for this wedding next June". I can't turn around and would, wouldn't even occur to me to say: "But there is no way you're going be here next June." What I need to do, what I think is essential to do, is help the patient utilise the time they have, the here and now, certainly there is the obvious things that you can sometimes look at and maybe bringing the wedding forward, but that's a big, a big step and a big What's more important is to actually think about some photographs that the daughter now or what happened when she was engaged "Have you got any pictures", what sort of things, you know, all ... things, "Why don't you go home for a week and visit and, you know, to the new house that they are planning to live in". I think it's actually trying and and that is important, sometimes it's making them think about what they can achieve now, but the weekend, tea in the garden, you know, "Why don't you bring them in when your daughter is planning things about the wedding, why don't you go and have some tea in the garden?"

PS: As if the future is drawn into the present

R: Yes, absolutely, I do, I do think that that's something very important to actually, not to rule out those goals that are far away but to help them make goals that are nearby and that are very important, and small goals, obviously. But things that they can actually see as qualitative events that

are taking place here and now, that it doesn't have to be far away and big events that it can be a very small thing. "Well, that sounds nice, where, what's the church, that would be nice just to go and see the church on Sunday or whatever", to have a look at things, that's where and that is sometimes necessary to help them plan those things there and to to think about. And I think in many of the cases: "I know exactly what you do when you're doing that", they know that you're suggesting that they think about now and and doing, it's the family as well, but I think that, I suppose it's actually trying to help the patient utilize the time they have as best and ... hope they would want to. But of course, it's not doing it on a personal level, because it's not me, it's not my time, it's their time, it's them; so it can only be when you know the person reasonably well and when you know the family reasonably well and when you have the confidence and assurance to feel you can talk to and that happens on an individual basis. I mean, often it may be our cleaner that comes in and says: "Well, Mrs so-and-so said she'd like very much to do that" and and I think that's important, that you realize that it's it's a very general things, that everybody does it, that you're not going to be able to do it for everybody. You will only do it for a proportion of people, you certainly can't be everything to everybody. It's impossible. But I think as time draws nearer for a patient and as that becomes more obvious and perhaps many of their goals are goals in the distance, there is an element in me that thinks that they have to be addressed and you have to look honestly at them rather than hope that they're not going to feel cheated if they do start to die and if, if: "Well didn't anybody realize they couldn't do that and wouldn't do that" and that won't be the case for everybody. But there is a percentage of patients that I know I [won't] have time to do that, comes too late, the realization and that sometimes I think they do need help, ahem, and guidance to see that: "Well, yes, that's a possibility for the future, but what about now, what could we do now, what would you". And I hope that that's something and they are not huge goals necessarily but I do mean that that is important. Alternatively I think that, we've also and I think it's it's, you can look at your situation and we certainly have arranged weddings here, the usual type things that hospices are involved, which we, we've brought weddings forward, we've arranged Christenings, and I think aeh, that can be very positive as well, but that's a compromise, but somebody needs to somewhere recognize somewhere that that's a big need for this person and that you've taken it on board that that's important to address that issue before an opportunity is missed really. Ahem, because sometimes, and I do think and

feel fairly certain that some patients hold on for certain events before their deaths, most deaths as we know and I think and I truly believe in that theme. But that is essential and the peace of mind and the spirit of soul can only come after certain events, whether that be a certain relative arriving, whether that be a certain event, maybe even just getting a will sorted out because there are special things you want left to certain people, seeing home again is a very, very big one for people, often just being in your own environment; and it's recognising that it's more important to get that patient home for half a day than planning the discharge that will take two weeks that they can't get to, but you can get them home for the afternoon on a Sunday to have tea in their own house. I think the biggest thing that I can remember that influenced me is, when I was nineteen, twenty, training, in my training originally, I went to a lecture on the original matron of this hospice whom I never met before and never met in my time here and she talked about quoting Cicely Saunders and she talked about it, and she talked about the usual that it's better to have a cup of tea given slowly on your last afternoon than to have drips and infusions in all directions and that it's possible with the right use of narcotics to do that. I never forget that and that sounds a bit corny but right the way through, I think if anything is how I believe a person should die, that is how I believe a person should die. And I do think we have the ability to make the difference, not because we are special people, because I don't think we are; I think it's just having time and facilities to recognize needs in patients. I think as human beings we perhaps all have that ability to recognize in other people that if you're seeing this and to them what they really want and if we ask them, you know, tell them what they need, but that was the biggest thing that influenced me towards palliative care before I came and probably the biggest thing I haven't forgotten all the way through palliative care, that that really that is the most important way to die achieving the things you think you can. And just as a funny small incident ahem, the firemen came through and did a drill here one day and I think what filled them doom and gloom when they ... they were coming and went away afterwards "This place is much more cheerful than we felt it was going to be". And one of the nurses turned around and said: "There is a lot more living than dying that takes place in this hospice" and I think that that kind of is quite profound as to what really, if you like, to empower, I think a lot of living does take place really. (Thanks - both talk together)

R: It is quite hard and often it doesn't hit you at the time necessarily how you do feel because of course you're doing the professional part and the practical part and it's only actually when you do reflect, not necessarily immediately afterwards but after a period of time afterwards, that you realize the effect something did have on you and how important it was and how whether it went well or whether it went badly, 'cause you know from both types of incidents, it is obviously, but how you can improve on it and how the biggest things how individual is, that there is no generalizing whatsoever, it has to be very much and individual thing what a patient and their family need and help them with their death, very very much so, rather than a general thing.

(Thanks again - interview ends)

Transcript Interview C 4

R: Participant C 4

PS: Interviewer

R: Right, aehm, well I'm probably a little more distant from the ward in the fact that I'm the senior nurse here, so I don't have constant contact with patients and relatives. I do tend to have sporadic contact, particularly if there is a problem when people ... facility to see me perhaps if there is a lot of anger about care or decisions they made. So I tend to go in to quite stressful situations without the luxury sometimes of knowing the people beforehand and I find that very difficult, ahem, because I'm going in to solve problems, and I'm sometimes not sure where the problems are coming from, particularly when it's anger and that can be anger expressed as a member of the nursing staff. I find those situations are very challenging, they are very rewarding when you resolve them and I would state that most of the time you are able to resolve them; it can sometimes take a lot of energy on my part, ahem, and I sometimes have to hide my resentment, particularly if I feel it's a very unfair complaint, because it isn't really the complaint that's the issue. It tends to be some baggage that the relative is bringing with them, perhaps about a delay in diagnosis, inappropriate treatment right at the very beginning. And I think because the hospice is such a caring environment, we encourage people to let go when they're coming here, we encourage people to be very honest about their feelings, and if you encourage them to do that you got to be prepared for the repercussions. And I think the repercussions sometimes are that people dump everything on us and I think that's [indipidite] of probably most hospices that I know. We are used as dumping grounds which causes extra stresses and strains for staff and particularly nursing staff who are very much at the sharp end. I remember vividly seeing, coming here one morning at seven o'clock in the morning, to see the night staff and finding three members of night staff crying because in one of our bays was just one gentleman and his family had camped in the bay and although we encourage relatives to make themselves at home, had made this barrier where they would not let the nurses near the gentleman's bed, they were, they were rude to the staff, they were very verbal, they were very verbally aggressive and their non-verbal communication was very aggressive to such an extent that all three members of nursing staff were frightened of this family. And they were experienced my staff, experienced nursing staff, but they'd had a very very bad night and they

all looked very traumatised by it. And, I then had to go and see this family and I really did view that it was going to be a confrontation and I really didn't want to go and see them, I really, if I'm honest I wanted to get in the car and go home because I thought 'I'm not going to handle this any better than the nursing staff have', and also because I'm very protective of the nurses staff. I was, I was angry as well that they had done this to three very good nurses, so I really went along, I suppose myself carrying a bit of baggage to find a very aggressive family. And I went in and I thought 'I've got to be honest with them' and I said: I come in this morning, I found three distraught members of staff, I am hurt that they are so distraught and I feel they're distraught because of your behaviour and I want you to tell me why you are behaving like you are." And we initially had a lot of abuse, or I had a lot of abuse and I ought to be coming to apologize for the nurses, not ticking them off, they hadn't done anything wrong, and we had, I had about twenty minutes of listening to various members of the family and there were nine of them, hurling abuse and generally being very derogatory about the hospice, before they seemed to burn themselves out and then there were lots of tears. And then gradually we were able to work round to what had happened before, the fact that they hated nursing staff generally because they felt they were being cruel to their relative, that they view nursing staff as being very powerful figures and they were determined to dis-empower them, to show them that they have power, and they had actually done that very well. And I did say to them: "Well you have done that, you have dis-empowered this nursing staff, but you've also left them very [frightened/brazened] people." And we discussed why the nursing staff felt like they did, we discussed in turns, again, how they would, the relatives balanced out their feelings and had to reach a working agreement if the relative was to stay here. Because I was very clear to them that I had a duty of care not just to the patients but to the staff and I couldn't allow them to carry on traumatizing nursing staff. The fact that their reasons to their [may] have been sound didn't excuse what was happening within the hospice; and we'd have to reach a compromise with regard to behaviour if we were to continue to try and care for this relative and to care for them. So we reached an agreement whereby some of them would go home and would take it in turns to come backwards and forwards, though we didn't have nine relatives, we agreed that five was a ... number. That other patients would have to come into that bay and therefore they would have to make the smaller space to allow other patients to have some freedom of movement and that they

would be more open to the nursing staff, that they would stay all the time, that they were free to observe whatever the nursing staff did what [accounts] to hands-on-care, that we would never ask them to leave the patient's bedside, we would ask them to move if we needed to perform a procedure that they would be allowed all the time to stay, that we will explain constantly what were doing, but we would expect them in turn to allow us to explain. And we ended up with ten points, behaviour points, which after a lot of anger we agreed on; and I think that took a whole morning, ahem, and I know I came out of there and went straight into lunch and really felt that was very very hard. The patient died the next morning, the night was much better, ahem, we changed the night staff deliberately because I didn't feel the night staff could come back and cope with another night, because I knew they wouldn't sleep all day because they dread this family again. So we organized all the rotas so that there were three completely different nursing staff and they had a better night. Ahem, the relatives the next morning was very upset about the death but were able to talk through it and their anger had dissipated. I asked them to come back and see us and I specifically made sure that one of the night staff who was there the first night handed the death certificate over so that they could reach a compromise, because my major concern was that these three nurses had completely lost their confidence; they felt they'd handled it badly and were worried about how they would cope again in that situation. So I think that's the worst that I've ever had but I think it was a very good marker on how something can spiral down to almost a state of anarchy, ahem, where you have, you have to confront it, you have to face the issue and you have to deal with it, but I think the severity of it was a great surprise to me that people could do that to us here where we are kind and we do try very hard to please, but in doing that we encouraged it, we allowed them almost to behave like that. And I think the biggest area that I struggle with is, what is the acceptable behaviour and unacceptable behaviour and trying to make it, and trying not to be dogmatic about it, but at the same time get people, give people boundaries to say: "This is what the establishment can cope with, we can't cope with anything more than that, so please comply with it", without saying you can only visit from two to three and without being very rigid, we have to have some guidelines and I'm frightened sometimes the pull with other disciplines is to not have any guidelines. Let's be all things to all people. And I think my, my discussions with them are: "Yes, you can probably do that because you are a small group of people, I have nearly hundred nursing staff

here, we have to have a parameter to work within, we can't, we can't have this brother-and-Bob environment all the time". And I think that that sometimes is a big pull. So I would probably highlight that as my most traumatic experience of dealing with relatives where anger was an issue and one which I think I learned a lot from. Ahem, and at sometimes it's nice to balance that against good things, one night, the night staff phoned me at home and said: "One of the patients had been given some bad news in the evening, the fact that his scan was also very poor, that his hope for a cure was taken away from him. And not only was his hope for a cure taken away from him, but appropriately his prognosis was given to him, because he was planning a holiday in a year's time. And it was made very clear to him that he did not have a year, in fact, people didn't really think he had a month. So they covered a lot of ground in a short space of time, but in turn left this fellow very traumatised to such an extent where he would not, he couldn't stay here unless he had somebody sitting with him all the time, because his fear was going to sleep and dying on his own. His family had withdrawn from him, they couldn't cope with the situation, I think because they'd been badly prepared for the bad news and wanted to go home and couldn't stay and comfort him. And the night staff felt very torn in the fact they had a distraught man, but because there were only three of them, one could not sit with him all night. And they phoned me and said: "We don't know what to do". So I said: "Well I come over". Ahem, so I came over at about ten and I came in uniform because I wanted him to see that I was a nurse and I spent the night with him, just sat by his bed, ahem, we discussed how we'd been told, why he was so frightened and eventually about three o'clock in the morning he dozed off to sleep, but I promised him that I wouldn't move, even while he slept and that I would wake him up at six because I was going home and he would then, the light it was in the summer, so it would be light at six. Other patients would be up and about and he would feel that he'd survived the night. And that's what I did and that was very nice, because that was me taken ... as well. He was grateful, his family were grateful, he went home the next day and he died three days later at home. And when his wife wrote in, she wrote and said, she didn't know who I was because I didn't tell him I was matron, I just said I was one of the other nurses because I didn't want him to feel intimidated by the title which sometimes people do. And she said: "I don't know who the nurse was that came and spent the night with him but could you thank her". And that was really, really nice. So that was probably a bit of a luxury really for me.

I suppose my other experience that I carried with me from the start is right at the beginning when I took up post here, we had a twenty-one-year-old patient who her was a [lay/late] referral to the hospice and had curative treatment over many years and it suddenly became apparent that his disease was escalating and curative treatment was suddenly stopped and he was acutely ill. His family were desperate that he wouldn't spend any more time in hospital, but they couldn't take him home because his nursing needs were so great they couldn't cope and they didn't want, he didn't want to go home. He classed home as going when we was well and he didn't want to take his illness to his house. So he came in here; he was a delightful young man, very very intelligent, very ahem very articulate with a very articulate loving family and he had hoped that he would have months and he had a project that he wanted to finish, he was ... architect, starting architecture. And our doctor who was here at the time, ahem lady doctor, went in to see him and he asked her very straight questions, and I sat in on the interview, and I found it very painful to watch him being so sadly disillusioned about what's left of his life in the fact that he wasn't going to finish his project and it was, it was like watching building blocks being taken away from a child. I viewed, as I watched him, that he'd made a pyramid of brightly coloured boxes, beautiful pyramid, beautifully structured, because he was a very organized structured young man and that, as the doctor spoke to him, blocks were taken away. But they weren't taken away from the top, they were taken away at odd places so you were aware all the time that you were weakening this structure, that if you took the wrong block away, the whole thing would collapse. The easy way would have been to start at the top. But he didn't want to do that. We started with him where he wanted to start which was a a very, a very fundamental question which removed one of the main blocks; and we ended up with a shell of blocks where he still had some structure so he could still go on but he was very very weakened by it. He was very sad, there were lots of tears, I felt, part of me, that if it had been me doing that I would have ignored this first question and gone to the easy option and the easy blocks, because I didn't feel that I could pick up the pieces if he crumbled. But I had great admiration for the person controlling in the interview really, ahem, in the fact that she did have the skills, which I am sure is why she did it. Ahem, he expressed his sadness at not achieving this long-term goal and then after his parent would come in and he wanted his parents to hear exactly the same thing that he'd heard, with him present. And which again was very painful because they were distraught at the thought of losing

their son. And I think were surprised by the short time he had left. So it was discussed that his father would carry on this project in memoriam for him and his funeral was organized and what he would like, so it was all very final, ahem, and very very painful. But in hindsight, he died three days later, and he had a peaceful death, and he was grateful for what he'd been told and expressed that very well and his parents in turn coming back expressed it very well. But I very often use in teaching staff now, the analogy of the building blocks because I think it's important sometimes when you are dealing with those situations that you have a pattern in your own mind that you can make some sense of what you are doing, because otherwise, ... you can lose it. Ahem, and if you are going to learn from it, perhaps it's just me, but I find I need a picture so that I can perhaps [hark] back to that and think about where those blocks were and when we took them out what we were left with. But it was, it was a very moving experience and it's one that, people talk sometimes here about being very privileged, to be part of it, and I think sometimes that sounds very grand but it is a real privilege. It is an opportunity in our own lives for us to grow, because of it, ahem, and perhaps to use it in everyday life in our homes and in situations, sometimes with our own family and with our own friends, in ordinary situations, in ordinary arguments. So sometimes have something like that that you look back and think 'Well I could use that' and I could carry it forward. So that was a very very very special time, very special moment, which probably most nurses at some stage have, ahem, have had I hope, ahem, and perhaps use in other areas really. So those are probably my major experiences that I had, that I recall very quickly.

Ahem, the other experiences tend to be very transitory of going in and out of situations, of sometimes watching nurses in that situation and how they're coping with what they're dealing with. Ahem, particularly perhaps if I see a nurse is struggling, perhaps she has a record, or relationships with colleagues are not very good. I sometimes listen to that nurse communicate with a patient can give you an awful lot of clues as to what's going on, ahem, inappropriate humour, I think is a, is quite a good marker that somebody is struggling. I remember a nurse vividly saying to a patient here: "Come on, you are like a dying duck" and it was patently obvious that that was very inappropriate to say. She was a very, a very professional nurse who would never normally have said it, it was a very good marker for me that she was having a real problem, and I think in part she had probably not deliberately I think

subconsciously she said it, knowing I would hear it, to perhaps prove to me that she was having a problem. The patient was fine, laughed about it, thought it was very funny, the rest of the patients in the bay thought it was very funny, staff were very cross about it, felt that she shouldn't have said it and I think it was used as an example, ahem, a bit unfairly for what nurses shouldn't say. But it was interesting that it didn't affect the patient and in fact they thought it was funny, and I think that area of normality we need to remember, that we needn't protect the patients. It's like on birthdays, people always get very cross if somebody says: "Many happy returns" on the day, but it's a normal thing to say and I think if we stop being normal and patients will notice. Like we celebrate birthdays, we celebrate Christmas here, we celebrate Easter. And sometimes other people outside us will say: "Well, should you be doing that?" And I say: "Well yes, because everybody does it and why should we not." And our patients enjoy it, not just because they think it may be their last Christmas, but because they enjoy Christmas anyway. But I think we, the normality is very important and we do need to say normal things, as we would do because we're normal people, our patients are normal people, ahem, just because we are in this environment doesn't mean that we should channel things totally differently. Ahem, and I think new nurses coming in do try and do that. They try and be very aware all the time and get very tired because of it, because you can't keep that level of heightened awareness up permanently. I think when you're new to a place you do because you are learning, but I think to try and maintain that, that heightened sensitivity that some nurses and some doctors seem to, to want to do is unrealistic. And we have settle back down to the fact that we will make mistakes, there will be certain patients we won't like, ahem, there will be certain symptoms that we don't pick up on, because that's normal and we're normal human beings with a normal, we're not, you know, infallible. We are not infallible, rather. So, I think the use of normality is very important and as I say, this patient was quite happy to be called a dying duck. And it actually conjured up memories for him of a family, a member of his family that used to call him that, so it was quite a, ahem, a familiar; I think he found it quite a warm comment to be called that, it conjured up nice memories for him. So it didn't actually do him any harm. But in fact proved this nurse that she wasn't doing very well and she had a period of time off and re-evaluated where she was going. So it, it was quite useful. I think those are my overlying memories with patients.

