

DAY HOSPICE CARE: PERCEPTIONS AND TABOOS IN PALLIATIVE CARE

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Abstract: Stimulated by Downs(2003) article on Failure in Palliative Care the author reflects on the workings of a day hospice focusing on the difficult and challenging issues for patients and how the hospice setting can enable these issues to be raised and addressed. The issues are explored and illustrated using patient comments and experiences. Acknowledging a dearth of hospice day care research and literature the author seeks to motivate others and encourage a wider appreciation of day hospice and thereby influence future practice.

Key words: day hospice, fullness of life, isolation, depersonalisation, taboo topics.

Introduction

In her article *Dealing with Failure in Palliative Care* (Downs 2003) Dr. Downs raises the question of whether the buzz of the therapeutic, social environment of the day hospice causes us to miss something. She observes patients are reluctant to discuss certain issues in a social group or even privately, because of deep feelings, embarrassment or anticipated stigma. Personal experience of a day hospice environment suggests patients' *reluctance* can be overcome and for many patients understanding the concept of day hospice is the first difficulty to be overcome, and once overcome their experience provides opportunities for dealing with the failures suggested by Dr Downs. Once patients are comfortable with the 'setting' the difficult issues mentioned by Dr. Downs may be raised and addressed.

Spencer and Daniels (1998) observed that there was a dearth of research relating to day hospice care. Regrettably the situation does not appear to have changed. A literature search returned a handful of articles on day hospice care. However, reflecting on the author's personal experience of the Paul Bevan Day Hospice in Ascot, this article seeks to add to the literature available and to stress the positive effects on patient care of the day hospice environment and the opportunities it affords for assessing and addressing patients' needs.

Perceptions of a day hospice

That the word hospice is associated with dying and that papers and discussions about spiritual care in the hospice tend to focus on the dying is perhaps inevitable. When we consider Cicely Saunders' pledge: *'You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die.'* (cited in Twycross) it is not surprising that the focus seems to be on the end of life.

Where the patient really is at the end of life the concept of 'living until you die' can take on a macabre aspect, especially if the bodily realities of deterioration are ignored or glossed over (Lawton 2000). The words 'living until you die' appear to convey activity or doing but may equally convey a fullness of life which is not just about doing, even may not include doing, but is about being. If we understand 'living until you die' not merely as physical self-expression but as being loved, valued and respected, regardless of the ability or inability to contribute, the concept takes on a different dimension. Hospice care is about approach and attitude – it is a philosophy rather than the provision of a building (Spencer, Daniels 1998).

When a patient is only known for a short period at the end of life the help towards fullness of life may

be limited, but when a patient comes to the day hospice the scope is much wider. The Paul Bevan Hospice in Ascot is a day hospice with a focus, due to the nature of its foundation, on cancer patients. Since it has no beds there is no temptation to think of it as giving the patients a chance to get used to the place where they will die. Patients attend, generally on one day a week, for support and friendship. The support may be social, physical, psychological, spiritual, medical (Higginson et al 2000). They may be offered counselling, massage, reflexology, craft work of all kinds, but above all they are offered a safe place to 'be' with their diagnosis.

The first thing our patients learn is that 'hospice' does not mean death. Rather our 'hospice' is about life and living to the full. They discover that they can talk about their illness as much or as little as they choose (Langley-Evans, Payne 1997). They are helped to: *retain a sense of integrity in the face of progressive losses* (Thompson 1990). Where appropriate they are supported in their transition from curative to palliative care (Spencer, Daniels 1998). A few people will be with us for only a short period before they die but many will be with us for several years. In that time they have the opportunity to reflect on who they are, what they believe, what they want from the remainder of their life. They assess their quality of life and prioritise (Stevens 1996). It is an opportunity which many healthy people do not make time for. One of our patients, Anne, wrote:

*I am one of the chosen
For I have been given the opportunity
To step off the treadmill of life
To have time to see, hear and understand
To look around and experience the subtleties of
...our world
...our universe
...our galaxy
Much of which I may have missed.*

Consequently, some patients come to a point where they are almost grateful for the cancer because it made them reflect, consider their priorities and adapt their lifestyle (Hopkinson, Hallett 2001, Mickley, Cowles 2001). Many feel that prior to their illness they had not really lived – they had not understood the meaning of 'life' (Stanworth 1997). They may have lived as they felt others expected them to (Thomas 1999) or they may have had a poor sense of self-worth (Hopkinson, Hallett 2001) or never have valued their true self.

