

The experience of uncertainty for individuals with HIV/AIDS and the palliative care paradigm

Jackie Cochrane

Abstract

This small qualitative study investigated the lived experience of individuals with HIV/AIDS, exploring the uncertainty related to episodes of life-threatening illness followed by recovery, 'revival'. The themes that emerged related to the unpredictability of when death would occur. The participants described the dilemma of living with a chronic illness with a totally unpredictable disease trajectory. Following periods of being extremely unwell, individuals would then recover and experience periods of relative wellbeing, only to succumb to another infection later. The findings highlighted the uncertainty that pervades all aspects of HIV-positive individuals' lives as they face death. An awareness of this may be important in those offering palliative care to those with HIV/AIDS.

The palliative care paradigm was developed in response to, and has concentrated on, meeting the needs of those facing death from cancer (Saunders, 1984; Higginson, 1993; Grothe and Brody, 1995; Downey, 1997; Field and Addington-Hall, 1999; Craven, 2000). Furthermore, this paradigm reflected the fairly predictable trajectory of late metastatic disease. In the current literature on palliative care, the author suggests there is an assumption, or possibly an inference, that the paradigm is directly transferable to other disease categories.

Although the principles and approaches of providing palliative care to those facing death are frequently referred to (Standing Medical Advisory Committee/Standing Nursing and Midwifery Advisory Committee, 1992; National Council for Hospice and Specialist Palliative Care Services, 1995), it could be suggested that the scope of this model has largely not been questioned since its inception. Higginson (1993) has suggested that the current model of palliative care, which was developed for people with cancer, could be adapted for those with HIV/AIDS. However, this was before the introduction of highly active anti-retroviral therapy (HAART), which has altered

the disease trajectory of HIV/AIDS from acute to chronic. Questions remain regarding diseases, such as HIV/AIDS, that may not 'fit' the current model (Grothe and Brody, 1995).

The concept 'revival' has been used in discussing the experience of clients who were perceived to be moribund then recovered. Individuals with HIV/AIDS can experience this many times as the disease progresses (King, 1997, 1999). What became apparent when initially discussing the research with clients was that they were not familiar with the term 'revival', but were able to associate the course of the disease with the term 'roller coaster' used by Foley et al (1995) and Grothe and Brody (1995).

Literature review

A systematic literature search of AIDS-LINE, CINAHL and Medline, was performed using the key words 'HIV/AIDS', 'revival', 'roller coaster' and 'palliative care paradigm', either singly or in combination. The search was conducted at the beginning of 2001 for articles published since 1980, which is when the causative virus was first isolated. It should be noted that published articles reflect a time 2 years or more before the actual publication date (Wilkes, 1998).

Grothe and Brody (1995), who reviewed the palliative care literature for HIV disease, suggested that there were problems with the fit, because of the unpredictable manifestation and progression of HIV. In the 1980s, when HIV first emerged, AIDS presented as an acute illness. At this time being diagnosed as HIV positive was equated with imminent death. However, this was before advances in treatments and the introduction of HAART in 1995/6 in many Western countries, which has led to an increase in longevity, albeit only for some (Nicholson, 2000). Now, active

Jackie Cochrane is
Community Palliative Care
Clinical Nurse Specialist
(HIV), Ipswich Hospital
NHS Trust, Pinewood
Surgery, Shepherds Drive,
Ipswich, IP8 3SL, UK

treatment until the point of death and long-term prophylaxis are possible. It could be asked whether this is this palliation. In 1987, Kubler-Ross described AIDS as the ultimate challenge of palliative care. She suggested that the application of palliative care to those infected with HIV needed further exploration (Kubler-Ross, 1987). Later, McHaffie (1994) stated that, as an infectious disease, HIV had exposed anomalies, dichotomies and dilemmas that have forced health-care professionals to scrutinize previously familiar principles of palliative care. Namely, that the model of care developed, was for a specific illness, late metastatic cancer, whose disease trajectory is fairly predictable (Foley et al, 1995). Yet the divisions between active treatment and palliation with HIV/AIDS are less well defined, as shown in *Figure 1*.