On a daily basis I find their expectations of us are sometimes very tiring. They do expect an awful lot of us which most of the time I think we give but sometimes when we don't, ahem, they are very unrealistic about it. So I find that we are a very hard act to maintain and patients in full-bedded bays obviously have the comparison of watching what's happening on other people and will become very jealous if somebody else is having more care, even though it's very clearly demonstrated that that other person needs more care. The other patients in the bay are not always understanding of that, ahem, you know, "Why do three nurses come in to move him?" ahem, you know, "Why have you spent an hour-and-a-half bed-bathing her and I haven't even been touched yet?" Partly I think to goad us into being more open about how that other patient is, in saying: "Look, they are really very ill now" or "They are dying now", ahem, so part of me thinks they need more information than perhaps we give them, but I think also partly because of their own fears, they are watching somebody else deteriorate, they are finding it hard to cope so they latch onto something that they can, is tangible, like the fact that three nurses are dealing with that patient all that time. And being understanding of that is quite hard all the time, particularly if the patient who is saying those things perhaps is not the easiest of patients anyway. It's much harder sometimes to accept criticism from a very nice patient, partly because people will say: "Oh, that's so rare for them to say it", but sometimes if you got a generally complaint patient who then adds more complaints and is quite, ahem, selfish about the needs of other patients, I think we as nurses find that very hard. And they will be the patients that get labelled as the 'difficult patient', ahem, and I think it's very easy for that to happen. You have to be very quick to stop it becoming fuelled because then people do come in with prejudices about that patient, because as nurses we hand over [facts] in reports and it be very easy for a nurse to be very judgmental about a patient and that would affect the next nurse coming in. So perhaps the next time that patient rings the bell the nurses will be slower to respond because it's so-and-so and 'she is always running anyway. And it may that that's a very genuine reason that she is ringing and she then almost be punished. So I think the area of difficult patients in the hospice environment is just as well as a ward [or] acute area but because we are a small unit can also be more of a problem because you are not, you can't dilute it, it's more evident, it's more clearly visible and it causes more disruption here than perhaps it would do in other areas. And talking to a relative of a difficult patient, they suffer dreadfully because of it, because

they will frequently say to you: "My mum's never been like this before, she's always been very kind and very considerate of others, I don't understand this", ahem, you know, "I know you nurses don't like her" and that I find, I hate if relatives say that, because I think we must be demonstrating clearly then that we don't like this person and that's awful. And how do we overcome it? And then talking to the relatives, they have a double bereavement. They have the thought of losing a much loved mum or dad but also in the fact that that person has lost their appeal to other people as well and they have this comparison and will talk after the death, sometimes they will be the ones that will have more unresolved grief and perhaps take longer to console because of the fact that they had a bad experience with mum or dad being so difficult and feel they have to apologize for them as well. They take that, they owe that, they take it on themselves and say: "I'm really sorry that mum was difficult" or "I'm really sorry that dad did so-and-so". And I think in turn that's a very hard emotion for them, ahem feeling that they have had to own a parent's or partner's behaviour, ahem, it's never a good idea anyway but I think in the case of end of life situations it can be very detrimental to how a person moves on through the grieving process and ultimately what they're left with. And my fear sometimes is what they may be left with is a bad memory of a much loved parent and not being able to put that to one side and remember the real parent and I think it's very important that we explain to relatives that what they're seeing sometimes is a side effect of medication, is part of the disease process and to give them a reason for the behaviour. So they are able to rationalize it and see that mum or dad are still there, they are just manifesting different symptoms now and in much the same way that we're sympathetic with a patient with pain or with a very sore open wound we need to be sympathetic to a patient who is abusive because that is another symptom. It may be that their pain is causing them to be abusive, it sometimes is the medication we are giving them, we've done it to them, ahem, unwittingly and we're then not very good at dealing with the consequences. So I think those are my major experiences really, ahem,

R: I can't, I don't think I can think of ahem, and it does for the personal, I suppose ... a patient in the hospice in ... who came in and came from a certain part of Ireland which is where my father came from and the area in Ireland had, people from there have a very unusual accent. And my father had died about five years before I met this patient and he had exactly the same accent and I found it very difficult to ahem, to talk to him in a work environment because I

kept treating him as I would my dad and, ahem, he whenever he said my name, because I encourage people to use my Christian name, whenever he said my Christian name, he was the only other person to ever pronounce it like my dad did and it was very very hard when he said my name and I used to almost be drawn to going in to see him, but for the wrong reasons. I wanted to talk to him because for that minute I had my dad back and I wanted him to say my name because that was a very comforting thing for me and I was acutely aware that I could not be around when he died and did everything I could to avoid being there when I knew he was deteriorating, to the extent that I took a day's holiday as a safeguard when he was deteriorating, just in case it would happen, because I didn't feel I could share any of those feelings with the rest of the nursing staff and, 'cause it to me it was very private and also I didn't want people to then watch what I was doing. It was a very very odd situation, it was a situation that I found I had virtually no control over with him and I'm very pleased that I knew him and I'm pleased that I had the opportunity to hear that accent again, ahem, and to hear him talk again, but it was a very selfish thing for me, it gave me a lot of pleasure, ahem, and he had a good death and I'm very pleased he had a good death and that we did look after him well. But that was a very very personal thing and for me it was it was quite hard because that very rarely happens, ahem, I'm normally I suppose, you know, I cope and I'm normally able to sort of deal with situations fairly well but I found that very very hard. And I hope at some stage it's, he died about a year ago, so it's still fairly new, that I will be able to share that with other people. Perhaps in an environment where somebody else is struggling with a similar thing, ahem, 'cause I think it's, I'm sure it must happen to staff all the time, it had just never ever happened to me. Ahem, and when it did, it was an amazing feeling. And I [feel] now and again, whenever I go into the bay where he was I can every now and again, I deliberately will conjure up his voice. It's ... it's a ... situations but aeh, that was very personal to me, very special, and aeh, really quite challenging for a person that is not used to feeling like that. Very interesting.

Aehm, we had a member of staff who died here, not so long, well, four years ago. Aehm it was a much loved member of staff and I think, then we had a member of staff in the hospice in ... who died two years ago and I think the handling of staff death is very important. People are very critical of us sometimes, we are very critical, our staff are very critical of us, particularly as a management team, if we don't pull out all the stops for staff they say things like, you

know: "Well look we're doing this all the time for other people, the least we can do is look after our own." And sometimes it isn't appropriate, ahem, and the patient, the nurse that died in (name) did not have cancer and the staff were very angry that we would not make aeh, we would not give dispensation for her to come into the hospice as a patient. And we, you had to be very clear what that would mean for other people that the care she was getting where she was was not bad care, she was being supported, we were supporting here the arm's length way, if we brought her in we actually be doing it for us and not for her and also how could we then fairly say to other people "Well you can't come in." And there was a lot of anger, a great deal of anger expressed and particularly I think anger directed at me because I was the one really to, at the end of the day saying "No" to the admission. Ahem, but in turn conjured up, brought forward a lot of other things with people, about how they felt very guilty because they got cross with her when they worked with her because she wasn't quick enough, she was miserable and they'd not been sympathetic. So, they were trying to transfer onto me, I felt, a lot of their guilty feelings about their relationship with this nurse and almost thought that they could bring her in and make her comfortable, they could make up for what they'd done in the past. And in getting them to say, and saying to them: "Well, why don't you go and visit her and say these things to her", they couldn't. They couldn't verbalise it with her, but in turn they wanted this gesture and even two years on, two of the staff still maintain that she should've come in and with very little provocation will bring it up again. And really find it very hard to let that resentment go, ahem, and with not, without my nurse manager's hat on, I can see that somewhere along the li-, along the way something has happened to them and they are again transferring this anger onto this situation. Ahem, I think the dealing with our own mortality and particularly when we are clearly reminded of it with staff again is quite a hard situation; and physically nurse a member of staff is, I think is very difficult.

I think it's one that you have to give nurses a choice about, in much the same way we have to give people a choice about nursing their relatives. There is always a lot of discussion about whether or not it's appropriate for a nursing, member of nursing staff's relative to come in as a patient. And the view I have is that if we say 'No' we are prejudicing that person against hospice care, we are discriminating against them, purely and simply because they have a son or daughter or wife who works here; and again what we try to do is discuss the dangers of the admission

and protect that member of staff from physically nursing that patient unless it's what they choose to do, and being very aware of it in our dealings with it and that's particularly important in nurses being honest about what's going on and honest about their feelings. When it's somebody else's loved one, a colleague's loved one, so the nursing of relatives I would think is probably the most stressful thing for the relative who is a nurse and for their colleagues to support them and to perhaps feel they have to do that bit better because that person is a relative of a colleague. I think is quite stressful in itself and is an area that causes nurses a lot of concern and a lot of soul-searching afterwards, ahem, but I think the only way of not doing it is to say they can't come in and that would be very unfair, so I think we have to weigh out the balance and certainly in talking to the patients themselves, they very much wanted to come and have been very worried that they would not be allowed to come and are very grateful for being here and will also say, you know, "My wife, or my daughter, or my son has always said such nice things about here and it's really good for me to see it for myself now." So they express very positive emotions about being here and being part of a, a relative's life as well, because they will see where they work, how they work and that in themselves can bring on quite a bit of comfort really. I think I'm running out of steam.

PS: I have a question about generally working in a setting like this. How do people deal with facing their own mortality. They are constantly reminded by seeing people dying and people in bereavement. So I imagine it's quite an issue one has to come to terms with when one works in a setting like this.

R: Yes. I think some people will tell you they dealt with it when in fact they never have and there will be a situation that perhaps can be a catalyst ahem for it. You, I think the only way of dealing with it in this environment is to be very open and very honest. We all have [tansens] that we dread, we all have sort of we all bargain I think and say: "God, if I got that I wouldn't, I'd take a bottle of pills, I'd hit the gin." We've all got some area that we we dread more than most. I think we have heightened emotions about cancer and we view it as a very negative thing which we have to careful of because we're only seeing the failures with regard to curative treatment, really, and we forget there is an awful lot of good work going on out there with an awful lot of people living very long fulfilled lives who've had treatment, who we don't see. So we have to be very careful as nurses that if we diagnosed ourselves with cancer we don't

immediately write ourselves off; and I certainly found that with colleagues who have been diagnosed with cancers. They have been immediately traumatized and very very negatives and it's very important that you get them good help straight away, good counselling because unless they are positive, you know they're not going to do well. You know there is a great deal of evidence about positive thinking and cancer treatments and I think it is very very important. And therefore that's the biggest worry that I have with nursing, with staff and their mortality, is the fact that if they are ever ill themselves, they cope with it very badly because they have such negative feelings about it. Or, alternatively and sometimes more worryingly, they will ignore their own illnesses, nurses with [breasons] won't go to the doctor. With all our knowledge we should be the first ones beating the path to the door, we're sometimes the last because we are frightened to hear bad news, because we'll think, 'That's it, when will I die?' And I think it's important that we do encourage nurses to to maintain healthy lives and if somebody is ill and is diagnosed with having serious illness, we're very supportive of it. There has been a nurse in (name - Senate?) one of our home-care team, who had a major life-threatening illness, and had major surgery and when I went to see her at home, post-op, she was very traumatised, not by the surgery, but by this life-threatening diagnosis she'd been given and was fortunately very honest about the fact that she couldn't face patients. She said: "I don't think I'll be ever able to face a dying patient again". A whole ahem mix of emotions that she had and we discussed very calmly that she needed a long time to recover. She would need much longer than other people to recover because although her physical scars would heal, the emotional scars would take much longer. And if she came back to work too soon, those emotional scars would broke down again. And her feeling was that she would need six weeks off work, my feeling was that she would need six months. And she was to start with very shocked by having the thought that it would take six months, also felt that I had a hidden agenda by suggesting six months, that perhaps I then could get her out after six months. And I had to be very, you know, I was very honest with her and saying that that was not my intention but I didn't, I didn't feel I could put her at risk or the patients at risk by her coming back to work too soon and in fact she returned to work after five months with some negotiation well, and is now very realistic about that time and has, and surprised by the fact that she needed it; and I think that was very, that was to me very clearly evidence of the fact that we are very fragile as nurses in this environment about our own mortality. Ahem, I have a

theory, I don't know and it is just a theory, that sometimes nurses come into this environment to bargain. If I come into this and I deal with people who are dying, perhaps it might happen to me. And at interview it's an area that I try and broach a candidate to see their reaction of it. Most people will answer "Oh, I thought about", but I just, it's a theory have, it's a theory that I sometimes think I may have used, ahem, and it's just, a bit of bargaining, a bit like a patient will say, you know: "If I can just have another month." It's almost as if we feel, as nurses if we look after these people so well, that we will be rewarded by living long lives ourselves. Yeah, but it doesn't work that way (laughs). So, I think, that would be my views on, on our own dealing with our own mortality.

I think also it's important not to explore it too much because if you explore it too much you can sometimes engender fears in people that perhaps aren't there, or in turn make feel they ought to be fearful and they are not normal! If we are constantly exploring the issues and areas, people will start to almost make things up, ahem, and I think one has to be careful that it's kept in balance and that we allow people the privacy of not sometimes expressing their their fears about their own mortality or in turn recognizing that some people do not have any fears about their own mortality and let's not make them fearful if they don't have it. Ahem, you know, if something is not broken, let's not try and fix it, ahem, and perhaps we could do that otherwise in exploring issues make an issue where there isn't one there to start with and aeh, perhaps at times we're guilty of doing that. I think sometimes we are guilty of doing that in relationships with our patients. We will sometimes say "They are in denial" and it's a phrase that particularly the medical profession will use that [of] patient: "Well, of course, they are in denial". And then want to encourage them to confront death. And I don't think that's always very fair because sometimes that person may not, may not be in denial, it may that they may just not want to share their feelings with us. And if we continually poke at them to make them do it, is that right? We invaded their privacy. Ahem, because it makes us feel better sometimes. Occasionally you'll hear nurses [and] doctors say: "Well, I'm pleased that went well because they cried." And I always find that a little alarming, I always want them to explain what they mean by that because I don't necessarily see that as always being a very good thing to perhaps deliberately engineer a situation where you make somebody break down, it's not always right! Ahem, it's not always very courteous to somebody to do that and I'm [of the view] very suspiciously sometimes people that always see

that as being positive and good, that they achieved something. I will sometimes view it the opposite, that they've they've hurt that person, ahem, was that necessary to do? And who were they doing it for? To prove to themselves that they could do it? Ahem, to prove to the patient they could still cry? Ahem, but aeh, that that worries me! It doesn't, and I think we do fiddle and probe sometimes too much when there isn't a reason to do it.

PS: Yes, I had the same issue come up in a different hospice. One of the doctors said that she didn't understand why they have to deal with this concept of the whole person, that you have to go back into the past to find out if they've been abused as children. And she said 'some of these people have just two weeks to live, why do we have to deal with issues that are so far back in this person's life, we reactivate an issue like this?' But she said that it is commonly done. And she was perturbed about this.

R: Yeah, I think, I think it, I don't think we do, I hope we don't too much about here and in fact probably I think our doctors are, are very sensible about that in saying: "Hang on a minute, do we need to know this? What are we going to do with this information if we get it?" And I was very encouraged to hear that. Aeh, because I don't always think we need to know it. Again it can make us very judgmental then, particularly sometimes if there has been an area of abuse, and the abuser is still part of that person's life; it could colour our relationship with that person. Ahem, you know, if it's a parent, it could it could be very very prejudicial. And also I think sometimes in sharing those things if we encourage the patient to tell us these things and I don't, I won't use the word sharing, I think it is telling us these things they then find it very difficult to face us afterwards. Ahem, and then that can, that can prevent any further relationship because they, they perhaps have divulged something they didn't want to, ahem, they then feel very guilty about saying it and then this huge worry about confidentiality because we're not very confidential! If we write it in notes, a lot of people have access to those notes, so immediately perhaps the one person you told, it is possible that another hundred-and-twenty people could know that. And I think that's that's a very unsafe practice, aeh, it could totally destroy a relationship. I think if it's relevant in a case of perhaps sexual abuse, the times I have seen it relevant are when we're discussing ways and procedures. I think sometimes we need, it needs to be an area that we tentatively explore, if we're going to talk about putting a catheter in, if we're going to talk about rectal

intervention, if we're talking about catheterising somebody who may still have an active sex-life. I think, there it is relevant because we're going to do something with the information. It's going to effect our decision-making. But I think if we're just exploring it because it's on our tick-list, I don't think we should do that. And I think we need, I think doctors and nurses need to be very robust about refusing to do it and not, not apologize for that, because we're not going into psycho-, psycho-sexual counselling, in the last six weeks that somebody's

PS: That's what she meant too and I see your point. But I think it may come from the idea of dealing with the whole person

R: Yes

PS: but may it be the wrong way or having the wrong concept of a whole person?