Common Patient Experiences

Isolation

Isolation and loneliness may accompany cancer. No longer fit enough to work or be sociable, the only outings are to clinics, chemotherapy or radiotherapy. Pat said she made friends with another patient at the treatment centre but when the treatment ended she was back on her own. Day hospice patients – young and old alike - have expressed thanks for their day because it is the only day of the week on which they meet other people. The community of the hospice provides a safe place to admit to loneliness, and once admitted it can be addressed.

Depersonalisation

Despite recent advances in staff training some patients still feel that some oncology centre staff treat cancer patients as if they are not human. It is now generally recognized that depersonalisation may be a sign of inability to deal with suffering (Soelle 1973) - but for staff recognizing and acknowledging it in oneself is hard (Downs 2003). The staff of the Day Hospice can support patients when they are on the receiving end of such treatment, helping them to express their feelings in whatever way is appropriate. Anne wrote poetry:

*I'm not ill
I don't look like them
I don't want to look like them
I don't want to be labelled a "Cancer Patient"
I'm ME
Not a condition
Not a statistic
Not a prognosis!
And Helen wrote: *We are not 'patients', we have a name. Please speak to us properly**

However, coming to terms with this kind of depersonalisation can be a growth point in inter-personal awareness - for some patients it appears to be the first time to consider that what they saw as rudeness from a professional may be a sign of that person's own difficulties. Coming to terms with that rudeness can be a source of humour – of a male consultant Jenny said 'he must have had his period that day'.

Guilt

The process of coming to terms with the shortcomings of those who are treating or helping them may

reveal guilt for making such an observation. Patients are often reluctant to criticize a long wait, the loss of papers and test results, the failure to diagnose. A safe atmosphere will help to ensure that these feelings are not suppressed but brought into the open and accepted.

Guilt may also occur when there is an adverse reaction to treatment. A safe environment encouraged Jane to explore how she felt, to accept her body's apparent failure to respond to treatment and to devise a coping mechanism.

Time to reflect can bring awareness of guilt, of the need to be forgiven, for reconciliation – the day hospice is a safe place to explore shortcomings and poor relationships and, perhaps with the help of psychologist or chaplain, to find ways of attaining reconciliation and peace.

Taboo areas

Body functions, sex, ageing, death and funerals tend to be taboo subjects in society generally, so we should not be surprised if patients take a while before raising them.

Body image : sex and ageing

Concerns about body image and body failure affect self-esteem (Nelson 1992), but a patient who feels accepted and valued by others is thereby encouraged to accept and value his or her self regardless of what is happening to the body. Sharing the horror of losing one's hair can turn from a painful experience into a source of gentle humour. Accepting that the body may not be as agile or as strong, that activities may have to be curtailed may be frustrating – especially in the area of sexual relationships. Humour was again the medium for an exchange about such difficulties. There was a danger of thinking that problems were entirely due to the cancer until the problem was shared and somebody pointed out that you don't have to have cancer to 'have a headache'! However, it should be noted that the group who shared the sexual confidences were female – I am not aware of a similar sharing amongst male patients.

Also discussed was the fact that as we get older we have less energy, need to be fair to ourselves and not expect too much. The effect of ageing on energy

levels is generally not acknowledged in society - to the extent that tiredness may be seen as failure.

Death and funerals

In contemporary society the effects of ageing and death itself appear to be avoided as topics of conversation lest we actually bring them about. If we do not mention them perhaps they will not happen. It would seem that a substantial percentage of the population pass their three score years and ten without ever considering that they are not immortal. In contrast a small percentage of people have apparently come to terms with their mortality and, whilst they may not be totally calm about dying, accept it. Some want to arrange their funeral – once he felt at home at the day hospice Mike had no compunction about asking but was concerned not to upset the staff. He said *'I want to sort my funeral out whilst I'm still able to – it will save the family a lot of bother. We'll agree the hymns, the music, a poem... but I'm afraid I can't tell you the date yet!'*

God-language

Whilst discussing the funeral the nature of faith may well arise if it has not been discussed earlier. The most common issues seem to be around speaking to God 'when I have not spoken to him, for years', from older patients, and 'how do I speak to God?' generally from younger patients. For example Penny, who was thirty-eight at the time said 'I don't do God – but I guess I'm going to have to now.' Older patients may well have some knowledge of the Bible and the Christian faith. Something like *"The Lord's my Shepherd"* learnt in childhood is remembered and it may be possible to encourage the patient to use it. However, many younger patients have less or no knowledge of scripture but may have an awareness of the numinous and this can be the means of helping them explore their spirituality, what they believe and how they might wish to address God.