Another theoretical model of palliative care, proposed by Ahmedzai in 1996, emphasized the entwinement of treatment and care modalities at all stages of disease (*Figure 2*). The Sheffield Theoretical Model makes a distinction between palliative care and terminal care based on the point when: 'adjuvant attempts to either

prolong life or to give curative therapy are stopped' (Clark and Seymour, 1999).

Although the immunosuppression caused by HIV cannot be cured, many of the opportunistic infections can be treated and prophylactic treatment of some adjuvant diseases can be actively continued until the point of death (Welsby et al, 2001), hence the dilemma posed. The author suggests that the Sheffield Theoretical Model (1996) (*Figure 2*) needs to be adapted, with the misleading 'curative' heading re-named 'active intent' because at present there is no cure. The distinctive line of division between 'curative' and 'life-prolonging' could be amended to replicate the one proposed in Foley's model. This would then be more reflective of the experience of the roller coaster and uncertainty, particularly around identification of the terminal phase (Jennings and George, 1996; Pickhaver, 2002).

The phenomenon of revival has been described as the Lazarus syndrome (King, 1997, 1999; Scott and Constantine, 1999). The syndrome being related to the experience of the Biblical character Lazarus, whom Jesus is said to have bought back from the dead after 4 days in his tomb. The phenomenon is apparently unique to HIV/AIDS, but likened to the feelings of trauma suffered by Holocaust survivors (France, 1998), both groups having seen friends and family members die, and expected that they too would die, but survived instead.

Very little literature was found on the phenomenon. Only two research studies were discovered relating to treatment responses and disease progression, Brashers et al (1999) and Trainor and Ezer (2000), from America and Canada respectively. No studies conducted in the UK were identified.

Method

A qualitative phenomenological research methodology was used, the philosophical origins of the approach being those of Husserl (1962). Phenomenology is a qualitative research method that is used to explore the lived experience of a phenomenon (Streubert and Carpenter, 1999), in this case, revival. An understanding of the experience of uncertainty could make a contribution to the existing palliative care paradigm.

Ethical approval was obtained from the local research ethics committee. One of the

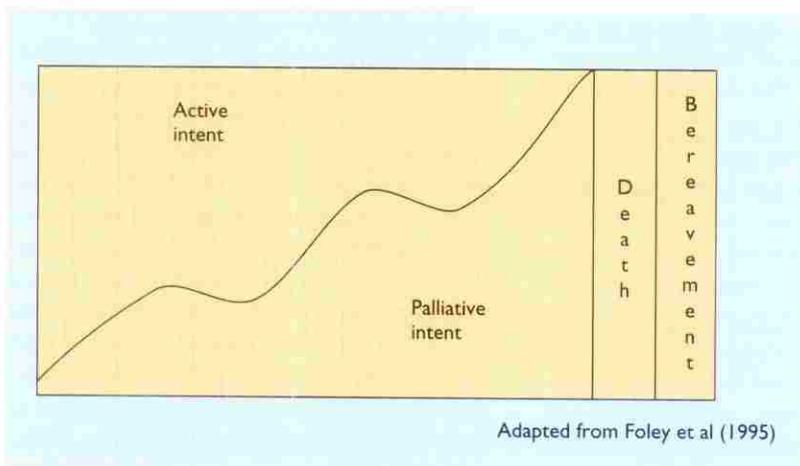


Figure 1. HIV/AIDS palliative care

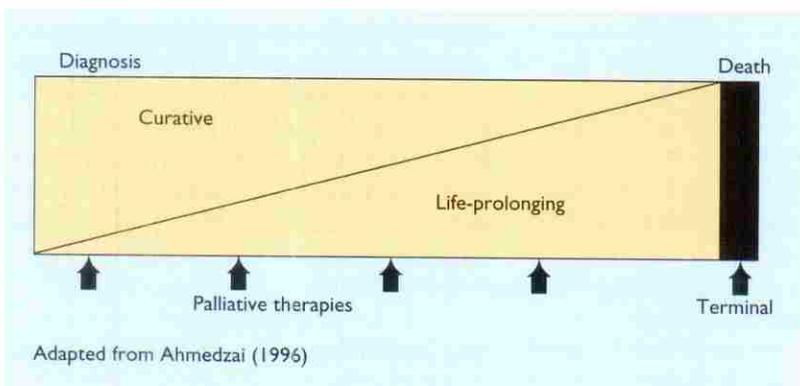


Figure 2. Sheffield Theoretical Model for palliative care

'The researcher started from the position of an 'insider', as a nurse involved in participants' care.'