R: And also sometimes that may not be the whole person now! That may if you talked to that person thirty years ago, perhaps when the abuse took place, that may have been the whole person then, but I think sometimes people do move on from these very traumatic thing and that now isn't part of them, they've moved, they've moved on from it. And then us shifting them back to it, we could do an awful lot of damage, ahem. I mean the only time I've seen it perhaps, aeh, we sometimes with the elderly who are very confused, who will sometimes relive childhood situations, aehm particularly nightmares and you're aware sometimes there that there is perhaps an element that comes out where they have been abused in the past. But my way of, I think, in encourage-, in dealing with it is to be gentle on that ... on symptoms now. If that person is afraid of the dark, then don't turn the lights off! If they don't like being touched at night, then don't touch them. Let's not explore too much why but let's make them comfortable with how they are now and being gentle and being slightly more aware that this problem may have occurred and we need to be more sensitive about it. So perhaps male doctors did not, should not be examining that patient. We should not be doing invasive procedures unless it, you know, and only with the patient's consent, an informed consent. So I think those areas are relevant but I think to just pick up because it's on a list, I I don't like and I'm pleased that somebody else has raised that.

PS: Yes, it was quite an issue for this person and it was understood how it could become an issue. On the one hand you're trying to provide the quality of life for this last phase of life and on the other hand you raise issues that may damage this idea of quality, because you're bringing stuff into it that may not be of relevance [of present] person. And again as you mentioned the confidentiality. She was under the impression that certain people were pressured to give more information what the patient was telling like, she mentioned the Chaplain. Some of the staff said he should talk more about what he was experiencing with the patient and he said: 'I can't, it's confidential'. And she felt there was sort of an undue pressure on him to say more of what he was being told and he resisted

R: And I think again that's part of this hospice-caring-sharing environment that we, we don't always allow people privacy in their relationships with patients, ahem, which in the relationship between a patient and a counsellor would have that really. I mean our counselling notes are not left out for the people to see, quite rightly, but counselling doesn't always occur where it's convenient and it, and we have to make sure that we do allow that, that privacy to people. I think also sometimes that doctors that push more for that information, it's because that area is of special interest to them! I mean some of our doctors have do great expertise in psycho-social counselling, it's an area that holds great interest for them and I think it's important that we balance their interest and their expertise against the patient's wishes and don't allow some of these doctors and nurses indeed to explore areas, because they are the areas they are more interested in, and not the patient, and not in the patient's interest really to do anything about. So, yeah, important.

(Both say thank you. Interview ends.)

Interview Transcript S 4

R: Participant S 4

PS: Interviewer

R: And I think it's sometimes just, I don't know how long, I, my communication system is a system as such, it's developing a rapport which sometimes is quick to develop. I've just come from a patient in his home who, we both felt very comfortable talking about issues that he never thought he'd ever start talking about and it was very quick. But sometimes you could be working with patients for months and months and months and never be allowed in very close. Yes, I think there can be some usefulness in guidelines and some initial training. I mean I know I probably improved my technique in interviewing patients and not blocking. It's very easy to start a conversation with a patient and say: "How are you? How is your dog? How was the holiday?" avoiding perhaps getting straight down to the business of "How is your pain today?" or "What progression, what have you got to tell me today about your illness?" And I think I, you can, it depends on how busy you are and how many other things are happening to you as a professional and whether I've got dozens of people waiting to see me, phone calls happening, and a lot of on-going problems in organizational something, is to how you focus your mind in concentrating on what the patient is saying to you. You might, I find it sometimes it is a stressful situation because I know I'm having to say to myself: "Concentrate on what the patients are saying and pick up on the relevant bits". Patients may feed you an awful lot of information which you can take at face value and write it all down and say: "Well, I've had this interview." But, in fact they are giving you hints of where their problems are that you can actually miss perhaps on purpose and a very good example that we know as a team and probably in the whole of palliative medicine is an example, is the sexual issues in a patients life. Because not many of us have had any training at all, we avoid the issue so that we don't have to get the information because once you got it you ought to do something about it (laughs). So we don't actually open the box, because you don't want to find out there is a problem, that you know you can't deal with. So I think we do in talking to patients we mould conversations into maybe our own biological well-being. If you are feeling good that day and tuned in and not having any other pressures, maybe you have very good interviews and maybe on days where you got a lot of business and ward rounds and meeting to discuss money or something that [need] the service, maybe your mind isn't sort of

working as good, so perhaps you don't pick up on cues. I think it's an interesting area because I don't know whether it's, I had a good feeling about the interview I've just come from with a patient. But whether that was because I have, sort of pointedly gone out there and decided: 'I'm not going to think of any other issues except this patient' and actually focused. Or, when you are distracted, perhaps in the hospital wards where a lot of information is coming to you, whether you don't actually focus to the same and you miss things and maybe that's why you feel dissatisfied with the interview, maybe it's yourself!

PS: Yes, a sort of overload at the point

R: Yes. Yes. So, ahem, but, I think it's discipline, self-discipline is very important in concentrating on what the patient is saying to you and it's not actually sometimes all that's been said in words that you're actually picking up on. And maybe that's where the development of trust in a relationship is perhaps the single assessment, is not in some patients of value because they don't, they don't trust you. And I mean just coming from hospice and the man I've been to see seemed to [various], he was absolutely alarmed that he was referred to the hospice team, because in his agenda he's going to get better, he is going to beat the cancer. And the fact that (hospice name) has rung him and said: "There is a doctor coming out to visit you from (hospice name)" he thought 'Am I dying? Does that mean I'm dying?' So we went in feeling quite defensive. [It's/he's] not as quite interesting really, he already has his opinions of what we were coming to talk about. But there is a whole lot of things that seem to influence how your discussion goes. I mean, on a first meeting with patients, you are frightened; he got probably, possibly anticipating that here another doctor is going to tell me something else has gone wrong (laughs). And so, I think yes there is a lot of different agendas that influence the communication and I don't know.

I come away, I've had one or two very distressing and uncomfortable interviews that haven't gone the way that perhaps textbooks should say they should go when you feed the right line and it sets the right answer (laughs). And that, especially breaking bad news, for instance, that's one of the areas which I find; if a patient doesn't give you the opening that you anticipate to lead the conversation, you're left perhaps in a vulnerable position because you've started a conversation, it hasn't been led on in a way that maybe you would have hoped and sometimes you have started a process and there is no process of backing out of it, but

you've got to lead it round a different way. And it depends really on the patient's capability of handling information to make it possible to turn conversations to more painful issues for them.

I had a patient last week, he was absolutely, categorically wanted to know how long he'd got to live. And he wouldn't be deflected. And I said: "Well", we talked about his cancer and that it would possible that it would shorten his life expectancy. And he was seventy-odd anyway and then coming back to well he said: "Well, how long have I got?" So, we sort of said: "Well, how do you feel about things?" expecting him saying: 'well I feel pretty rotten at the moment', "Well, I feel marvellous!" (laughs). So, you're, it's, you feel you had a pattern that you established that worked in a lot of cases, it's also worth knowing that your pattern can go wrong! And completely misfire and then you're left in a very unsatisfactory sort of situation with patients basically. I'm always surprised at the patients that you perhaps had a preconceived idea of how they are going to respond. Ahem, and there are people never cease to surprise me in their manner of ... and taking the news: "Oh, I knew all about that!" "And I anticipated you saying that, now let's get on to getting on with moving!" I mean usually expected to have a very painful discussion about their illnesses and perhaps forthcoming changes or transitional points where they becoming less well. But people seem to, there are some people you expect won't be able to cope with it and surprise you and are marvellously capable in sorting themselves out; and then there is the really strong people that come to you with loads of space and one of the typical examples of patient that I found extraordinarily difficult to work with, are nuns who are facing terminal illness. And they have all their faith there and they've been a model of good human behaviour in their Christian faith, and yet when faced with death their spiritual being is challenged: "Why should this happen to me? I've been punished for something"

PS: for leading a blameless life?

R: Yes, yes. And I think they are very challenging issues during the interviews because I mean, lot of us have in palliative medicine, although it started off probably in a Christian foundation, many of us have our own faith, however strong or however ahem weak. I think most of us would admit to having a belief because you, I believe you, having a very hard time I think if you didn't belief in anything.

PS: Especially in this work?

R: in this work. But it's very difficult when people who are, you think, whose faith is absolutely unshakeable, then come to you in the last illness, doubting themselves, doubting their whole existence and doubting their lives. And those conversations I find traumatic. Yet again, receiving information about people who, working - you don't open conversations to get to lead you into things that you don't feel comfortable with yourself and spiritual and faith and belief in God and those things may be not comfortable with some people and the sexual side is not comfortable with another. So your interviews are already blinkered when you start them, if you're, if you're interviewing from your experience, from your life experience, and that's all we can do! We can only go from our own life experience, ahem, I think there is a whole lot of different aspects. I don't know whether you're interviewing some of the home care team?

PS: Yes, I have.

R: 'Cause we get into quite philosophical debates at times to how much information you should be, how much you should be getting patients to disclose about family trauma and past life. We are all very good when we have our own problems in our lives but putting them into the correct places and pocketing them away and not allowing them to be part of the process. Should we as a team of people when you're approaching a patient's end of their life try to poke about in issues that have been really very effectively dealt with in patient's life. Should you be finding out whether there's been a background of child abuse or when these things are already been buried in people's minds and the way that we work with our brains, painful issues are tucked away and not forced out of.

PS: But what if the patient or the family itself brings up these issues?

R: Oh, I think that's possibly that's when they are not tucked away. But I do feel there is a tendency amongst palliative care teams to perhaps feel that we have to drag out every item of a patient's life story and relationships which sometimes I feel probably, if patients have actually dealt with them and unless they bring them up themselves, we shouldn't be raking them out!

PS: But why do you think there is a tendency to do that?

R: I think it's because palliative care teams over the years has been revolved and recognized that we look after the total, the whole person. And that includes the physical, so I mean you do a very detailed history of all the symptoms and all of the things that have happened to people. And we take a social history of family and even sometimes sort of financial and all the other things that are, and work and what the relationships people are. The psychological and spiritual elements which I think because, perhaps because of earlier teaching in palliative medicine there is a feeling that nobody can die well, or have a good death, if they have a lot of burdens on their mind and it will cause spiritual unrest and terminal agitation and that it is our duty to actually see if we can relieve those burdens. (interruption by a colleague). No, I think it's because we are instructed as we start out in the field that you have to bring these issues and perhaps put them all into comfortable pockets and make patients feel comfortable with them in order to have a good death. And I think we probably got too far, that we feel it's our duty to push patients and families to exposing areas that they've already dealt with. And sometimes really you haven't got a lot of time, if you've only got a week of life left, there is absolutely no value in raising issues 'cause they ... floating about and you can't do anything about them! I think that's (respondent left the room, tape stops)

R: So, where were we?

PS: You were talking about having a good death and dealing with the whole person and bringing up issues

R: Yes, it's the timing of bringing up issues as well as whether we should be bringing them up?

PS: Yes, I wonder what your opinion is. Do you think that it may lead to a good death to resolve issues?

R: I think people who got a lot of anxiety and haven't put their house in order, I think, probably do when they come to the last forty-eight-hours are more restless and perhaps, 'cause they haven't got the strength to express that and they get more agitated and frightened and it's all internal. But, ahem, I think there is a limit to how much people can do! Sometimes, you can resolve superficial family differences by talking to families, bringing them together, allowing them to talk through their differences, if you got that sort of time. But I'm not sure that we can put pathological families right.

PS: And then in the short time to do this.

R: Yes, and we are all working in a short - ahem, and it just isn't my anxiety that I have sometimes when I listen to or see written-up histories of patients, whether we are deluding ourselves that we can do things about patients' lives and whether the anxiety is worse by talking about it (laughs).

PS: Yes, it's again an open question if you bring up issues that are in a way lived with and now brought to the forefront and become a central focus, so it may not be anxiety-reducing rather than producing.

R: Yes, and it's only what we judge as being awful to the patient or, you know, things may be a terrible experience but for some families it may be part of the normal life! One of the home care sister recently has been in a household where there are constant fights going on in the house; it's a very ahem violent household. But that's the norm to that patient. And should we be imposing with our norm, in fact the quality of life issues, how can we judge what somebody else's life should be like! 'Cause we are only imposing from our own experience what we think

PS: is right and good. Yes.

R: Yes.

PS: Well this is the whole thing too about the quality-of-life concept, isn't it? Is it sort of an ideal, sort of an abstract ideal that we try to sort of say: this is the way it is or should be?

R: But it is very difficult to say what might be completely normal for you and still quality life, for somebody else especially in a different generation perhaps; and I think we are crossing not only cultural and generation gaps as well, what's normal in a household of young people today with television, computers and TV news and sitting in, round as a family in front of the television with the news, completely alien and different to how our parents ... at life, which is focused perhaps around the meal times as being the family life and people sat together talking without this television influence So, so then quality of life would be a different thing! It's just how culture and age and all the other influences, maybe some families would say if they won the lottery that would be the most brilliant quality of life (laughs). So, it's trying to I suppose avoiding being, you find yourself avoiding issues because you don't know how to deal with them if they come back to you, if you open a

box up and [something] jumps out that you don't know how to deal with, so that automatically puts you at a disadvantage. And no professional likes to feel that they can't deal with a problem so if we don't open

PS: Especially if they raise it.

R: (laughs) Yes. So in a way we protect ourselves that way and I'm constantly aware, should I be intruding in patient's lives and family and - we are in a very privileged position in palliative care. I do feel that we do get offered very intimate secrets of people's lives and confidentiality and who we tell; if you are in a very closed bedside discussion with somebody who is clearly dying and they want to unburden themselves, whether it's therapeutic or whether it's just unburdening or passing on something that happened to them in their life. Again, should you broadcast it? Is it going to influence how the rest of the team think about that patient? I mean you know that human nature is judgmental and if a patient reveals to you and innermost secret of some dreadful thing that he's done in his life, ahem, should you be more like a priest and keep it to yourself or is it in the interest of the rest of the team that they know about this so that they can deal with problems that arise that may or may not be related?

PS: Yes, I see the dilemma, there is a dilemma, isn't it?

R: It is. And sometimes you have to make a decision as to whether you keep it to yourself and don't write it in the notes and that's just between you and the patient. I think what I tend to do now is if I feel that it needs to be, other team members need to be aware of something, I ask the patient if it's all right to share that information. And if they say 'no' then I won't write it down. But there are a lot of interesting sort of dilemmas that you get into. I suppose there are [six] really, behaviour and when people give you confidential information; because our teams are so big they tend to be growing all the time, I think patients would be horrified if they realized that something they told one doctor was being discussed by a team of twelve people (laughs). You say, can I share it with a colleague? (laughs)

PS: But you think that it is this desire or need or urge to talk in that way to you, for instance as a doctor, is it, again it comes from the patient; it's sort of seems again to point in the direction that they want to

R: They want to talk, yes. And sometimes that's a certain cathartic exercise isn't it? And probably the doctors don't actually receive that much information as our nursing colleagues who get a much more, or sometimes get a much better one-to-one relationship, whether they are in the bathroom bathing them or they are bed-bathing with the curtains round, ... curtains are an artificial privacy but I think they are more likely to be given secrets, patient's secrets in those situations. And again it's whether they should be sharing them, I mean, sometimes secrets once they've been told and the person who's receiving it doesn't, I think sometimes they are not asking for judgement, they are not asking, but they, they observe that it hasn't shocked the person and it's not. Ahem, and I think then that solved it! They've spoken and they said their thoughts and sometimes it doesn't need any further - I mean, I suppose if you are then given a great burden that you recognize that you are not qualified to help to relieve, such as a ... an aspect of their faith, and maybe a priest or a clergyman might be the person, you possibly could say to the patient: "Well, thank you for sharing those terrible thoughts with me but it may be more helpful for you to now share them with somebody and I will help you to make that meeting if you would like so you could share this burden", because - maybe you are giving them opportunity to resolve conflicts in their own lives. It's just where you take information, whether you should expose it to everyone. I mean we, the priest that we had on our team had a classic priest ahem is the hospice chaplain in my last job, and he was constantly getting rebuked by the rest of the team, particularly the nursing staff if he had long conversations with patients, he didn't record the information that he received in many - and they said: "We know that you had a deep and meaningful conversation, can we know what was said?" And he said, it was between the patient and himself as a priest and a sublicant that he should be talking and not - it wasn't, I mean he did acknowledge that if there was something that he felt the team needed to know in order to help that patient, then he would have probably spoken, again like I would say: "Perhaps you need to speak to the doctor about this, because it perhaps will help to resolve spiritual pain if you, if everyone knows". But he was also pushed to being, whether he should receive information and then pass it on. And another member of the team who was also often quite pressurised is the psychologist! We have a clinical psychologist on the team and they have conversations with the patients, sometimes there is an awful lot of pressure on that person to share the results of those conversations which perhaps isn't what's needed. It's perhaps the decision-making

process that has evolved from the conversation and again to try and [solve] hypnosis or whatever and those are the results that the team wants to know but they don't need to know perhaps some of the very important conversations that they have had before them. But they are all dilemmas that you have when you start letting patients talk about more than their illness! How you structure an interview, maybe you don't want to receive it, maybe you are not in a very receptive mood but say: "Well, let's talk about your broken leg." (laughs). So I think we can hinder the progress in an interview by our own mood, our own feelings of well-being and confidence as well as; I have that on one side and then I have the other side and me saying: "Should I be asking or pushing? Does it matter that I know more than the patient wants to tell me? So, it's that's really the difficulties in the experience, but it's also wrapped up in time and how much time you've got to explore things, what do you do when you've got to the end of a period of time with the patient and they suddenly give you an opening and you've run out of your allocated time? Do you say: "We'll talk about it tomorrow?" (laughs) or do you realize that you only get one chance of this piece of information being explored because it's just been handed to you. And then perhaps pressurize yourself in a different way when you're running with the next patient, 'cause, you know, 'Don't start [telling] me this'. Anyway, those are thoughts.

PS: As you said before, 'Is it now the time? Is there time enough for this? Is now the right time?'

R: And we get it wrong so often with times. I mean patients want to know how, and families sometimes want to know: How long have we got? When is the death going to happen? And we think, ahem, we rarely get it right. I mean we can do within forty-eight hours perhaps, but sometimes we even run then when we think somebody is going to die. So, is it ...