Staff perspectives

There are a variety of articles on staff perspectives in in-patient units, but there is little material on day care staff. Nevertheless it is possible to observe that self-awareness is as necessary an attribute for day hospice staff (Mitchell 2000, Hopkinson 1999) as it is for in-patient staff. Also, day hospice staff need to be comfortable themselves with issues, or at least have sufficient self-awareness to recognize

when they are not comfortable and channel it to someone who is (George 2002). They may not feel able to deal with issues generally regarded as religious or spiritual, such as forgiveness, reconciliation, life after death, but appropriate formal and informal training may help them realize that spiritual care “infiltrates all aspects of nursing care” (Carroll 2001). Confidence to differentiate religious and spiritual needs and then handle these issues may be further enabled and supported by the chaplain.

Humour

As a means of expression for specific sensitive topics humour is very helpful. However, humour also contributes to the ambience or atmosphere – those who are new to the day hospice often remark that it is a very happy place. Patients, staff and volunteers bring in copies of humorous articles and jokes that have amused them to share. This may be a way of affirming ‘normality’, of reassuring themselves and others that a cancer diagnosis does not bring an obligation of gloom. At the end of a day it is not uncommon to hear “*I haven't laughed so much in ages*”. Such laughter, whatever the cause, has often helped the release of tension, the dispelling of potential gloom.

Discussion

In the literature there is a clear bias to in-patient hospice work. There is therefore scope for research to demonstrate the role of a day hospice in terms of patient benefits.

The importance of humour has been researched in other areas (referred to in Langley-Evans, Payne 1997) but its role in day hospice care may not be fully appreciated. There is also scope for research into the role and perspective of staff in the day hospice, possibly in comparison with in-patient staff. Only one of the current nursing staff in the day hospice has also worked in an in-patient unit but preliminary exploration with her suggests that whilst there are common required attributes there are also marked differences in the duration and nature of relationships which make different demands on the staff.

Dr. Downs may well be right in suggesting that there are times when we miss patients' issues (Downs 2003) but it is what we do with the realiza-

tion that is important. To regard the situation as ‘failure’ risks a negative reaction - from demoralisation to self-condemnation. Indeed Dr Downs observes: *By enabling patients and carers to identify their own personal and spiritual resources failures can be challenged* (Downs 2003). I suggest it is the very concept of failure itself that should be challenged. To say *In Palliative Care our starting point is failure* (Downs 2003) may be technically true but it casts a negative shadow, lending support to the idea that there is a right and wrong way to do this. To regard the starting point in Palliative Care as love and hope is positive, energising for both staff and patients, and giving the freedom for each to find his or her own way. To put it another way, the concept of success/failure is not just inappropriate in the practice of palliative care, it can actually cause us to miss things because people are not behaving or reacting in ways that can be analysed as success or failure.

Conclusion

A diagnosis of cancer, whatever its nature, can lead to reflection and assessment such that the person covers in a brief spell of time what would otherwise be covered in a lifetime. It is therefore necessary for staff to be sympathetic not just to the difficulties of the issues relating to the illness but to the speed and possibly unfamiliar nature of the process. Just as staff provide a safe place for patients to talk so the staff themselves benefit from time and a safe place to reflect on their own psycho-spiritual journey. We need to find ways of encouraging staff to undertake such reflection.

Whilst I am not unsympathetic to Dr. Downs' argument I think we should be more concerned to ensure that we do not miss people, or rather that people with cancer do not miss the opportunity of attending a day hospice. When a person only comes to a hospice at the point where in-patient care is needed there may be little time remaining, putting additional pressure on the person, their family and on the hospice staff. Attendance in the early days of the diagnosis can help reduce the pressure by assisting and enabling personal spiritual and psychological development. To achieve such attendance day hospices need to improve their image and raise awareness levels, to ensure that all professionals connected with this area are aware of the nature of the service offered. In seeking to promote such awareness we

need to be sensitive to the professionals' own reactions to the issues described in this article – for we are not yet a society in which isolation, depersonalisation, guilt, sex, ageing, death and funerals are normal, acceptable topics of everyday conversation.

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