main areas of concern for HIV-positive individuals is that of confidentiality and the potential risk of identification. However, according to Dean (1995), the personal experiences of this particular client group should not be ignored. Qualitative research may allow marginalized groups to have a voice and be heard, while protecting their anonymity (Humphreys, 1970; Hardy, 1998). By giving clients the opportunity to participate, through telling their stories, they may derive meaning from living with a stigmatized disease, possibly making the experience of research participation a positive one (de Raeve, 1994).

As a community palliative care clinical nurse specialist in HIV, the researcher consciously selected a sample of six clients from her caseload, using her professional knowledge of the study population, making it a purposive sample (Parahoo, 1997). Blacktop (1996) suggested that there is a need with such sampling to trust the researchers' expertise, knowledge and unconscious bias in selection. The researcher started from the position of an 'insider', as a nurse involved in participants' care. The criteria for inclusion in this study was that the client had been diagnosed as HIV positive for more than 5 years. This made it likely that he or she would have experienced the phenomenon under investigation. The average length of time since diagnosis was 9 years. The source of infection was not a defining category, because it was not important where or how the virus was acquired. The participants varied in age from 37–62 years, five were male and one was female. Clients were contacted by telephone and invited to participate, with written consent obtained before interview.

Participants' views were obtained through semi-structured interviews that were tape-recorded. The interviews took

between 45–120 minutes and were carried out at a location of the participants' choice, usually their own home. Predetermined questions (*Box 1*) were used to focus the interviews, while allowing clarification of feelings and probing of issues through further questioning (Rose, 1994).

Analysis

The author transcribed the interviews verbatim (Payne, 1997). Their content was then checked for accuracy against the original audio recordings. Content analysis (Miles and Huberman, 1994) was used to make sense of the taped interviews through data familiarization. The transcripts were carefully read and re-read in their entirety several times in order to capture an essence of the experience of 'revival', getting a sense of the whole. The actual process of comprehension and synthesis was iterative, being back-and-forth, with the data being scrutinized and significant phrases, sentences and paragraphs highlighted to isolate thematic statements. The themes identified from the reduction of data were coded as they emerged, with each piece of data being 'lifted' from the transcript. The need to check the substance of the emergent codes was done by constantly referring back to the original transcripts.

The interparticipant analysis involved comparing the transcripts of several participants and the analysis of themes was achieved through the sorting of commonalities and natural variations. Both facilitated cognitive processes that enabled the author to synthesize, interpret, link, see relationships and enable verification of the related themes to the experience of uncertainty and 'revival'. These were then checked out with the relevant participant, for confirmation that the data were truly representative of their descriptions, so contributing to the reduction of researcher bias (Beck, 1994).

Support for the researcher (Coyle and Wright, 1996), during the process was received from her clinical manager and university supervisor. The researcher also kept a diary to self-reflect on how the data gathering and interpretation may have been influenced by her own biography, theoretical frame of reference or view of the world (Taylor, 1995; Ingleton and Seymour, 2001).

Findings

The main theme, or core variable, identified from the transcripts was related to uncertainty, with the other themes, 'time

Box 1. Interview questions.

Please could you describe your feelings when you found out that you were positive?

Can you tell me about the times when you thought that you might be dying?

In what way did you prepare for your death?

Can you explain what it feels like to have been close to death and then to have recovered?

What are your hopes for the future?

'It would appear that the theme of 'certain death' related back to the moment when participants were told that they had HIV.'

related to a future', 'revival', 'wellbeing' and 'certain death', being interrelated. The presentation of the findings includes appropriate quotations, which are used to illustrate and substantiate the themes identified through analysis of the data (Sandelowski, 1994; Ashworth, 1997).