R: and that. I think you start to recognize, pick up on, you start to realize that a transition is happening. But how long you got from that point is also not easy to gage. But once you recognize you're going into say, maybe the terminal phase, last forty-eight hours or so or last week if not, I think it's important at that stage not to start bringing issues that, just bringing them up.

PS: Yes, I can see why. There is no way to resolve it.

R: Can't resolve it. It just leaves turmoil in the family because they perhaps hear something they didn't know about. There is turmoil with the patient and leaves the whole team uncomfortable as well because they realize they brought up an issue that they can't deal with. But it is, it is an interesting, I think the whole area of team work and who tells what to whom and who gets information and how they use it and what it, where it's recorded and if it should be recorded and how much should remain confidential if something is said very confidential and does that patient - you are breaching a confidence by giving that to somebody else and maybe they wouldn't have told you at all if they thought you were going to be passing it on. So, when I look at interviews, I think they are a minefield really. First the conductor of it with the patient and for the whole team, the team's expectations in the period of time spent with the patient, if they see a doctor, they are having an interview, or a doctor or a nurse having an interview, you expect to be related of what that was about. And many people get a bit cross if you don't tell them. But should we have a right to have every information, every piece of information that's given to one member of the team in confidence? I suppose it all comes down to Cecily Saunders and her 'good death'.

PS: Yes, I imagine, I read her works. I am amazed that many people really feel the urge when they sort of have a glimpse of their, sort of, raising issues that were years ago really finished or are basically un-resolveable.

R: I'm not sure that they want to. I'm not sure the patients would in an environment, either in their own home or in the hospital environment where there wasn't a team who have somehow perhaps through the culture of palliative care or hospice care felt that it is right to look for more. And I'm not sure that maybe we're going to an extreme that maybe is uncomfortable for patients as well.

PS: It's sort of an expectation

R: of a post-care situation where if the GP and the patient that is dying at home, ahem, with a General Practitioner and the District Nurse, without the palliative care team, and everything seem to be according to expectation plan, I mean I know that there are things would under those circumstances would anyone be looking at the death that we are looking at here? We are said to have more time and sort of a bigger team and you got trained to communicate with the patients, are we - I'm just really sort of just throwing - I mean are we actually doing all that we should be doing? Do

patients need to have this, because they perhaps wouldn't if you experience death in the hospital wards, death can be a very peaceful experience and I've seen a lot of patients die and it doesn't; patients die - I don't know how the percentages are - but only about ten percent of patients die in hospices in the country. Patients die well in other places without this huge team of communicating people. I mean we have expertise at pain control and symptom control and some of it certainly is difficult to achieve without getting people's anxieties and fears resolved and some of them are resolvable, fears of pain and I mean the idea that people get cancer and that there will be in overwhelming pain and a painful death. Those are the things that the media put across to the public and those things can be resolved with patients, but I'm still in a muddle myself as to whether a lot of the other issues which are totally insoluble should even be explored and since death does happen calmly and peacefully in other places without this soul-searching, are we going along the right track? Should we be exploring in the depth we are? But there is perhaps I don't know how other people, I haven't really explored with other people how they feel. Only that I know the home care sisters, one of them I was speaking to recently feels quite anxious that we are trying to intrude further than we ought to and maybe we should be even more aware of patient lead rather than perhaps leading the patient up avenues that are painful and then we don't know what to do with them. There are patients who you can meet time after time and never get any further than: "I'm all right, doctor, don't worry". They don't want to talk about it. And maybe they are all right. But we all feel terrible if we haven't, if this patient keeps coming back to us and saying: "Oh, it's OK doctor, I'm fine, I'm not frightened of dying, everything is under control", should we disturb that equilibrium that he has achieved somehow. He says he's all right. Maybe we think he's not all right, maybe he's giving us other signals that he's not all right but he's saying he's all right. And we get patients that we never ever get to deeper than that. They are telling us they don't want you to talk! "I'm all right, doctor."

PS: But it's not the sort

R: It's not [consable] when patients tell you that because we are getting messages saying that their pain is under control. Now we look at pain being physical pain but it's also the, it's influenced by anxiety and depression and all the other things and if a patient's pain is not responding to the medications then maybe there are other reasons why it's not responding. This is the patient that's telling you face-to-face that he's

OK; "I have got pain doctor but I'm all right and in every other way I'm fine, just sort my pain out."

PS: Yes, I see what you mean. So, you can't really sort it out unless you approach these other areas which influence the pain.

R: Yes, yes. And then it's how far you go. When you start to unravel something, it's like the bottom of a jumper (laughs). How much do you need before you're running into causing more pain or painful issues that you can't do anything about, unresolved crises or patients' bereavements or sadnesses that, there is no way, there is nothing you can do about, maybe listen to them, but I don't know. Maybe that's help to just to listen to it. I'm still not sure, uncomfortable and maybe that's how your interviews are moulded, to your own comfort in dealing with things. Maybe that's, maybe that's wrong! I mean I question myself, I question and I'm doubting all sorts of things.

PS: But again it's a two-way thing. And I'm sure all conversations in this world are limited by the amount of self-investment one can afford to do at the moment. I think it's both ways. Doctors are people and have to watch too that they don't exceed their limits as far as going into a thing like that is concerned.

R: I suppose it's also the culture. When I was a medical student, you were told 'never get emotionally involved' with a patient, that was completely taboo. And I think over the last twenty, twenty-five years in medicine, it's recognized now that you can't be a good doctor unless you emphasize and maybe do get emotionally involved with your patient because you can't, you can't really get a good rapport or trust with a patient unless you show some empathy with that patient's situation. We were never expected to be able to say to a patient: "Oh, I know exactly how you feel" because you never would - but patients have to feel that you are at least thinking along the [wavelengths/very events] that they are thinking.

And the emotional, I mean, you've got you perhaps in a palliative care situation, as you got a very strong team that you've grown with, then that's safe area. I'm a new doctor in this team, a new leader of this team here, ahem, and everyone is feeling pretty fragile at the moment I think [over] three months; and I think having lost (name) who was here before, who was here for fifteen years, ahem, I think there is a degree of not feeling quite safe and

comfortable in the team which makes how you talk with your patients because you don't know what, who is going to carry on. With inpatients for instance, you have a, an important conversation and you share that conversation with other colleagues, you know, like being re-explored by different team members who possibly at night, the night staff when somebody is settling you down to bed, say: "I had a talk with the doctor today about this", and they continue the exploration or the listening. If, if within the team there isn't a sense of trust and knowing how that person is deal-, then there, those conversations too, patients at this point, you know, transition of a team, are probably more vulnerable in a way because we are not working as, as a team yet. It takes time to build a team. And maybe my own insecurity at the moment is probably higher because I don't know how other people are working and how other people are responding and whether you're feeling safe! And I don't feel safe at the moment to express my - with the team I wouldn't express any lack of confidence in what I'm doing or saying "I'm feeling unsure about this and perhaps somebody else would be better talking". But because I haven't established the relationships that I can do that in, that I feel safe, so, ahem, at the moment I'm having to say that I'm strong, I'm doing this, I know exactly what I'm doing and appear to everyone that I do know exactly what I'm doing (laughs). And patients have this image of doctors too: the doctors know exactly what they're doing. They know how to treat us, they know that they're going to [be in trust/trouble]. And I think that everybody's image of this person is being in control and knowing

PS: A heavy demand too on this person, isn't it?

R: And it's, when you've got a good strong team you can share and I think at the moment we are feeling [whether/better] to talk to other team members you'll find there is probably an uncertainty throughout the team at the moment and that's something that happens. I mean, change is good and I wouldn't ever say that change was a bad thing but it's, it's resisted because everybody feel comfortable not changing. And when something's going well, why look at changing it. But I think the whole team is feeling a little bit uncomfor-.

So those things will come through in your interviews with people because there is change here and change is never, never as comfortable for any, for a whole team! I mean it may be comfortable for one person to change everybody else, but it's not (laughs). But yes, I think there are lots, a

hundred and one different; I suppose it's something I haven't really thought through until I was thinking about coming to see you today, the different things that actually influence how you manage your conversation.

PS: Yes, there are a number of factors that influence. I've read some research in Germany that the death rate of patients is influenced by the relationship between the nurses and the doctors on the wards. The worse they get along with each other, the higher the death rate appears to be.

R: Oh God! (laughs)

(Interview ends here because R has to leave)

Transcript Interview S 6

R: Participant S 6

PS: Interviewer

PS: I would like to talk about what is happening regarding the communication with patients and families, what are your experiences, your thoughts, what are the issues for you as a doctor.

R: And you're, so you're meaning just in communication aspect, just

PS: Communication, relationship building, what happens between people

R: And that would involve between staff and between patients

PS: Yes, the focus here is on the staff and patients and not on staff and staff or patients and patients

R: OK. All right. Hmmh, well, to me communication to me when I am in a communication situation with a patient I think I tend to take off the ...[cloak] cloth of being a doctor because to me it's about one human being to another. And I think particularly in the situation of palliative medicine. People are frightened, they are faced with life-threatening aeh conditions and, yeah, they're basically frightened, they are faced with their own mortality and I think that also brings me face to face with my own mortality in a sense that meant particularly when patients in your own age group ... but I think that it extends to other age groups because you are aware acutely of your own finite existence as it were. Still, so that to me is the first stance, trying to put myself in the person's place and say: 'How would I feel if it were me?' And that to me makes communication very very easy because once you open up and you show yourself as a human being to another person they because communication is a two-way thing and I always think that if I distance the patient then the patient would distance herself or himself aehm from me, because that's my own experience. When I am a patient with doctors, 'cause I have been in situations where I have been a patient and if I feel that they are very cold and professional and distant themselves, then I become distant too. So for me I find I find it a very relaxing experience when I am with patients because I really, my heart and soul is in this speciality and aehm, and and and so yeah, I really feel that it's possible for

me even with all that's going on around me to really seek myself into the moment aehm, and it becomes easy. I know when I say this to my students when I taught when I teach [this] I know that I get sometimes strange looks from them saying: 'Oh you make this sound so easy'. But as I said once you put the human factor into it aehm and stop hiding behind the cloak of professionalism and the doctor-patient whatever, aehm, it it's becomes it becomes easy for me.

PS: And they respond to you as a person, they don't get sort of stuck on the doctor part

R: Yes!

PS: They go through directly to the person

R: Yes. Yes. And I think that has nothing to do with touch touching because I'm, it's strange, I am not a very, I am originally from (name ---) and [say] that's in the --- and in a way we are a very informal kind of culture even though I've lived in this country now for twenty years or so, but you would have thought, sometimes I surprise myself I think 'Oh gosh, why am I not this sort of touchy touchy sort of person' but I think it's because I had to unlearn touching when I came to Britain and it but when you are very human and natural with someone aehm, yes, it's it's it's about it's about communication or communicating and being on the same wavelength with somebody but these are the things that matter [don't] seem to matter that much.

PS: Is this special vulnerable situation that patients in palliative care are in, does this help to establish trust and rapport faster than in a different setting where mortality is not on the horizon so to speak?

R: I think you can see that in two ways; I mean vulnerability can also [super] up defences it's like somebody faced with danger and you feel at the corner [threatened] and in a way, well I don't personally think that that, as I said I think that vulnerability can work either way aehm I am trying to think of my other experiences with patients outside of this palliative care setting. I think anyone, yes they they must be that, yes there is that measure of vulnerability but whether it makes our patients more wholeheartedly trusting I am not sure, I think it can work either way. And, you know

PS: But there is a sort of, how shall I put it, a special situation because death is sort of present even if it is in the

future it is an issue in the presence. So I wonder if this changes the way how one relates and communicates.

R: I think you can only experience that from being, I mean from only being my impression, from getting inside of the person's head. I mean no matter how closely we are to this, in this situation with patients, aehm, I think it's very difficult to really say with any certainty how patients are really feeling. I mean there are there are so many defences that that we we use, ..., mainly primarily, and I think it's this, this [name] of cloudy issue aehm, as I said, aehm, for me when I am dealing, I think I only deal with myself as a person in in these situations and, yes, people are afraid; but people are afraid when they feel you as a carer that they're not maybe communicating with you as they would like to when they feel distanced from you. When hope is taken away from them and I am not talking about, you know, giving people false hopes, but it's about I always introduce things like the role of of the mind, the spirit, the will to live. We don't know as medical practitioners nobody can go and measure this, you know, when you measure all the physical things you can predict and say you know: 'Your life expectancy is six months, two months', whatever it is, but we don't know. I mean I've seen it so many times here that patients with with this inner strength this will this fight, and I really feel that as the caregiver that these are the things that that I can build on or give nourishment to in my interacting with patients. So when you talk about intensity in a, people I know the view of others, people on the outside looking in I get this every day, they would say things like: "And how can you deal in a so intense setting?" It's no more intense to me than you know, people out there walking down the streets, you might be run over with something. I know that in our situation here people have been given a diagnosis of cancer and cancer equals death, it's a terminal illness and I know that whereas somebody walking out there is not aware that it would be, could be run over, I know that there is that difference, but when you talk about intensity, I think for me it's about hope and I know that if I were in that situation I would feel a hundred times better if I were told: "Well, look we as medical people we feel, that, I mean, this is what you have, you have cancer, but on the other hand, there is little that as a doctor that I know about, your will to survive and the role of the spirit, the role of the soul in all this, I don't know, but I am willing to fight with you on this and give you as much support and emotional and spiritual encouragement as you need." And so for me, I I really know in my heart when I approach interview situations like this where the patients

that ahem, that I get on to a very human level to people and it makes it no more intense than my interaction with aehm soul mates (laughs), you know, that I that I feel close to 'cause I think we can't ... we can't divorce even the doctor, I can not divorce myself as a person from from the people that I ... I never believed that since I started medicine that you had to distance yourself and put on this professional thing and and that if you were, you had to be accepted in in a to really deal with patients, I don't believe that at all, and so as I said for me it's it becomes a very easy interaction and I can sense that in patients, I mean that's the feedback I am getting because communication is a two-way thing and if you're not getting any feedback you are not communicating. And

PS: I have talked to other doctors in these interviews and they seem to have quite a range of responses in respect to this issue: some were trained to keep a distance and to be as objective as possible and gradually, with time, changed the mode of interacting while others seem to prefer the objective mode, prefer the distance. So I imagine there is a range of responses

R: Hmmh, yes. But we all bring our whole biographies with us to the situations. I mean for me my background is I am a sociologist and before that even I did nursing, before medicine. So for me I bring everything with me. I also bring a cultural background from another country of perspective altogether in a way that aehm, human beings operate. So these things you can not divorce from any communication, you bring with you what you are and aehm, but, at the end of the day we are all human beings and that's what we bring with us and we are communicating with another human being and we emphasizing and we can [bring] ourselves to aeh; or for someone to do medicine, I think, if someone, I think if I ever had to feel any different. So for me in palliative medicine I think whether I am doing this speciality or whether I am sitting in a casualty department or in an acute ward the bottom line is that people are afraid because they are in a situation where they are vulnerable. I mean you go to a doctor you immediately feel a sense of vulnerability, OK we mentioned just now that may be this situation as you put it, has heightened vulnerability is heightened by the the fact. But in the actual interaction, the basic bottom line is the same. So I mean, I personally, the thing that pains me I find most going home at the end of the day is not the patients, I think the patients in a way revive and rejuvenate me, it's the it's staff interactions that that I feel worn down by, that that's the communication with people who may be

not like-minded. But once I am with the patients, it's as I said, it's a different a different mode for me and I feel almost energized by it because one gets, you know, one knows that as [you/we] said when we talked about myself, when I am in a situation face to face with the patient I know that I am getting through, you feel it right away and it it's it doesn't itself [eats] back on you, you feed each other, and it's good. So in a way for me palliative medicine I wouldn't do anything else I mean I wouldn't, I couldn't, really

PS: Is there more time, inclination, is there more personal disposition in palliative medicine for communication than in a different type of medicine?

R: Yeah! Yes, there are I mean yes of course there is the the factor of time in that you make time you have to make time. Maybe palliative medicine are trapped onto the kind of people who I know that's a gross generalization I was saying people who feel that the need for this hurried five-minute consultation; I know that's what drove me from general practice aehm, that I I found it impossible to look at somebody holistically in a very short consultation time. So yes, the time as we care even though it means that you don't clock off at five o'clock because you can't clock off if you have people who need their private ... number of communication, so so it's that aspect of also being able to give up yourself and of your time but in your individual consultations with patients you, yes, you have you have to give the time, you can't hurry people in those situations, whereas somebody with a cough and cold that you can see is a slight viral there you can, you don't have to no, exactly. So yes, so that does help the level of communication that you feel that you have the time to offer. There was one person in all my training one mentor that I all- that stands out in my mind and when I was [inter/with her] communicating with patients in absolutely something I have not seen but she was able to gain the attention of the person, a very busy consultant, and would sit with them and literally in three to five minutes would get that person's attention, would deal, and I have seen it on a very deep level, and be able to get up, leave the bedside, move on to the next patient, and I won- and I, what I used to observe was a patient who felt 'Gosh, I really got her attention' and with a satisfied look on the person's face. I have not been able to master that and ... try to master it because it is not my personal style, but, yeah, I think at the day it's your being effective as a communicator, getting a message across to or putting someone at ease is the important thing. Some of us take longer to get there. But I saw this person in

operation and it, it really and she doing. But to me, the whole business of just sitting down, you know, I remember we were told not to sit on the patient's bed and never to sit at all because that looked as though you are idling around the patients (laughs) you always have to have this air of being busy but ahem now it's just so natural to just pull a chair and sit down and that must mean so much people you know, we don't think about it often but, yeah, I guess yeah, I do consciously now think 'Gosh, it must[n't] mean so much to them', so I do it, you know, do everything in ac-, would even say things like: "Let me now get a chair and sit down so we can have a chat and I can hear all your troubles" and ahem, so its, you know, you learn these; if you know something is going to make someone, you know, feel at ease and comfortable you make even more

PS: And good. If I would be a patient and see a doctor pull a chair and sit down, my self-esteem would rise, I am more important now than before. The time spent would also be an issue, I would imagine?