The main theme of uncertainty was related to the unpredictable disease trajectory associated with the HIV virus, which is unlike that of metastatic cancer whose disease trajectory is fairly predictable (Foley et al, 1995), as Participant 6 explained:

'You can say with cancer, you've got 6 to 9 months to live. Well people are able to prepare themselves and then it [death] happens, that's not so for us.'

It would appear that the theme of 'certain death' related back to the moment when participants were told that they had HIV. This is an experience similar to receiving a cancer diagnosis, which still remains a metaphor for death (McNamara, 2001). Participants described how they are faced with a provisional existence, which affected personal, social and interpersonal issues:

'I had to give up work... for me as a man, it feels like I've been castrated.'
(Participant 6)

'Sometimes it takes me 4 days to do what I could do before in one [general activities related to helping around the home]'
(Participant 2)

'My body is slowly shutting down, soon I'll need to use a wheelchair all the time.'
(Participant 5)

The uncertainty created also meant that the individuals who had previously withdrawn from the future had to try and reintegrate themselves back into society. They had to live with the knowledge of a certain death, but did not know when this would occur.

Being infected with HIV, created uncertainty for participants that was related to the unpredictable progression of the virus, the uncertainty of when death would occur, the difficulties in planning for the future and living a provisional existence.

'I haven't got a future, I don't look to the future anymore... its only since becoming ill that its been like this.'
(Participant 2)

As Van den Berg (1972) explained:

'The beginning of every serious illness is a halt. Normal life ends. Another life takes its place. One suddenly becomes uncertain about things most taken for granted: faith and integrity of the body, one's role in other peoples' lives and their role in one's own life, and faith in the future.'

For many people living in a Western society, time is linear, sequential and related to clock time and calendars, indicating the present, yet unable to show the future or reveal the past. However, for those who have a HIV-positive diagnosis there is a disruption of time, which is normally taken for granted, in relation to the future, by most people. Participants spoke about the paradox of living one day at a time while trying to hold onto a future:

'I take each day at a time...'
(Participant 1)

'I don't plan for a future, it's like I say day to day.'
(Participant 2)

'... it's just a question of taking one day at a time and see how things go.'
(Participant 3)

For some participants, the achievement of revival and having outlived a predicted prognosis was significant. Participant 5 described how, having received an HIV-positive diagnosis in 1981, he had remained well until 1996, at which time he developed an opportunistic infection. However, he described his sense of achievement from surviving several near deaths:

'I think it's quite an accomplishment to have survived this long... I'm proud of myself.'
(Participant 5)

Likewise, a participant diagnosed in 1982, a haemophiliac, spoke about being 'immortal in the early days', and now wants to be the 'last one [haemophiliac] left'.

The term revival, as stated previously, was not one that appeared to be familiar to all the participants, although they could see where the proponents of the term were coming from. Some did not consider that they had experienced being 'raised from the dead'. What they were able to identify with was the 'roller coaster', which they related to periods of uncertainty associated with being very ill and then recovering:

'Although uncertainty is an inherent part of human existence, most people are not aware of it until a disruption in their reality occurs.'

'It's a roller coaster, because one minute you're up and the next you're down and it just goes on and on...'

(Participant 6)

The participants experienced daily the existential pull of the two realities of life and death, with the phenomenon of revival being repeated as they became seriously ill only to recover again. Their adaptation to each revival, or dip in the roller coaster, being dependent on how each unique individual viewed the disruption caused by the illness. This disruption required the individual to reconstruct their life and maintain a sense of personal integrity in the face of a disturbance to their normal identity, customary routines and established relationships.

HIV seropositivity does not present the infected person with an established prognosis and the uncertainty related to disease progression appears to heighten the level of stress for the participants. They recognized the negative impact that stress could have on the immune system and so strived to maintain a sense of wellbeing. All participants mentioned that the medical profession were strongly influenced by improvements in surrogate markers of health, i.e. an increase in the CD4 count and a decrease in the viral load as measures of wellbeing:

'That's the doctors Holy Grail... CD4 and viral load. I just want a decent life. So, no I don't worry too much about the counts.'

(Participant 6)

'My personal barrier was 250 CD4, but now I've learnt not to count too much on the figures. My own sense of wellbeing is my measure.'