R: Yeah, yes. Hmmh. But the fact of doing, you see patients also know that they're not the only ones, unlike when you are in a therapist and come in for a consultation of, you know that you are scheduled in I don't know for how long, you know, half-an-hour, that you realize, you know, we are in a five-bedded unit and they see, the observe, very im... patients look at what's going on all the time very intently and you know that you have to to deal with all these other people. So they're aware of that and I'm sure that by your going ... and pulling a chair and sitting down and even if you get up again after five minutes I am sure that that in their mind, because they know that you, that's not just you, I am sure that that means a lot to you sat down I think in that context that's significant. And ahem, and you know all the things about noticing cards whether it's their birthday whether the flowers that look so pretty around their bed and taking in you know the whole personal ahem thing; or if you see, like rings, I am a ring freak, I love rings and if I see a patient with nice rings on or something and you make the comment, it's it all adds and it comes very naturally you know, and I think people pick this up right away, it's not put on, ahem. So this is about what I mean about bringing in yourself to the situation. For me too, it's colour. Well I am not very colourful today, but usually I wear colours and, you know, colourful earrings and things, and this means so much to patients, you know, I didn't realize that until recently, relatively recently, about three years ago when so many people said to me that I thought 'Oh gosh, this thing

really is important' about, you know, wait for you to see what colours you are going to wear today and things like that and then I started making a point of the colour business because that influences communication as well, that if they felt a sense of well-being because the source of my ... looks is a breath of fresh air to them, then why not? I mean if they so feel [imbued] a sense of well-being to me that you do influencing another person and I knew, I may be, may be patients do it all the time, they look at doctors how they dress and what they wear, I mean, it's it's part of being human again. But that is a very ... and the colour thing I remember how it it really, you know, I started thinking deliberately about the use of colour.

PS: Communication is much more than just words?

R: Oh gosh, oh definitely, as I said, it's about the using using yourself and little, I mean we don't have mirrors to see ourselves at a ... of expression and your eyes must light up when things really please you if you are relating to them. I mean I always give something of myself to patients like if I've just been often to the Caribbean, I said often, once a year (laughs) but if it is around the time that I am ready to go or just been back, you know you relate these things to patients ahem, aeh, you can see that again that must mean something that to their sense of importance or self-esteem that I [brought] it to to relate these other things and ask them if they had any experience of travelling to my part of the world or things; and it's amazing what, you know, their stories that you're just giving air [and that], so I think I [knew] so much just so much of me have to give and it's not just about taking from people, I mean it's it's about giving and giving you receive, you really do because you, you you allow them to either ... that to me makes you more effective ... because if you can really get to the bottom of this you can make someone feel ... from one human being to another, then you get so much more from them and then you can be more effective, because when you come to a [high sugar] diagnosis or, you know, hypotheses of what's going on, I mean [naturally]

PS: And if you relieve the anxiety to some extent, that will help the medical side too

R: Hmmh! Oh definitely, yeah, instead of I mean to give somebody Valium and Diazepam, if you can have them relax then then then good and I mean just recently, I mean patients give you so much do. I walk into the ward and she says, this was just Friday, she said: "Whow, doc, when I see

you I see your face and I see relieve ..." and she said: "You know why? Because when you came to see me the other day [of hope] I remember the enormous sense of relieve I felt and two hours later I was so relaxed." And we had also given her some medication because of her her nausea and vomiting, but it was that, you know, and that made me, gave me to a sense of well-being and because I feel better then I am a better doctor, because I go round feeling happy, it made my day, you know (laughs). And it's very true, I think it's very true. Ahem, and I look for instances to be energized in the job, because I think it's important; if you feel energized you feel you give you give more you communicate better, you you feel better. So, I, yes, there is not enough, I said just now I look for these things and yeah, maybe I do, maybe I do round ahem looking for things to feed my, sort of ... my battery ... to [make] it more charged for the rest of the day, ahem, but that's just me too. I mean, as I said, we bring our personalities to think, to think in situations and I need to feel motivated all the time, I I couldn't do something if I felt all worn down every day. I mean, I am not saying there aren't days when, of course, you feel like this, we all feel a little bit ahem it's just [makes] the load too much lighter.

PS: What about the content of communication? Is it about day-to-day things, apart from the illness side, do patients bring personal life problems to you and one step further, the spiritual level, does that enter communication at all or sometimes?

R: Hmmh, yeah, I must say. You see it depends how, on, the business of spirituality, that is so open to interpretation but I find that there is spirit, there is soul in all these things that we've just been talking about and that spirituality to me isn't about otherness or something how can I say, that ahem, that will in any way with religion or religious belief or anything, but spirituality to me is, is about when you get into another person as a human being that is spiritual experience and that is so so - I really do not I mean I find I tend not to maybe that's something I need to look at closer, but to really delve into how yeah how people're feeling about things beyond. I mean I find ...

R: Yes I mean into existential issues how people feeling about life after because ahem, achm, I must say that most people in my experience want to dwell on life now and hope. ... people have things, issues that they unfinished business and these things most of the time tend to be things

that they want issues, family issues the next big issues; I, I can think of one situation where she was a very [fine; finally ill] woman with breastcan-, started breast disease with the brain a fast disease, and she said to me (whispers): "...[Look on] well, will I, I mean will I go to heaven?" and this came out of the blue, we were talking, she was a a into books and novels and writing and we were talking about other books and she said, oh yeah: "Is there a place in heaven for me?" And I was really taken aback because I wasn't ready for the question, just in the context that we were, aehm, just the previous conversation, and I said to her: "I don't know". But she made me go back and really think about things. I remember there was some book which she told me that I must go and look at and aeh it was about it was they started in their Hindu philosophy. She, I think, she did die in having come to terms with, because she was this particular place was struggling with the issues of heaven or hell because she had never addressed them before but I remember that one did make me think that, I mean, as I said at the time, I wasn't ready for that to [answer] that question but I, I was determined to invest and I, I didn't do enough, I felt I ... and she looked at me and I got the impression that ahem, that it was, that she saw honesty in my answer, so I felt comfortable although I didn't have any answers but it is an area that I, I mean I tend ... I tend to, that I feel, maybe it's my own death ... spirit that I don't see the separation between the God out there and the God waiting for me in heaven because I think, but that's my own believe that I bring to the situation, ahem, that we're all God-like and we [own/all] the things we do in our lives, should be God-like as to, because I['m confident/find comfort] in my own view of of spirituality But that does not mean that one should not delve not into other people's view of of spirituality and I am glad in a way that this has come up right here now ... situation, because aeh, yeah, it's it's an area that I need to work on I think we are all growing every day and aehm,

PS: and being confronted too with the issue from somebody else may be a catalyst that set it in motion within oneself

R: Yeah, yeah. But as I said, my experience in that it's about faced with very limited time, the times of conversation that I get with people, it's it's about spending about this time that they have and how finishing business that's undone and I don't know to whether an element of this is not, is also that we have here --- the, have you met him? Yes. And whether it is patients see, you know, his role as [seasonal] spiritual ahem guide and passage [worth]. And and it would be

interesting in a way to sit in to some of his conversations, ahem, with patients; so you see what I am saying, the patients see the doctor as dealing with one aspect of things and nurse with another thing, ahem, ahem, spiritual guidance as another one, so, yeah, so in terms whether it is one can say that, you know, is it that I block [their] leads into this direction or is it that they do not really wish to delve into that with me? Ahem, it's it's some of them, some of both [ways].

PS: Do you sometimes have the feeling that they struggle with meaning? What does it all mean, their lives, their illness, this being confronted with an urge or drive for some kind of meaning?

R: Hmmh, yes, ahem, yes there is a lot of that and I see people drifting in and out of aeh, some people are just staying in a state of denial, from beginning to end, aehm, even though research is now showing that people who stay in denial tend to have longer remissions, remission ... and again if someone is in that mode who am I to change anything? That is their way of coping with the things. So I see that and then you see people who drift in and out in all the different stages that search the quest for meaning, aehm, or just accept it, aehm, you know, so it's again, you see the whole spectrum, aehm, yeah, you do. Again, I must say that in my conversations it's, I mean, how much of it is that people sort of put on a brave face to for the doctor, you know. But just now when I started talking to you [in the] stages it may, it could well, very well be construed as as dealing within, you know, un- un- the very sort of superficial things around it Really to me I see that as I explained to you, it's part of ... coming out and if I view all that too as a spirit and as a giving to that person I feel that I draw out from them the things that are important, in what I say important to who, important to the patient. But communication is a two-way thing and you know when you're getting through and I often leave the situation feeling that I, that I have, that I've been communicating, I haven't just been talking and that should quant- quantify to me about feeling of that one experiences from from talking with someone.

PS: That is a good feeling, isn't it?

R: Yes, of course. It's about ... for me, for each ... structures. We always think it's as true for patients but that's not true at all. Hmmh, hmmh. Yeah I think it's it's hmmh, unravelling, I think when you're ...[seating] in the situation

it's not very easy to always stand back and try to ... tried that out or, you could only, yeah, maybe that's where the mystery comes in (laughs) and you can only just pick up these feelings. Yeah, I think, yes. I try not to wear the white coat, or don't any more because I am sure that has a lot of, does something to patients [psyche] in their communicating with me, ahem. I keep coming back to what I said to you at the beginning, 'cause we can, you approach another person and give something of yourself and because of that you get back the whole ... - And I, you know, so I, I guess I really do resent the times that I have been in a patient situation where I have been a patient and when I see my own colleagues, I mean, it's just looks so ridiculous to me when I am looking at it from the other side (laughs); they just look many really are a sad sight, they really think that they are getting through to me and they're not because I felt ill at ease and therefore I don't give anything. And I think it's that acute awareness that make me try so hard when I am in a situation to to really to be a human being [around], so, so that I can be more effective. Because, yeah, patients have a lot of control over what they want, they can see what they want; I know aehm, in a way, their leisure how even, it doesn't always work that way, I don't have [family/any of those] concerns (laughs)

PS: Well, they are dependent on the medical people; but with all dependency, apparent weakness is not always weakness, there can be strength in a weakness.

R: Hmmh, hmmh, yes, it is, the doctor patient interactions always it's, need not to be as complex as if (laughs) as if - as happens, but its made complex because, I think, yeah, people in sort of professionals, most of the time the doctors, I am talking about, the really having a [hard time] communicating with the patients, really communicating with patients, what it makes it ... complex ... and an ... to be.

PS: Is there any training for doctors in communication?

R: There is a lot in this speciality, but when I was in training there wasn't as a trainee in medical school and as a trainee doctor, not really, but palliative medicine you make a point because it's all communication, not all but it's a very important part. And of course general practice too, yes, we're coached in that, but I think for the rest of medicine it's a very poorly developed area, aehm, still, very very much. And the whole issue of breaking bad news where otherwise, that is another big big area that is badly done, all the time every day [as I see it]. Again, they make such heavy

weather how difficult it is to breaking bad news when in fact (laughs) again it's all about putting yourself in another person's place and say: "Would you want to be given a whole lot of bad news sitting by yourself without your family around or with a whole ward full of people or with a whole string of doctors standing over you, or ... just fact it ..., just compassionate humanity, it's all, it's about humanness, that's all it is. I mean you just be human (laughs) then. You know, they make the whole issue into such an academic exercise, you know, to me there is nothing about it. What is the expression? Life is what happens to you while you are busy making plans. Yes that is very true. So why do we aim to build order in, in. I couldn't think of, yeah, our whole situation here in the hospice setting, I think it's very clinical in many ways. (R speaking about personal ideas for own hospice)

R: We talk about a multi-cultural society in Britain and yet you look around hospices and this is not a very heavy ethnic populated area but we had Indians, we had a Muslim woman here once who died and I mean it does cause chaos when the families want to carry out their own religious ritual and things and wash the body in a certain way and in a way taking over control from the professionals and I mean people just fall apart because it's out of, you know, the ordinary, it's not the way we are used to doing things, and, and, but, you know, this is to me if we're talking about giving care, individualized care then you have to allow for diversity and people doing things differently, that sort of caring and communicating as well, it's, you know, it's not just about sitting at the bed side and trying to find out what's going on in their minds and heart and souls but it's the message that you project to the outside, you know, is this a place for white middle-class people? What about all the other poor people who see life differently, whose life's experiences are different from this. Is it that the message is that you are excluded, maybe that's how they feel, maybe that's why they wouldn't come near hospices. All that is communicating, it's the messages that you give out to the community, because this is part of the community, but ahem, yeah, and is it that we sort of neatly, like visit God when we talked about ... [total] institutions, yes? I mean that's, yes, if you want you can see that you, when you walk through the door that these are the rules, you know, follow these rules because it is making it easier for us if you follow the rules. (R talking about 'own' hospice again; conversation about 'chaos')

R: What I am talking about is accommodating diversity because life is about diversity and if we are really truly reaching out to people then we have to accommodate it or else we are failing people in the community, you know, if not reaching out. And I guess it is when people come here we kind accept and are not even going into things like religion; I think of somebody here, a young girl, she was only in her twenties, you know, she wanted to put posters on the wall, as a, you know, break order in her different room, why not? I mean, it's, all it need was a little paint job when she was ready to leave, so I mean, things like that are frowned upon, that's not allowed, it becomes to me almost like in a prison, that's taking away from people's freedoms, but (sighs) yeah, so is sometimes, your ideas and views might not be totally in line with your co-workers that it does bring stress, so maybe that's why with patients it's total, it's lovely, yes, very refresh for me, because people I allow them to be the way they allow me to be, yeah, because they allow me to be. Maybe I pick up that ... vibrations from them ... that they allow me to be myself, so. So I think communication is easy (laughs).

PS: Well, you may be right; it may be made difficult by putting too much into it as you suggested.

R: Hmmh.

PS: Yes, communication may be easy and there is certainly a gift in some people for communication

R: Oh yes, I am sure.

PS: Yet skills training can take you away from communicating?

R: Yes, you would be communicating on one level, certainly, and maybe they would get all the facts they would need, but if you really want to get to the essence to really read somebody, that can only be reached if the other person, really the whole is ... trust, you mentioned, the trust comes, I will only trust another person if I see them as human. I ain't trust anybody else (laughs), right, so that's the way I see it, because you, you approach, if I saw another person and they really were compassionate and understanding, 'cause they have my trust, that's somebody [I] can really believe in, and it's to me, that's the bottomline and I see, perhaps you've mentioned the models and things and what you do and how you do and what you say and those things that certainly detract from my communicating because when

I would stop being relaxed and at ease. 'Guess I have the advantage of having different cultural experiences, growing up in ---, part of the time in --- and here, but you see, television has taken over, now the computer and therefore, I am not surprised that people have to learn how to communicate, because first in traditional families where there are so many of you around, you know, there were nine of us, ... actual with a mother and father, I mean, you're communicating, and there are always people around and people to listen to you, you to talk to them and these, this skills, this humanness was all part of family life, you don't have somebody rushing off sitting on the computer for ten hours a day and the mother there and the father here and everybody in their own living rooms and all this business that we find [around us], you know everybody together all the time, and, so this is why I really feel very very uncomfortable in any situation where things don't seem natural to me and maybe in my communicating with patients and this is the crux that I delve right away through to get to the human part of that person and once I find it, it's easy [say/day], you know. And, yeah,

(tape ends here)

Interview Transcript: W 6

R = Participant W 6

PS = Interviewer

R: I was thinking of a couple of situations because I've perhaps being doing this for a long time there is a lot of different situations I can think of, you know, rather than, you know, a couple that stand out.

PS: But perhaps one or two that particularly stand out in your mind?

R: Right, ahem, I suppose a recent one with communication with patients and families, ahem; I think first of all I need to say how I go into a situation really and I feel that I am like a blank page of an open book that on this, if you open a book on the left hand side you've got your experiences and the knowledge and then you've got two blank pages that need to be written on in this interaction with the patient and the family and on the right hand side, you know, that's future sort of knowledge and information and expertise I suppose, it comes from a certain interaction. Ahem, so I go in I think strictly with an open mind to see what comes from the situation. The difficult one I think comes to mind more (laughs) yes; there was a family recently that I went into that the husband, he was the patient, was reluctant perhaps to have any help, was denying really what was going on with him, family wanted probably as much help as they could, could have really, ahem, and this particular one is an extreme one because it was almost frightening for me really because he was getting very angry during the interaction, physically the fact that he was [thorping] with the side, with the arm of the chair, ahem, he was raising his voice, and he was using very strong language. And it was all out of character apparently for him. But it was difficult to find a way in to reach him. He was just being very angry about, about everything and denying what was happening. I saw him on his own that, when he was, when he was like that. The family, it was very difficult for them, he was rejecting his family. He actually asked his wife to leave the house and she had to, ahem. I, I started off letting him actually get all this out and on future visits I was turning round what he was saying to me back to him, but he still wasn't getting too far, really. Psychiatric team called in at some point, he was threatening to commit suicide and he was very choosy of who he'd let in to talk with him, ahem, he let me in. I don't know why he let me in as opposed to anybody else (laughs), ahem, but it was very difficult to know how to help this

man. He, but on reflection and on reflection with his family after he'd died, we concluded that he played it his own way and in a way we were expecting that. His wife actually leaving the house, knowing what probably would inevitably happen, was respecting that, was very difficult at the time. But communication with him was was extremely difficult.

PS: And he stayed in this stage of angry

R: Yes!

PS: he never moved to any other

R: No, I think he may have done but I think physical condition caught up with him; but and the last contact I had with him, I phoned him on a Monday, he was due for an outpatient appointment on the next day and I said "Could I come in the afternoon, after the outpatient appointment so that we perhaps could talk over what's happened?" And he, he agreed to that and I felt that was the best I could do at the time but he physical- he sounded physically really very unwell I must say. He was letting the district nurse go that afternoon, so somebody was in contact with him. He didn't turn up for his outpatient appointment; he, the clinic phoned me and said he hadn't turned up, could I follow it up. So I did, I phoned him, there was no answer at the house, I phoned the district nurse and she'd been over the previous evening and obvious-, he was obviously poorly but didn't want any intervention, ahem, and between the district nurse and I we discussed it and I phoned the family, the daughter's house where I knew his wife was and said to them that he hadn't turned up for outpatient appointment although he was very keen on going. And my hope was that they'd admit him and we could sort some of the physical things out because on top of not communicating, being angry, he was not taking medication, this was his choice, he knew he had an ulcer. So I said, I spoke to the daughter and I said he hadn't turned up for outpatient appointment, ahem, and I, I sort of explained what they might find when they went to the house, that he may have fallen, he may have collapsed, and he may well be dead. And the daughter said that they thought that might happen. I offered to go with them to the house but they wanted to go on their own, mother and daughter and they went and I phoned about an hour-and-a-half later to the patient's house and he had in fact fallen and died and they found him dead when they went in. And they had, they knew that might happen, they didn't want that to happen because they'd been a close family, ahem, [having] supported one a little bit up until now. I saw them after the

funeral on a bereavement visit, they were together. I saw his wife first and she was upset, in a way I think she was relieved. And she could talk about how horrible ... he'd been to her but ... that knowledge that perhaps it wasn't him, that it was the condition and just the way he'd reacted to it. And the daughter joined us and again, similar things were said and she knew it wasn't her father, although she hadn't seen him for two weeks because he'd rejected her. And when he was alive we talked around this how she could physically touch him and be prepared for him to repel her, ahem, and she was reluctant to going to him because of the rejection. And I don't think she ever actually did do that, she wanted to put his, her arms round him, because when you looked at him he was a very lonely man in all this anger, ahem, but at the end of that bereavement visit they were remembering good memories of him and were laughing at things he'd done and how he was. So I think for them it's ended as well as it could end, but for him it was, it was the way he wanted to play it but it was very difficult.

PS: How much time did he have?

R: I think I was visiting him two, three months, I think. He told the doctor to leave at one point, 'cause he thought the doctor was colluding with his wife in the fact the doctor was given a sick note to be off work and he didn't wanted to be off work, he wanted to perhaps think himself all right but he didn't know he'd [need her at home] and I had to on my visit some times stop rounds between them, not not stop them but to sort of monitor them and not let them get out of hand really and leave them on a, sort of an even keel really 'cause they they could easily row, because they, neither of them were doing things that ... wanted to.

PS: And this all happened after the diagnosis?

R: Yes

PS: He was different before because they were a close family before

R: Yes, they were a close family before.

PS: So something happened as soon as this diagnosis

R: Yes, I, he was going to an outpatient appointment at Cheltenham hospital, seeing his consultant. I phoned them and asked them whether they could do or what they thought about his personality 'cause they'd seen him before and

whether perhaps a brain scan might be a thing to do and they did do that and nothing showed up. We thought maybe his personality was an independent one before his character was an independent one before, ahem, 'cause duty d... went out to see them as well, so she, I had somebody to, you know, to compare things with and we thought perhaps he'd had an unusual personality before and this had been exa-, you know, sort of exaggerated by the diagnosis and by the fact that he was denying it all.

PS: Does that often happen that it changes people?

R: Not as extreme as this, I think this was the most extreme and the most difficult, ahem, no it doesn't, perhaps it makes people reflect more on what is gone on before and speculate on what might happen but not change their basic personality as such which I think it did with this chap.

PS: It must be quite an ordeal for the family if they have been a close family before and then something like this happens and turns it almost upside down

R: Yes, yeah. And she did, the family just didn't know what to do for the best really, they ended up doing what he wanted because that's the only op- real option they had because if they'd gone against that he may have become violent I think. But I have to be careful that if I wanted to contact his GP about anything I did initially about medication that I told him and I would phone from the house in front of him, otherwise he'd get a bit paranoid about what was happening. So I think I handled it carefully but not, I suppose, to my satisfaction really because, like the family I couldn't do any more and as I said in the bereavement visit we ended up feeling that we'd all respected his wishes having sort of talked about the option he had and he'd chose the options and knew the consequences that if he didn't make, take his medication or if he was on the, in the house on his own which I said sort of openly to both of them, wife and husband, when I was there and I think it was probably inevitable that it ended the way it did really. He'd lost control, he'd lost his independence and was fiercely trying to handle to both, but he was physically quite poorly and mentally I think quite exhausted but trying to hang on to those things,

PS: a sort of hopeless battle?

R: Yeah, and it could have been quite different, but

PS: But that wasn't a typical experience of yours, it stands out because

R: It stands out in my mind because it was recent, yes, yes, and quite traumatic going through it with him I suppose.

PS: I suppose most patients and families look to you or to your colleagues as helpers

R: Yes!

PS: so that is more typical?

R: Yes, I think a majority of patients and families use us as sounding boards and to offload onto really, ahem, you know a comment that's often given back on say a second or third visit is: "I feel better because I got it off my chest" or "I just said how I felt and I feel a lot different now, maybe not better but a lot different now" and, ahem, they want to talk over and mull over things that might happen, know options that are there. Ahem, honestly and openly most of the time.

PS: But do you think that they primarily offload or do you think this off-loading is some working through?

R: It, it's, I think it's probably the beginnings of working through that they; I always think and often say to patients it's kind of putting thoughts into perspective from perhaps being muddled thoughts and concerns and frightening thoughts that if they can talk about them just sometimes just say them out loud, that they fall into place and perhaps they are not so frightening. And they can see their way through a muddle.

PS: They start out, I imagine, with very strong emotions and perhaps they need to be 'put out' and after that they may be able to deal with the 'rest' of it?

R: Yes, yes, yes.

PS: 'Cause I really don't know how the emotions play together with the content of reflecting "Well, I've got to get that sorted out, and here is a problem". It seems to me when the emotions come in, there is no room and no energy to think in a way of

R: That's right, yes. It, they almost or uppermost the emotions and the thinking beneath it is not clear; I think the emotions override perhaps the clear thinking. Ahem, yes, I

mean, again there was a recent visit, I've done a bereavement visit and this woman, it was a first visit after her husband had died, I only visited them twice, he was quite poorly when I visited; and she was angry and guilty and all these emotions were all mixed up and she just let it go when I was in there. She was angry with and guilty with herself for letting him go into hospital for a short space of time and for a very good reason he went in, ahem, and she talked for an hour-and-a-half, just just getting it out and, as I said getting sorted, perspective; and I went back again today on a second visit and she opened the door and she said "I feel so much different, so much better, from just talking, from last time". She was still tearful, she was still ahem still feeling a bit of guilt about letting him go into hospital but it was all, all more settled and more natural and normal and things that I would expect her to feel and think. And I think the first visit was very emotional and this visit was perhaps, ahem, more of a rational thinking perhaps.

PS: But how do you deal with this? How do you protect yourself from being 'overwhelmed'? All this coming at you and somehow you have to

R: Yes, I was finding that a difficult one to, to answer really because I (sighs); I don't, I think that I offload in the same amount of actually receiving it. As I am taking this in all day from different people I am not, I am not sort of after the day is finished, sort of getting rid of the same amount, you see what I mean?

PS: Yes, I see what you mean

R: Ahem, I think looking at myself over the years, I think I am a person that can take it for so long and then I have a good cry and it's like a safety valve and get rid of it that way. But I have no sort of set means of doing it, it is sort of, I know that it's sort of ahem overloading and I have a good cry and let it out. Ahem, along the way I suppose I do cry with the people that I'm with but in a way that I can still do my work, but it's not sort of overwhelming me at the time, I am still carry on. But then I don't think that's bad if somebody feels it you're actually with them ... that point.

PS: As long as you function in your work?

R: Yeah, yeah. I mean it's not all the time. It's certain things just get to you more than more than others (sighs). I perhaps focus on the person more when I'm with them, so I'm not getting overwhelmed at the time I focus on them

and try to work out in the head where exactly we're going, we, you know, with the patient and with the family, ahem. But I have no sort of, sort of formal outlet let's call it. I suppose here we've got opportunities within the team to talk about it informally and at our meetings.

PS: I suppose that would help to reduce the stress of

R: Hmmh, yes. But there again, it's it's work that I like, that I've chosen and I would find it extremely stressful to work in casualty. Well as I don't find this that stressful as a day-to-day job if you like, as I would find casualty, so I think I found an area that I feel comfortable with, ahem, that I think I'm working fairly well in and I suppose that in a sense takes a bit of the stress off.

PS: Yes, I am sure it does. And there may be also some satisfactions, some rewards of being in this work

R: Yes, yes. I think you have to set your scales down and as with the patients their goals are perhaps smaller than you or I because of their condition and of what they actually can achieve. I think your satisfaction levels are lower and the little things will give you satisfaction, you achieved a little bit with them is quite satisfying. Because you acknowledge that they are not going to get cured or better but the quality, ahem, the [concept] that can hopefully be achieved.

PS: Does it happen that you get sort of mixed communications, a separate one from the patient and a separate one from the relatives?

R: Yes, I am visiting a family at the moment where, what, two families actually that the patients telling me one different story if you like or one different set of objectives and the family it's totally opposite and I, it's hard to know how to bring them together. And you're almost talking to them separately and it's very difficult. One family, the patient's in bed, he's got continual oxygen and he's, he said to me: "I am going to explode in here"; he is absolutely fed up and [forehold] being in bed aeh, with the sides up. I realized today he is in bed in his bedroom with the sides of the bed up and I don't know why he's got the sides of the bed up, but he's almost trapped by that, he's in a flat, he's got the oxygen tube on, he's got a syringe drive at there (shows?) and he's absolutely feeling trapped. So we've come to address that, we, we, I've encouraged him to get up into the sitting room although there is not much incentive to get him there and a volunteer is going in to play cards and

hopefully we can get him to day-hospice if he's been sort of upright for a little while. And his family are saying: "Well he is not sleeping, he is vomiting all the time, he is drinking beer too much." I can get to grips with more he's telling me than what they are because I, my cues are from the patient, he's not being sick that often, he is enjoying his beer, ahem, his friends are carrying him down the stairs to the pub every week which he's enjoying, ahem, and, he is saying he is not sleeping the family say he is sleeping, so really I don't know where to go with this at the moment (laughs).

PS: Do they talk to each other?

R: They shout at each other. They sort of, their mode of talking is on the verge of rowing, ahem, and I think that's not new and his wife is divorced, has divorced him and has come back to look after him, so it's a very unusual situation and ahem, I suppose communication with the GP isn't that good on my part because this, this vomiting started a few weeks ago and there was, there was grandchildren there who sometimes live there and sometimes don't and they had a stomach upset with vomiting. His daughter who lives there takes care of him had a stomach upset and was vomiting, so I wasn't surprised when the patient did the same, but the doctor immediately put a syringe driver up and I really couldn't see, because he's keeping everything down, really, tablets, food that he is taking. So, as another doctor has taken over his care and I, I think I've done a better job of communicating to her, ahem, about ways round taking the syringe drive ... monitoring the sickness. So I think perhaps I was a bit flummoxed when I went in by the different stories and things and I actually, I wasn't the first nurse to go in, I was on holiday so one of the other girls went in, but I didn't have a good basis really, I had to sort of pick up in, you know, after after somebody else's visit but I think I am getting on top of communication now and perhaps find a gap from the patient what he really wants and how he is feeling things. But it's ahem, I feel at some point, that they need to be got together but whether that'll, but whether they've ever been together (laughs) and whether that'll be achievable? So, I don't know because it's a complex one, I think it's probably improving hopefully.

PS: And each family, each home you go into is, as you said, a blank page

R: Yes, yes.

PS: There is no way for you to establish any kind of routine, you don't know what you are confronted with?

R: You don't know, no. I mean we do an assessment visit on the very first visit where we try and find out certain things. I mean we have first part of our notes as an assessment part and there is physical thing that you go through and psychological things, finance, we try and cover the whole aspect but I can't go in and start from that page and go through to that page. I know a little bit about the family, the situation before I go in but I think I work to their agenda on the first visit because you can sometimes step over the door and they have something in their mind they want to talk about and we'll talk about it before you've said your name, where, you know, what the hospice is all about, ahem. I suppose on ideal visits you'd like to sit down, introduce yourself, say about the hospice and then get the information from them. But they've got things in their mind that they're worried about, that concern them, so I sort of feel my way really and see what they want to talk about and they get all the other bits in as I go really. And then at least I know where they are, if I listen to them first, and I suppose it gives, does it give them the cue that I'm wanted to listen to them rather than having my own agenda.

PS: What about the content when you talk to patients, to families, as they might have a different agenda? In addition to the illness and the pain relief, what is typical for you to hear?

R: Yes, yes. I suppose if it's a couple worries about each other, ahem, how things are going to progress, aeh, this quite often wanted to be talked about, aehm, what support is available. And perhaps things that haven't been resolved in the past, ahem, if there's been traumatic or non-traumatic deaths in the past they talk, perhaps they want to talk about that, particularly if the person died of a cancer, ahem, they almost relive that and compare what happened then to what's happening to them now, ahem. It is different things to different people, sometimes the burning thing that they're really concerned is finances and I sometimes go to families and feel that I'm getting no further than finances and that's all they particularly want from me but I feel I'm hanging in there in case anything else crops up, so it's sometimes a means to an end as if you, they want to know more about finance and benefits, we go in for that and sort of bring in whatever else we can offer and make them know that that's available for support. Ahem, the worries change as well, different things

PS: I have often heard that unfinished business is a theme that somehow to get that resolved before dying.

R: Yes

PS: What was interesting to me now to hear was that an impending death reactivates memories of a previous death and if it also was cancer, it sort of intensifies the

R: Yes, yes. There was, there was a family I've been visiting not that often, not that long, ahem, and he died this morning, and his wife, her brother died twelve years ago, her younger brother and she was really upset about that. This was in front of the patient, the patient wasn't that forthcoming, ahem, has never been, ahem, and she did a lot of the talking and she was really upset about this brother, whether she'd not resolved or gone through grief at the time but aeh, because it was a younger brother she was very fond of (tape ends here)

Side B of tape

R: her husband was now dying of cancer and it was all as though she was reliving the whole thing really and the patient's sister was also poorly with cancer in Lincoln so he hadn't had contact with her for a few weeks, she'd gone into hospital, which meant it was all a bit more intense for them really and I visited him, not yesterday the day before, and having said he didn't really want to talk to me on the first visit although the wife did, he was although feeling physically quite poorly ahem, I think was glad of the contact although it wasn't verbal. He knew I was around, he knew the district nurse was around and we were supporting each other to support his wife and his, ahem, so he was more amenable I suppose if you like on the second visit. Sometimes initially people have I suppose a wrong idea about hospices, they have a set idea in their mind that doom and gloom and death and that's all we're going to talk about and if we you know say about respite care somewhere that they never ever going to be seeing again. They have, you know, sort of vivid impression of hospice in that they had no contact with us before and I think the first visit is almost to get over that with a lot of people before they feel comfortable that you're just an ordinary person that they can talk with.

PS: Do they ask a lot of questions about the hospice?

R: About the hospice, ahem, funnily enough no. I tell them about what, how we made a ... team and how we work with

the primary health care team, ahem. They may, some people are maybe a bit apprehensive if I suggest day hospice that they feel that there is more than day hospice here, that there are beds and they're going to be here for more than a day, but I think once they get to know you and perhaps on the second visit or third visit, it's not, it's not

PS: You are sort of establishing a relationship isn't it?

R: Yes, that's right. That's right, yes. And then I think it's, perhaps I feel more confident, more confident in myself these days that I can bring things up that that visits, that perhaps, perhaps more quickly than I used to which got over that fear on their part of the hospice. And you got sort of to know one another, you can bring things up, why I can bring things up more easily with them, to see, you know, if there's fears or anxieties about but. I think and I tell students this, that you've if you're going to bring something up that perhaps the patient [has...s] openly that you've got to be feeling strong enough in yourself to cope with whatever is going to come at you as a reply really. And sometimes when people are talking, I I do miss things, but I feel I just couldn't take them up then, whether it is the right time for the patient or the right time for me, I couldn't, I sort of note them to bring up another time.

PS: Do you feel that a lot of the communication that is going on is on a non-verbal level?

R: Yes. Doing that if I didn't entirely agree with that, I mean ahem, sort of body language and touch I would go along with and say, yes, there is a lot of that, particularly for me there is a lot of sort of hands on if there is not words that could possibly be said to either situation and the silence, ahem. But I think sometimes you need to say and open the door for further talk if there is something really hurting someone or concerning someone. But I think it goes alongside, really, rather than instead of.

PS: Yes, I imagine that it happens simultaneously

R: Hmmh, hmmh, yes I think there is that, yeah, a lot of non-verbal communication, perhaps we're more aware of that and perhaps it's part of me that's why I don't, you know, ahem, [goes] along with it

PS: Can one consider it difficult, communication in a situation when someone dies, compared to how we

communicate otherwise in the world, yours is more difficult and different?

R: Yeah, yeah. I suppose it's more sensitive. I think perhaps we're aware of the time factor as well that that some people, and I think all of the people we visit generally haven't got as much time for small talk if you like, you have to fairly quickly get to the nitty gritty if you like, otherwise time is lost. But having said that you've got to go with the patients and the families.

PS: And perhaps another thing is the uncertainty of how long?

R: That's right and that is a question that probably we're always asked, you know, how long and we can't, obviously can't say that and it's hard to explain that you can't say and it's very difficult if a consultant on the way has said three months and some people work out exactly to the day when three months is and then on that day I mean, you've almost got to pick the pieces up really because they don't know what it's ... glad it's different (laughs) it's difficult. It's, I mean sometimes you have patients that have been diagnosed and then the diagnosis sort of restored and looked at and they've been told that perhaps the diagnosis was wrong. I mean this is on a, not on a regular basis, but I found that [old] people have been told that their x-rays are clear and now they're relatively ok, as ok as you can be but ahem they find that as difficult to grasp, as being told the diagnosis, to be told you, you know, it's ok. I have a patient come in here and we're almost, he'd been coming here and then he was told that everything was ok, his chest x-rays were clear and he was absolutely over the moon about this, but then once it did soak in, he he couldn't get to grips with it, he was very restless and he couldn't come to terms, he was so devastated by the diagnosis, he'd gone through trauma with the chemotherapy and now it's ok, what was he going to do now? It sort of set his mind on the road that he was going to be pooling and die, ahem, we've got him back to day hospice again, just to, to come to terms with the good news really.