(Participant 1)

Many of the symptoms associated with the virus are not directly visible and participants looked well. Those that were asymptomatic spoke about the dilemma of looking well, while feeling unwell. This also had implications regarding employment issues and the possible cessation of social security benefits and allowances during formal review.

Discussion

Initially it may have appeared that HIV/AIDS would fit neatly into the palliative care paradigm (Grothe and Brody, 1995). However, with the development of

new and improved treatments and with the prophylaxis of certain opportunistic infections, the trajectory of the disease and its subsequent management has significantly altered for those in the Western World. This has challenged the traditional palliative care paradigm, with uncertainty around progression and prognosis for those infected with the virus. Every time the client experiences a serious illness, there is a very real expectation that this could result in death. However, although a client could be moribund at that particular given moment, they may recover a few days later – revival. There is no certainty, which the present model perhaps does not allow for. If it is not clear where the delineations between active and palliative intent are, this creates uncertainty for all those involved in the provision of care.

Mishels (1988, 1990) theory of 'uncertainty in illness', suggested that uncertainty was the cognitive state that occurred when an individual could not assign definite value to objects or events and/or was unable to predict outcomes. Carricaburu and Pierriet (1995) suggested that those living with a HIV-positive diagnosis were entrenched in a situation 'at risk of illness'. Common nonspecific symptoms may acquire great significance, as possible indicators of a change from living with to dying from the virus. The ambiguity around the durability of treatments and, therefore, ultimately, the survival of clients will contribute to the level of uncertainty.

Although uncertainty is an inherent part of human existence, most people are not aware of it until a disruption in their reality occurs. Participants in this study were unable to project a future for themselves, the previous certainties in life having been removed. Taking one day at a time may be a means of reducing the uncertainty. The pervasive idea that having HIV is equated with death kept participants from planning a future.

Health within illness

The concept of 'health within illness' (Lindsey, 1996; Moch, 1998), is concerned with the increased meaningfulness of life through 'connectedness or relatedness' with the environment and/or awareness of self during a period of compromised wellbeing. The concepts of health and death do not appear synonymous and yet, according to Russell and Sander (1998), and

'The experience of living with HIV and its unpredictable disease trajectory could provide the palliative care domain with the opportunity to embrace health-promoting palliative care.'

Kellehear (1999a) should enjoy a complementary relationship. Kellehear (1999b) argued that, if the health needs of those who are living with a life-threatening chronic illness are not promoted, it could mean that palliative care is not truly holistic. The experience of living with HIV and its unpredictable disease trajectory could provide the palliative care domain with the opportunity to embrace health-promoting palliative care. This could be through helping with interpersonal reorientation, enhancing individuals' sense of control and enabling them to adjust to life with a chronic illness.

Conversely, although palliative care may be ignoring health-promoting aspects of care, health promotion may be death-denying and could be contributing to the stigma, isolation and rejection associated with those facing death. Health-promoting palliative care, the author suggests, could offer a model of social care drawn from the paradigms of palliative care and health promotion, in order to further enhance the care of those trying to live while dying.

Limitations

This study has attempted to investigate an under-researched area and does not necessarily reveal the phenomenon in depth, but has started to allude to the experience of uncertainty related to revival in connection with HIV. The sample size was small and the results are therefore not representative of all HIV-positive individuals (Paley, 1997).

The respondents' accounts may have been concealed or exaggerated for a variety of personal reasons, leaning towards more rational and logical explanations. There may also have been a tendency for participants to give the answers they assumed that the researcher wanted to hear, with their account not being consistent with, or reflecting their actual behaviour (Fielding, 1994).

Future research

It is not apparent from the current literature whether the lived experience of uncertainty related to revival/roller coaster is unique to HIV/AIDS, or whether it also relates to other illnesses. This could be an area for future research. Whether individuals diagnosed with cancers such as acute leukaemia, acute lymphomas or neutropenic sepsis also experience the phenomenon of revival could be investigated.

Providing palliative care for diseases with unpredictable trajectories may create issues relating to uncertainty for those offering care, which could also be an area for investigation. Gibbs et al (1997) discussed how patients dying from diseases such as HIV/AIDS, neurological conditions, respiratory failure and heart failure could benefit from palliative care, but that different models of care may be needed. Therefore, if there is a disproportionate concentration of palliative care on those dying of cancer, research into adapting the paradigm may enhance the care for those with other diseases and redress current inequalities (Connolly, 2000).

Conclusion

This small study explored HIV-positive individuals' experiences of uncertainty related to revival/roller coaster and may contribute to the understanding of palliative care of illnesses other than cancer. Palliative care appears to have become a somewhat accepted ubiquitous slogan within the health-care arena – its principles often unquestioningly accepted, despite their development being for a single disease. Perhaps now, over 30 years since its inception, the tenets of the paradigm need to be challenged and reviewed. They need to be truly person-centred, rather than disease-centred in order for consideration be to given to diseases other than cancer.



- Ahmedzai S (1996) Making a success out of life's failure. *Progress in Palliative Care* 4(1): 1-3
- Ashworth P (1997) The variety of qualitative research. Part one: introduction to the problem. *Nurs Educ Today* 17: 215-8
- Beck CT (1994) Phenomenology: its use in nursing research. *Int J Nurs Stud* 31: 499-510
- Blacktop J (1996) A discussion of different types of sampling techniques. *Nurs Res* 3(4): 5-15
- Brashers DE, Neidig JL, Cardillo LW, Dobbs LK, Russell JA, Haas SM (1999) 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. *AIDS Care* 11(2): 201-19
- Carricaburu D, Pierret J (1995) From biographical disruption to biographical reinforcement: the case of HIV positive men. *Sociol Health Illn* 17: 65-88
- Clark D, Seymour J (1999) *Reflections on Palliative Care*. Open University Press, Buckingham: 85
- Connolly M (2000) Patients with non-malignant disease deserve an equitable service. *Int J Palliat Nurs* 6(7): 91-3
- Coyle A, Wright C (1996) Using the counselling interview to collect research data on sensitive topics. *J Health Psy* 1: 431-40
- Craven O (2000) Palliative care provision and its impact on psychological morbidity in cancer patients. *Int J Palliat Nurs* 6(10): 501-7
- Dean RG (1995) Stories of AIDS: the use of narrative as an approach to understanding in an AIDS support group. *Clin Soc Work J* 23(3): 287-384
- De Raeve L (1994) Ethical issues in palliative care research. *Palliat Med* 8: 298-305
- Downey M (1997) Developing palliative care services for patients with AIDS. *Eur J Palliat Care* 4(4):

121-3

- Field D, Addington-Hall J (1999) Extending specialist palliative care to all? *Soc Sci Med* 48: 1271-80
- Fielding N (1994) Varieties of research interviews. *Nurs Res* 1(3): 188-97
- Foley FJ, Flannery J, Graydon D, Flintoft G, Cook D (1995) AIDS Palliative care - challenging the palliative paradigm. *J Palliat Care* 11(2): 19-22
- France D (1998) Holding AIDS at bay, only to face 'Lazarus Syndrome'. *New York Times* 10 June: 7
- Gibbs LME, Addington-Hall J, Gibbs JSR (1997) Dying from heart failure: lessons from palliative care. *BMJ* 317: 961-2
- Grothe TM, Brody RV (1995) Palliative care for HIV disease. *J Palliat Care* 11(2): 48-9
- Hardy M (1998) *The Social Context of Health*. Open University Press, Milton Keynes
- Higginson I (1993) Palliative care: a review of past changes and future trends. *J Public Health Med* 15(1): 3-8
- Humphreys L (1970) *Tearoom Trade: Impersonal Sex in Public Places*. Aldine, Chicago
- Husserl E (1962) *Ideas: General Introduction to Pure Phenomenology*. Macmillan, New York
- Ingleton C, Seymour JE (2001) Analysing qualitative data: examples from two studies of end-of-life care. *Int J Palliat Nurs* 7(5): 227-33
- Jennings AC, George R (1996) Palliative care of HIV diseases and AIDS. *Prog Pall Care* 4: 44-7
- Kellehear A (1999a) Health-promoting palliative care: developing a social model for practice. *Mortality* 4(1): 75-82
- Kellehear A (1999b) *Health Promoting Palliative Care*. Oxford University Press, Australia
- King M (1997) 'Lazarus Syndrome' perpetuates a new crisis. *Washington Blade* 28 November: 31
- King M (1999) Lazarus gets a third wind. *Body Positive (America)* XII: 5
- Kübler-Ross E (1987) *AIDS The Ultimate Challenge*. MacMillan Publishing Company, New York
- Lindsey E (1996) Health within illness: experiences of chronically ill/disabled people. *J Adv Nurs* 24: 465-72
- McHaffie HE (1994) HIV and AIDS: the nursing response and some ethical challenges. *Nurs Ethics* 1(4): 224-32
- McNamara B (2001) *Fragile Lives: Death, Dying and Care*. Open University Press, Buckingham: 28-40
- Miles MB, Huberman AM (1994) *Qualitative Data Analysis*. Sage, London
- Mishel M (1988) Uncertainty in illness. *Image J Nurs Sch* 20: 225-32
- Mishel M (1990) Reconceptualization of the uncertainty in illness theory. *Image J Nurs Sch* 22: 256-62
- Moch SD (1998) Health-within-illness: concept development through research and practice. *J Adv Nurs* 28(2): 305-10
- National Council for Hospice and Specialist Palliative Care Services (1995) *Specialist Palliative Care: A Statement of Definitions*. National Council for Hospice and Specialist Palliative Care Services. London. Occasional Paper 8: 6-7