PS: Good news are almost as hard as bad news?

R: Yes, because I think people are meant to change gears and it's hard to switch to another gear again, another way of thinking. There was another patient that came to day hospice for a long time and her, up to, you know, years they said, perhaps there wasn't cancer there in the first place.

And her family wanted to have a party and she said: "I can't do this because I can't think that I'm going to be well and I'm going to sort of live maybe for a bit longer than I anticipated". And she had great difficulty. She's now discharged and I think still going strong but whether it's, whether they're getting to a role where they are thinking and their whole life changes and one expecting them suddenly to change again. I think it's ahem being very sensitive and aware of what's going on all the time with, with patients with the interaction between patient and family, with your interaction with them, it's ahem, it's re-assessing all the time.

PS: It is hard work, I would say.

R: It is.

PS: As you have to keep a level of awareness and a level of presence which is quite demanding I think.

R: Yes.

PS: And from my own work, I know that if I take on too many clients per day I am exhausted and I imagine it might be similar with your work?

R: Yes. If it's a few visits per day you can, I feel that I can give the time and a good amount of time and therefore you feel at the end of the day exhausted. If you've got, because of the demand of work, a lot of visits, you still trying to give that time and take on board what they're saying but you feel, well I feel very unsatisfied at the end of the day on top of being exhausted because you, it's, it's just too many really and you can't perhaps give what you'd like to which is a frustration I suppose.

PS: So is there a limit to about how many visits and what length of visit you can work through and come home and say, well I am exhausted but I am ok?

R: Yes, yes. Yeah, it's been a good day, yeah, as opposed to trying to get a lot of visits in and and not perhaps giving the right type of time and feeling frustrated at the end of the day. I mean the time, I think, average visits per day in about four, I mean taking the follow-up work you have to do with liaising and ahem and in-patients we try to allow two hours and it's amazing that, that gets taken up some time on one visit. There was a lady recently I visited on a first visit it took more than two hours, but that, that was her agenda, she had to talk about certain things, and at the second visit

there was a lot more she needed to talk about, the background she hadn't mentioned on the first visit, about prior; we were talking earlier about things that happened in the past that makes now more intense, and it was about prior traumas, of death, of divorce and how she reacted but she needed to talk about, and made a lot of things clearer to me once I got the background information. But I felt that was good time and I feel I'm making progress or she is making progress. With some people you can see the work being done but in a, in a visit you can perhaps spark things off with somebody and the work is being done between that visit and the next and other people, especially when there is conflict within the family, you feel you're bashing your head against a brick wall, really. But sometimes a little bit that come out of that ...

PS: I imagine it's very hard for you to be in the middle of, to being talked to from two sides, supposed to be a mediator, but I imagine it's very difficult

R: It is, the way I managed that before is to get both of the points of view and then put it to both of them separately that there is a need to come together because of stresses and maybe lack of time, these things need to be ironed out and then perhaps like you say being mediator to when the both parties come together. And that has worked in the past. This particular family I was talking about, the patient's in bed and the family are giving me different stories, I find that scenario is going difficult to happen because I think their previous communication pattern had been difficult, ahem, and I think it's long-standing.

PS: But you can't know or do you instinctively know is it a problem of this trauma or is it a longer standing communication?

R: Yes, you don't know but sometimes, sometimes you're able to ask, you know, "Has it always been like this" or, you know, "Has his character been always like that or is this, that just something new?" I think it's, you know, you can ask about those things and some families have long-standing problems, I don't think anybody get to do anything about such a short time really.

PS: What about spiritual issues, do they crop up in your conversations with patients and families?

R: Yes, I tend to get asked a question to know about spiritual matters in on how us people how they're feeling

and sound and I feel that for me gives an opening for them to talk about spiritual matters as opposed to religious matters, yes, ahem. And I feel that some people can honestly get in touch with their spiritual side by answering that question and sometimes very profound answers really, ahem. But I tend to ask it more of the patient not the family, I don't know why that is. A patient I think perhaps is slightly more vulnerable that, it's their impending death and I think maybe they're a bit more in touch with their spiritual side. Yes, although although having said that because of a family, the husband is the the patient, he would almost stop communicating and between, the pattern of their previous relation- of their relationship was previously not to communicate, they felt they'd been married such a long time that they knew what each other was thinking, so they'd almost lapsed in their communication verbally (laughs), they didn't need it. But the husband was finding it very difficult now when he knew time to short and he would like to communicate and saying things, but she wasn't having any of it (laughs). Ahem, and he he was very drained spiritually, because he was looking after his wife at home and it wasn't something he thought at the outset he was going to manage but would have a bash at and did very well with a lot of support. He had let go what we renewed him spiritually, like playing music, listening to music, going for walks, ahem, and we put volunteers with her to sit with her while did this and it renewed him, it renewed him an awful lot. So he was, he was in touch with his spiritual side and knew what would refresh him, so yes, I think it comes up all the time and I don't feel a problem with, with asking that, or for patients to answer if I put it in a certain way.

PS: Do questions like "What does it all mean?" "What's the meaning of all this?" "What's the meaning of my illness?" come up?

R: Yes. Or I think a more typical one is: "I never thought I'd end up like this." Yes, they do question but I don't know there's an answer to this. Some people don't know what they'd done to deserve that or the family would say that, you know. "He was very kind always, help people, I don't know what he's done to deserve this?" A lot of people see it as a punishment I suppose, ahem. Something I talk round that because I feel that perhaps there isn't an answer but it needs a dressing a looking at and seeing what's behind it for them.

PS: The idea of illness as a punishment, especially cancer

R: Yes, I think that still comes out. (interview finishes here)

Interview Transcript W 7

R: Participant W 7

PS: Interviewer

R: Aehm, what I've done is to look just two people, like you asked about in the letter that you sent out, ahem and tried to pick out two people that did actually ... ahem, so if I tell you a bit about them, if you want to ask

PS: Yes, that's fine.

R: OK, well the first one was a, is a girl who is forty-two years old she's, about my age ahem, though she is probably still out in my mind a bit for that reason. She's also got cancer of the kidneys, is her primary and my father-in-law has got cancer of the kidney at the moment so I think that's another reason why she stands out in my mind, ahem, she's got quite a lot of disease, she's got spread in her lungs and her stomach, ahem, which makes it sound as though she is extremely ill and she is now, but I think up to about two, three weeks ago, she was working nearly all the time. Ahem, she's got a young teenage family, she's got a son who is nineteen and a daughter who is sixteen and she was seeing me during the time that she was working and she hadn't told them about what was the matter with her at all, although they did know that she'd had the cancer of the kidney in the past and had surgery and been off ... and as far as they were aware she was all right from that. So, the first time that I've seen her, she hadn't told the the children, ahem, her husband did know what was the matter with her and he is ... spread of the disease too and he didn't want the children telling and I think a lot about with, with who, who's patient, seen her own mum die when she was a teenager and she wanted to protect her children as much as she could from the distress of that, ahem, her husband, he's called ..., felt the same. He was quite angry as well, angry with [seeing the bill/her ill], and she's always been the one, although she was quite an anxious baby, she was not that you would (laughs). She was the one that's always made the decisions within the family and he wanted to back her up the her decision not to tell the children, but he was also quite angry and he wasn't very able to talk when I first met him. He was a professional man and he's got quite a high-powered job, ahem, and I'd heard from the district nurse before I went that he was quite a difficult man in that the atmosphere when you went round them was very tense. Ahem, and he's also [travelled or so], not wanting to ...light this, to go in, because I think they tried to sort, to see about telling the children. And he also got quite

angry with the GP on one occasion and almost, almost thrown him out of the house. So, things were a bit tense before I went to their home. And ... seeing her in my office though I've never actually been to the home until she got ill. Ahem, there was also the dad who was around he, he's in his seventies and he's been very distressed about ... being ill and he said things like: "It ought to be me, I ought to be the one that died, I'm old now and it doesn't matter." And I suppose it's ... that most people die old and many people don't die young and they're quite different in what they experience. Ahem, and he kept talking about things that she won't be able to do, like she won't see the children get married and she' won't see them grow up, so he he's struggling as well in the background really. Then (name) suddenly got very ill and it was really with her lung disease, spread the disease to her lung and that was when I started to visit her at home and I was quite anxious before I went in, because of, of know the situation and knowing that she hadn't told the children and knowing that (name) wasn't an easy person and I did find him quite hard to relate to. Mainly because he didn't really talk, I must say he was very bright and I think perhaps [I was feeling (laughs)] a bit inferior, ahem, he was a college lecturer and I just thought that I wasn't going to be able to match up to the ... he's got. And I think I'd, I probably [we/re-]start on supporting human, we only say to because I'm a senior [as] a high-powered professional who aren't afraid of him, I wasn't seeing him as a person who was very distressed, he loved his wife an awful lot and his children an awful lot and wanted to protect them. He kept quiet nearly [quite near me] all the time and he does ... everything, in an awful lot of [detail], he got friends in the college that ahem, was biochemists so he had access to a lot of information, he quizzed me on all kinds of ... about the ... But I didn't really get the feeling that he wanted to know. I just got the feeling that he was testing me out and that made me feel even more uncomfortable. Ahem, I think as well it was partly to do, I think, and I don't know whether this was him or me but I think that sometimes he ... that nurses are stupid (laughs) and so ... and if you are in there you are very angelic, you are very sweet but you are a bit dumb. And that, I got the feeling that that's what he felt, but that might have been because I wasn't feeling that comfortable with him anyway. So I felt like I had to keep trying to prove myself all the time and in the end I, I coped with all that by trying to see him as a person and trying to realize that he did have his own anxieties and the he did really care about the -. Ahem, the other thing that really helped was seeing [name] getting panic attacks at home and ahem she, she'd also had a deep

vein thrombosis and she was with me to hospital and her breathlessness wasn't really addressed properly although she did improve some. But when she came out again between us we did manage to get her symptom control really quite good and you get her manage with panic attacks. So, I felt then that I proved myself to (name) only because [name] was all right and he relaxed and I relaxed and I just felt that he just ... me more and the atmosphere was better between the whole team I think as a result of that. It was still and it's a I mean a situation to go into because he is the, she's got the young family and to some extent you can't help but identify; there's been some work done on nursing and the delicate balance of relationship between involvement and non-involvement but aeh yeah, the professional side of the role. And aehm, it's just quite difficult sometimes to keep to the boundaries where you can make and I find it quite difficult now still, to keep being aware of the fact that this isn't me and it's not what I'm going through and it's not what my father-in-law is going through and it, my situation is different. Ahem, and just trying to be aware of your own needs to support really because some people do affect you more than others and that's probably not how it should be and then I feel [well/worse] but there just are some people that you identify with more.

All the way along (name's) been frightened about dying and well, not so much frightened really but she just doesn't want to die, ahem, she wants to see the children grow up, she wanted to see (name) get [hurt] about this all, she wanted to see (name) married, you know, all those kinds of things and that can be quite sad and you can feel quite helpless because really when she says: "I don't want to die" what can you say? So to some extent that helped me to understand what (name) was going through too, because if I'm feeling helpless than if the district nurses has feeling helpless and the GP is feeling helpless and we've actually got some still, some knowledge that has a bearing on the situation, can you imagine what he must feel like really. Ahem, and we sort of, at this stage hadn't really managed to get (name) talking much about dying except to say that she didn't want to die. And the way that carried with it was really by talking about practical things and we focused on things like how she could cope with panic attacks. Ahem, there is some really good stuff that's come out of the (hospital) just this year that everything is being [breast] at this minute, it's being a very sort of medical model, there's been, you give vials of ... for a panic attack, you give ... [if breathing] is weasy, but very much to do with medical, but (hospital) says it looks at people as a whole person, and so we spent a lot of time

talking about what this breathlessness meant for her. She did think every time she couldn't breathe and had a panic attack she was going to die probably because her diagnosis of cancer and breathlessness had come quite closely together, so the association with that. Ahem, so we went through some of that, ahem, and she got on much better and I think she got a bit of control back, but she never really liked taking tablets, and even not to explain me about them. She's just doesn't really like ..., she's much keener on things like, she likes equipment and I think again that's 'cause she's quite young. A lot of people can't cope with drawing a ... and ... an enabulizer but (name) really liked all that and it helped with her things with certain, trying a way of different things with different people. I don't know about the tablets, ahem, sometimes I get the feeling that she feels guilty for having cancer and I think that's partly about the suffering that she is causing her family. And sometimes I think it's about, she says things like she's overweight and with that has caused her to have cancer and I think she feels guilty about that, although we said it's not related, but she still feels guilty about it. And I don't know whether she thinks that she ought to suffer in some way because it is in fact it's all way through it that she wants to keep some kind of control, so, she doesn't take the tablets because that's some way that she can have control, I don't know. You can speculate about all kinds ... And again, it can be quite hard if you know that something is going to help because sometimes she phones up and says: "I am really short of breath, I am feeling very panicky" and I say: "Well have you done so far, (name)?" And she'll say: "Well, haven't think of anything." And you think 'Why?', you know, 'Why haven't you?'. But I think sometimes she, she just wants somebody there with her, she doesn't want to take the tablets she just wants somebody there and as to things like nursing that it [seems] is very practical even though our role as specialist nurses isn't doing a lot of hands-on care ahem; we still have this tendency to if somebody says: "I've got a symptom" that you want to do something about it. But sometimes it's perhaps more important to be with somebody than to do something to them, I don't know.

There's also been like, the parallels with things that're happening in your own mind that at the moment and [things], they've been like, 'I just want to be able to go shopping, I just want to be able to walk to the car'. And you think 'Well it's not much' to ask and you almost feel guilty that you can do those things and she can't. Ahem, and it's trying to find a way to make her feel better but some of the distress you can't take away. Her symptoms have improved

quite a lot with the different things that we've been doing, also as how (name) has got to know, but we still have the issue about the children. And (name) is, this is sort of going back about three weeks is a lot more relaxed with her and ahem, the other person that (name) gets on really well is her sister-in-law, who is (name's) sister. And we did manage to get them to talk and they managed to talk to (name) and again, and I found it quite hard to draw the boundaries of how far you should go in trying to get a person to do something to to talk about issues. And you know that you should be impartial but it's quite difficult when you know that the children are likely to have a need to know and that they're likely to find perhaps some guilt, quite hard, I find it quite hard not to impose my own agenda. Between me and (name and name) we did decide that they, they would tell them, which I think was quite a hard decision for them, really and it was something that so I felt very relieved when they made such decision, but also a bit anxious 'cause they wanted me there when they did it and I knew that (name) was still quite angry and wondering how he would react. But in fact, they managed it really well, credit to them. Sometimes, and I think that's what happened, sometimes you can change things in palliative care and I think (name's) changed an awful lot. Ahem, so he's gone through not being able to talk about anything, just being quite angry to using this chance to ... to be closer and also it took for him and (name) be closer, so really he's just done wonders. And I think we all helped in that and that was quite nice really, I feel satisfied about that part of the job because he, he went from going out of the room every time that (name) got distressed and then as a professional you feel a bit torn because you're not sure there is only one of you, you are not sure whether to stay in the room with (name) or to go out after (name). But he then went to a stage where he could stay in the room and (name) would be crying and he would say, he would stay in the room but he would be saying things like: "Well, look who's out of the window" (laughs), but he'd be trying to change the subject. Ahem, and I think we also spent some to, to trying to role model how you can be with somebody when you're very upset. And it again that's hard enough sometimes for us, the to see through it, their whys. And about a week ago, I think it's been building up for some time because he's bright and she knows really that she is not getting any better and her condition is deteriorating. And we could see that she's been upset but she hasn't really been able to talk about it or we haven't been able to help her really with that, but we did manage to get to a time where she was able to talk very openly to (name) and crying very openly with him and he

just sat there and held her in his arms and held her hand and that was very good to see although it was very sad, it was good to see that they'd managed to do that. And a bit of me thought of wishes because they then talked to the children about when (name) was going to die, how it was likely to be, where she wanted to be and what the children wanted in that, ahem, and there's a bit of me that wishes that she could die shortly after that because that would be the perfect ending. Ahem, but she hasn't and she, she still doesn't want to die, she still wants to have some good treatment that there is and I think we have to respect that really, so we are doing things that perhaps we would do to somebody else because (name) is an individual and needs that time but things like I'm thinking about very high-dose therapy which has its own risks and of course, we, you know what there ... [side effects] ... You know you're subjecting somebody to possibly bleeding, to possibly character change a lot of other things, but we know, she just does want to live on really as long as she can. I, I don't think because it's quite difficult now, a lot of the times when we go round she is in tears, and I don't think that she'll ever accept the fact that she's dying and I don't particularly like the word acceptance because I don't think that a lot of people accept that they're dying. But she had come a long way and she is, she is doing things to prepare for her own death now, she's talked about where she wants to be, she knows what it's likely to be like, she knows the people that are going to be caring for her, she is thinking about things that she can do for the children and she really wanted to do things like like writing letters but she can't do that, it's I think it's too distressing for her. And sometimes I think we are ... people, you know, we talked about what she might want to do and it seemed like a good idea at the time but I think these things are so hard for people to do in practice, 'cause what do you write really? Ahem, but she is dealing with some other things, she's doing some she's meeting some ... so there is somebody to ... by her that they'll know she's had cancer, she's come a long way really. And that's all in our little unit.

PS: How long have you been seeing her?

R: About three months in all, yeah.

PS: It seems quite a bit of time

R: It is, yeah. They've just done some work with a team in London that says you'll probably get involved with people about two to six months before they die and we're going to make a difference because it does a certain amount that you

have to get through before people trust you. And I felt that with (name) in particular that he didn't trust us until we'd proved that we could actually make (name) feel better even if we couldn't make her better. But it's quite [vile/wild]

PS: Yes, and I can imagine the shock that if you had somebody that died after two visits, that there isn't this time to get acquainted and build a relationship.

R: That's, that's right, yeah. You get a lot more out of it I think is. I mean, it's, it is, I mean it all sounds a cliché when you talk about it but it is a precious time, but that's American, but it is, because he has access to a relationship that you wouldn't normally. All the experiences if somebody is dying often means that what they do with the rest of their lives is that much more intense and that much more important and that's the time that we are usually involved.