Key words

- Revival
- Roller coaster
- HIV/AIDS
- Uncertainty
- Palliative care paradigm

- Nicholson J (2000) Can the development of palliative care services meet the needs of people with HIV? *J Palliat Care* 16(2): 37-2
- Paley J (1997) Husserl, phenomenology and nursing. *J Adv Nurs* 26: 187-93
- Parahoo K (1997) *Nursing Research: Principles and Methods*. Macmillan Press, London
- Payne S (1997) Selecting an approach and design in qualitative research. *Palliat Med* 11: 249-52
- Pickhaver K (2002) Palliative care. In: Gazzard BG ed. *AIDS Care Handbook* 2nd edn. Mediscript Ltd, London: 241-55
- Rose K (1994) Unstructured and semi-structured interviewing. *Nurs Res* 1(3): 23-32
- Russell P, Sander R (1998) Health promotion: focus on care of the dying. *Int J Palliat Nurs* 4(6): 266-70
- Sandelowski M (1994) The use of quotes in qualitative research. *Research Nurs Health* 17(6): 479-83
- Saunders C (1984) On dying well. *Cambridge Rev Feb* 24: 49-52
- Scott S, Constantine LM (1999) The Lazarus syndrome: a second chance for life with HIV infection. *J Am Pharm Ass* 39(4): 462-6
- Standing Medical Advisory Committee/Standing Nursing and Midwifery Advisory Committee (1992) *The Principles and Provision of Palliative Care*. HMSO, London
- Streubert HJ, Carpenter DR (1999) *Qualitative Research in Nursing: Advancing the Humanistic Perspective*. 2nd edn. JB Lippincott Co, Philadelphia
- Taylor B (1995) Interpreting phenomenology for nursing research. *Nurs Res* 3(3): 80-91
- Trainor A, Ezer H (2000) Rebuilding life: the experience of living with AIDS after facing imminent death. *Qual Health Res* 10(5): 646-60
- van den Berg JH (1972) *The Psychology of the Sickbed*. Humanities, New York
- Welsby PD, Richardson A, Brettell RP (2001) Palliative care aspects of acquired immune deficiency syndrome. In Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd edn. Oxford University Press, Oxford: 1121-49
- Wilkes L (1998) Palliative care nursing research: trends from 1987 to 1996. *Int J Palliat Nurs* 4(3): 128-34

IJPN welcomes unsolicited manuscripts on all aspects of palliative and supportive care.

If you wish to discuss your ideas, please contact Ruth Laughton.

Tel: +44 (0)20 7501 6717
Email: ruth@markallengroup.com

Copyright of International Journal of Palliative Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Copyright of International Journal of Palliative Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.