PS: You are involved at a very particular, a very special time for an individual and the family.

R: Yeah

PS: I imagine that is also the feeling of being privileged to be part of this, of what is going on?

R: Yeah, yeah. And sometimes you can make things better though with (name) and (name) I went from a feeling that we weren't going to get things right ahem and particularly when she was very breathless because it took a while for her to get breath and sort it out because, sometimes you're lucky and you get things right first time, but other times it takes a bit longer. And ahem we did end up at one stage when she was very panicky, just having to sedate her and I really thought 'Well, this is probably what we'll have to do at the end when she dies'. But now I don't think that. I think we moved on a lot and it's good that we've had the time to do that and be part of it.

PS: Yes, I can understand that - and people do change, change considerably

R: Yes, yes. Although I think if we'd looked, if I hadn't I think if I'd looked beneath that in the first place, perhaps think would've changed more quickly, I don't know.

PS: Well, that's always the question as communication is a two-way thing and one really never knows what factor was more powerful ...

R: Hmmh, yeah. And I think (name) helped him a great deal to, I think she influenced him in all of that because she is the one who makes the decisions in the family. I think it took her a while to [uncover] what she wanted to do because she was ready to tell the children a long time before he was. Ahem, although it took a long while I think she is probably a major ... could he [just let go of her]. And then of course you're thinking 'Well, how is it going to be given that she is so central in that family, how is it going to be when she is not there any more.

PS: But now, when you are looking towards the future, does it concern you in any way when the death will come? In other words, do you think 'it's got to end at some point'?

R: Oh yes.

PS: 'she will die and it will be a loss for me because I have been so involved with her and her family ...?

R: Hmmh, oh yes. That will be because I, I think you never really get used to people dying and [summing] up what you do because you know exactly what to expect, well, most of the time you know what to expect the physical symptoms aren't so frightening. Ahem, also it's it's not somebody who is family but you do come in at a very intense time in the relationship. But also, it can be ... quite a lot recent than that, ahem, the effects on staff and multiple loss which is really what palliative care really is, although you do see people that will get better but there has been quite about that and I've had a couple of friends that had to stop work and had had problems because of it. But we get quite a lot barrack, ahem, in terms of support for ourselves. I mean most of my support comes from, I work half-time here and half-time in (name), I've got a joint post, and I get a lot of support from (name); particularly here the time is very precious and the will is there but we don't see each other that often because it's such a big area to cover. But I think you do have to be aware of the effects on, you know, on [you], particularly if there are parallels.

PS: Yes, especially if you identify to some extent with a patient?

R: Hmmh, I think so. And I think as well

PS: It's like losing a friend?

R: It's certainly like losing somebody that you know very well and I think as well that, you know, as specialist nurses we go in and introduce ourselves to the patients and we say: "I'll be there when you have a problem, I [will] be there to see you, I'll help you" and that's quite a lot to offer, really. Ahem, but you can't go all the way with them and I think that's what you have to hang on to. I mean I don't particularly have any religious beliefs, I don't have anything; there is some evidence that if you have a religion that people burn out less, I don't but I do have this feeling that ... that you can go with ..., you can't go ..., you can't go all the way.

PS: Each one has to die on their own.

R: Yeah.

PS: But obviously, there is this anticipation of loss but at the same time, these relationships are rewarding?

R: Very, very, yeah. And when you get to ... you'd

PS: You got a feeling

R: it's very satisfied, yeah.

PS: What is the rewarding element in these relationships?

R: I think maybe, I don't know. Maybe it's quite a mercy thing as well that you do most of the time manage to make things better though, and sometimes that is physical, and sometimes it's psychological and sometimes its [facial] and sometimes it's everything. So, although there is a bit of the they done, most of the time you're helping, you're actually making them to feel better and mostly I think nurses need to do that and simply aware of that, you know, "Oh, [bring] us the tablets", my immediate thought is say: "[No...] take the Valium, take this, take that" but in fact I think she just wants the contact, and has come to realize that now, that just by being there you are doing more than giving someone a tablet.

PS: That's an amazing thing that just being there has some kind of 'healing effect' or 'smoothing effect'

R: Yeah

PS: but something does happen by the presence of another person in a situation like that?

R: Yeah. I think so. And an even nicer thing it's that you can pass some of that on because of no, I think it's to, to, a nurse able to do that whether it's me or whether it's the district nurse, but that you can help some... with the same kind of things. It's often they say, you know, "I don't know what to do, I don't know what to say", and it's almost as if there is something, there is a right set of words and often there isn't, you know. (side A of tape ends here)

Side B

R: We have a couple, actually, he is also he was also here, and this is going back quite a long time for me now and I, he's somebody that stayed with me for quite a long time, what it was like, ahem, and I probably couldn't have talked about him until about about a year or two ago. He, and again that's probably why it's stayed with me for so long, he was a chap who was only thirty-two and he'd got Aids and he he'd had a temporary [colostomy] done because he'd also got a lot of ulceration in his colon and he'd had that for about two months before he was referred to me, really as a last ditch in terms of pain control because he'd been getting a lot of abdominal pain. Ahem, and unfortunately [it] made no difference to the pain control but because he was quite unwell and he had, his his general condition had deteriorated because of having the ulceration, ahem. I met him when he was just about to go home because he hadn't [booked with us for] after the operation and he was pain-controlled when he went home but he found the colostomy really hard to manage, he found it hard physically because he'd got [medical terms] so that he couldn't feel what he was doing very easily. And also from the point of view of out-of-body image ahem, and he'd lost a lot of weight which again didn't help with the out-of-body image-thing. It was particularly important for him how he looked because he'd been a a model, I mean, he was an absolutely beautiful man and he'd he'd been a model for John-Paul Gaultier and he'd modelled for Jaeger and he was very, most of the time that's how he, how he looked really and, of course, having a colostomy, having lost so much weight and the change in his appearance he couldn't work and his work, I think sometimes there is a lot of ... gay men ahem, I mean not with everybody but with quite a few of them because they don't have children and often they don't have traditional families, ahem, they do focus a lot on on work and so once he couldn't work he also lost a lot of motivation and got very lonely, in fact he didn't want to live. But on the other hand he was very afraid of dying. Because, I think, not wanting to live then wanting to die it's too ... So ahem, he's, he'd sort of, he'd got some family, he'd got a sister who died

ten years before him, she'd had a heart operation which hadn't really worked, she'd had a transplant and she just never really got better from that and died and that was very distressing for him and the family, the way that she died because, they felt that she'd died gasping for breath, ahem, which made, that might have been [transposed] breathing which happens, it does at the end of life, they really found that hard. But he'd also got parents, both parents alive who, they were quite elder, well, quite elderly. They are in their [fifties], compared to him, yeah. Ahem, and he felt very guilty and he only told them that he was gay and that he got Aids just before he went into the operation so they'd all that to take on board and he felt guilty that he was dying and that, then they'd have no children at all because there weren't any more children. And he also felt that it was his fault that he'd got HIV disease and that they suffer as a consequence. They on himself and they were the ones who would have to suffer. There were also, as a as a [wishy-wash] thing to deal with his parent but I don't really know what they were. He'd, I say that because he'd seen those psychologists on the team that I worked on them and he had seen the psychologists and I mean that he'd talked to her about about his parents and issues with them, but I don't know what was said. Ahem, he'd also got a partner who lived with, who was a Brazilian chap called (name) ahem and he was a student and he was working in the ... , so he was very, undecided really. Ahem, and he was planning to get married, to get to ... church and to thank God his future, it was just a financial agreement with somebody. And he hadn't been HIV tested so there is a lot of uncertainty with that as well. And we knew there would going to be a lot of issues when he went home because he couldn't manage the colostomy because of the distress and also we set up a package of care with the GP, the social worker, me, a home care team, and he wanted to die at home and we knew that. Ahem, after he'd been home for a couple of weeks, his condition really deteriorated a lot and when up to me, the GP rang up and said, could I go and start a syringe-drive [from/for] him which is what we do when people are dying, usually when they can't take tablets by mouth. So I went out and did that and we put some some Dymorphine and some [name] in, ahem, ... it has just been worked out from what he was having by mouth, so that was, that was all OK. And we let the twilight nurses know so there were people around. But I was quite tired because I'd been on call the night before and I didn't notice that, that there wasn't any prescription to increase the syringe drive during the night. Ahem, at, we then handed over to, we have an on-call service, a twenty-four-hour on-

call service, we handed over to them, but at that point I hadn't realized that I hadn't, hadn't ... or anything been prescribed. And what happened was that at about eleven o'clock, (name) phoned up the on-call service and suggested that, well, that (name) was in pain and he was really [uncomfortable] and could we come and do something. So my friend (name) who was on call, [said/that], because there wasn't anything that they could give in the house could he booth the pump which isn't very effective really because you don't give enough of the medication to help, but because she felt ... to do something she suggested that and told him to contact the GP and she said 'Get back in touch us' and ... And she didn't hear anything, so she assumed that everything was all right and went to bed. And at about four o'clock they paged her again and she could hear (name) scream with pain in the background which is quite hard to think on the end of the phone. And (name) was crying, and he said, that a locum doctor had come out and this is quite early on, about 1987, so a lot of people even in London didn't have much experience with HIV disease. And the locum had been, he had actually got a really nice GP this chap but the locum had come out and been really horrible and made it quite clear that he didn't want to touch (name) because he'd got AIDS and had had just given him, well, (name) went out at that point and and he hadn't even, he hadn't examined (name) or tried to find out what the cause of the pain was. And he hadn't ahem given him anything for pain control, he'd just given him some more of his sedation which probably wasn't very appropriate. Ahem, and then (name) had called the GP out and he prescribed some Valium so it wasn't a locum that time, it was actually the GP, ahem, at least one of that practice and (name) did settle then. And that took them through till the morning by the time they got the prescription and things and then I went out and I wasn't really going to go out at all because I was feeling very guilty because I hadn't covered that time. And I was feeling guilty about (name) having to go out because my own side really, and also, I thought they were going to be angry because, you know, it's not ideal, I mean as a special nurse I ought to have anticipated that. Ahem, and the GP was actually, had actually gone out, so I met the GP out there and we got him sorted out and went and had ... a few days ... sorted out, all the pain ... pain again, and the GP gave, me and (name) that he was still there a lift back to the station and she was very ..., very sort of ... the worse for wear and aeh, that, she was very great-, she was quite new to ... and she was very grateful that we'd been there and she'd never come across such a difficult situation and she really valued everything that we'd done. Ahem, and that

made me feel better because, because I thought, at least she appreciated it, I felt better ... and also it was quite nice to meet a GP who is [human] and very approachable, so that that was quite nice and I felt that the basis for a working relationship was there, despite the fact that I'd, I'd really made a mistake I suppose. And that night I was on call and so was the same GP and I went out to see (name) at about 8.00, just to make sure that he was all right and when I got there I [I'd be] horrified because the syringe ... which was expected to go on 24 hours shouldn't have run out so about 9.00 o'clock the next morning was almost empty because (name) had seen that (name) was distressed and he, he'd known about this ... because we told him and he [assumed] that maybe all the prescription of the drug was there. So, and it's quite difficult getting drugs outside hours and that is the issue in home care and that makes the situation more tense for everybody, [all] the situation is quite tense anyway because (name) has had difficult pain control, partly because of us and partly because he had anyway, so he'd, you know, he'd got bad memories of pain and I'm sure that has done its part. Ahem, so I had to ring the GP to come out again and we gave him some more Diamorphine, ahem, and we gave him, we had to give him about ... doses, so four lots of injections to get him comfortable and, and that was just very tense and very worrying, again [you] felt quite helpless because is he going to die with uncontrolled pain? And if you are a specialist nurse, their expectations of you both from yourself and from professionals and from the patients and families, but we did get him, well pain-controlled and and peaceful. And about [two hours ...] (name) paged me and said that he, (name) has died and that he'd been, he did die peacefully. And at first I was very glad that he'd died peacefully after all the sad and that he'd not been in any pain but on the other hand I sort of got mixing, I was glad it was over but with the other thing I remember feeling I was just so relieved that the whole thing was over and that it had ended up all right. But I also felt a bit guilty because I felt that we'd killed him by giving him so much Diamorphine and I talked to the GP, who, who, she was with ... she was very [bereaved] ... to talk to, and she also felt that but we sort of, again, you know, you just all get the things perhaps when you think about it, we talked about the ethics of it and how, what we'd been ..., how we'd been able to control his pain and not to killing him, but it may have contributed. Now, looking back, I don't think it did contribute because usually people going to, going to die their own death it's [nearly] half an hour of the injection so I don't think he did that, but that's what I thought at the time. And the GP just said that she was and said again that she valued our

help and so, again, I felt a lot better, but it was only temporary. And the next week all I could think about what ... think about (name) because we do some bereavement follow-up, when I talked to (name) I just kept thinking about (name) and hearing him screaming in pain and I just thought he had a dreadful death, for which I, I felt partly responsible too. And I, again I'm not sure that I think that any more. I think, I think I was quite new to palliative care at that stage and I think that I wasn't very good at planning things in advance, not as, not as good as I am now and so I think (name) lost out because of that. I think he missed that because none of us, neither me, 'cause (name) me too, it was a need even that was set up, and none of us really had the experience of pain control to think, well, if the Diamorphine isn't working, why isn't it working? And, and now I wouldn't, I would look through the codes of ... before I increase the dosage of that, although we were increasing it in an appropriate way I would've tried other things. I think because he was so vocal, because, you know, he, he cried and screamed in pain, I think that made us all panic because we, we didn't have the experience and I think, I think we all were ... out of control and distressed and I think the others did too and I think they [maybe] picked up on that and I think we have a vicious circle where he was distressed and that distressed us and that distressed him more. So, I think that might have been happening. Ahem, I think as well because he was screaming and he he couldn't talk to us we couldn't really assess him properly so we couldn't do much to help and, and the other big issue that I think now is that because he expressed his pain physically ... that we all felt the need to do something, you know, and I can't say about (name), but I think you just think you need to do something, ahem, and I think the Diamorphine probably didn't help because first of all, it might not have been the right drug, secondly (name) expected a certain amount of pain, whether that was because he felt ... or because he had pain before that hadn't really been controlled, ahem, but I think we missed the bigger picture as well with him. I think we missed that that he had his sister's death, that he was very much afraid of dying, that he was concerned about his parents, but he was concerned about (name) and what was going to happen to him and he had this experience with this locum who really had been fairly unpleasant, ahem, and I think we missed all of that. And I think, I think that can be quite hard to take ... out, I think all all that's too late for (name) now, but you, you can't, you have to know a certain amount before you even [note] to us for help and I think at the time, apart from the set-up for the drugs where I hadn't prescribed anything extra, that ... was OK. So, I think now I

do things very differently, although it didn't, it doesn't help him, it helped me and change what I do. So, if a bit of positive to come out it is that.

PS: How long were you with (name)?

R: Not that long. Only about three weeks, 'cause he died quite quickly. So, again maybe that's partly why, why I missed things because I hadn't really got to know the family at the ..., I do if I get to know them a bit longer. And time is an intensive experience, because if I, I think now if I'd met (name) I would have done things very differently, and I just wasn't aware of the fact that we didn't, we didn't see the need of being with him, we did all the, the doing to him but we didn't do the being with him.

PS: So it's a learning that you have done in that respect, a learning of how to be with and how to respond to and how to get in touch or connect with?

R: I think so, I think so, although I think as well, physically I ought to have done things different, I should have used different drugs. But yes, some of that.

PS: As a hypothesis now, when you reflect back, would you also be more aware of other things that might influence a particular situation?

R: I think so, and I think also it was the fact that he was screaming and, you know, that was awful. And the only thing that we could think of was to, to stop that really, to do something to make it better. Ahem, but I think now I've got more experience and I would, I would be a lot more [sure] of what I do, lot more of being with as well as doing those physical things. Ahem, yeah.

PS: With experience there does come confidence that does make a difference?

R: Yeah, I think so, I think in a lot, I'm not saying I get it right all the time now (both laugh), it does get easier to get it right more often and I think probably because when you first start you so much going through all the technical things in a [way/right] and at some level, family situation, psychological ... is, is there but you're going over all the technical of what you should do next and that gets in the way sometimes of, the more intrusive, and now I find, some of what I do is intuitive, I just do 'cause it feels the right

thing to do and I don't know the always the way. Ahem, I think I'm better at that now that I was then.

PS: And so there is free capacity to pay attention to other elements?

R: Yes, yes, yes, 'cause I think you, I mean you pick up the non-verbal

PS: often we are too busy to

R: Yeah, you think should I give him the ... or the morphine now.

PS: In your work, do you come across spiritual issues with patients and families?

R: Hmmh, yes, if that's spiritual, you don't always mean religious

PS: No, I consider them to be two separate things.

R: Yeah, yes. And well sometimes there are religious issues, sometimes it's not, it's about how people find meaning in their lives, you know, like with (name) and her family, how she fits into the family, what she means to them and what she can do for them, though they don't ... at her, because the thing that's most important in her life. Yeah, yes, and it's all the time I think.

PS: It's a situation in one's life when those questions will turn up?

R: Yeah,

PS: because, when should they turn up if not then?

R: Yeah, that's partly what makes the job interesting, you see, because nobody really know what's going to happen after you die and you can have amazing conversations with people to ..., if the relative is somebody on the ward, and then you let, and we have a conversation again with somebody who, she believes in life after death and my husband's is ... and we were talking of that [quantum] suicide, it's relevant that it's been done that, ahem where there might be parallel universes, so you have a universe in which you die a universe and in which you don't, although how long we die and we were talking about that and you know, you [do], I don't know, everything just

[stop/drop] it, everything from, I mean although we do a lot of hands-on care and we don't, but obviously I wouldn't leave them ... sitting if you've been incontinent and then wait for the district nurses to come round. Ahem, so it goes, you know, everything changing people, washing them, to talking about the meaning of life and that, you know, that's pretty [nice]

PS: [mix up a lot of things] all at the same time

R: Yeah, definitely. But that's, you know, that's what life is about (tape ends here).