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Stepping Stones

The role of hospice day care in the care of patients with terminal illness

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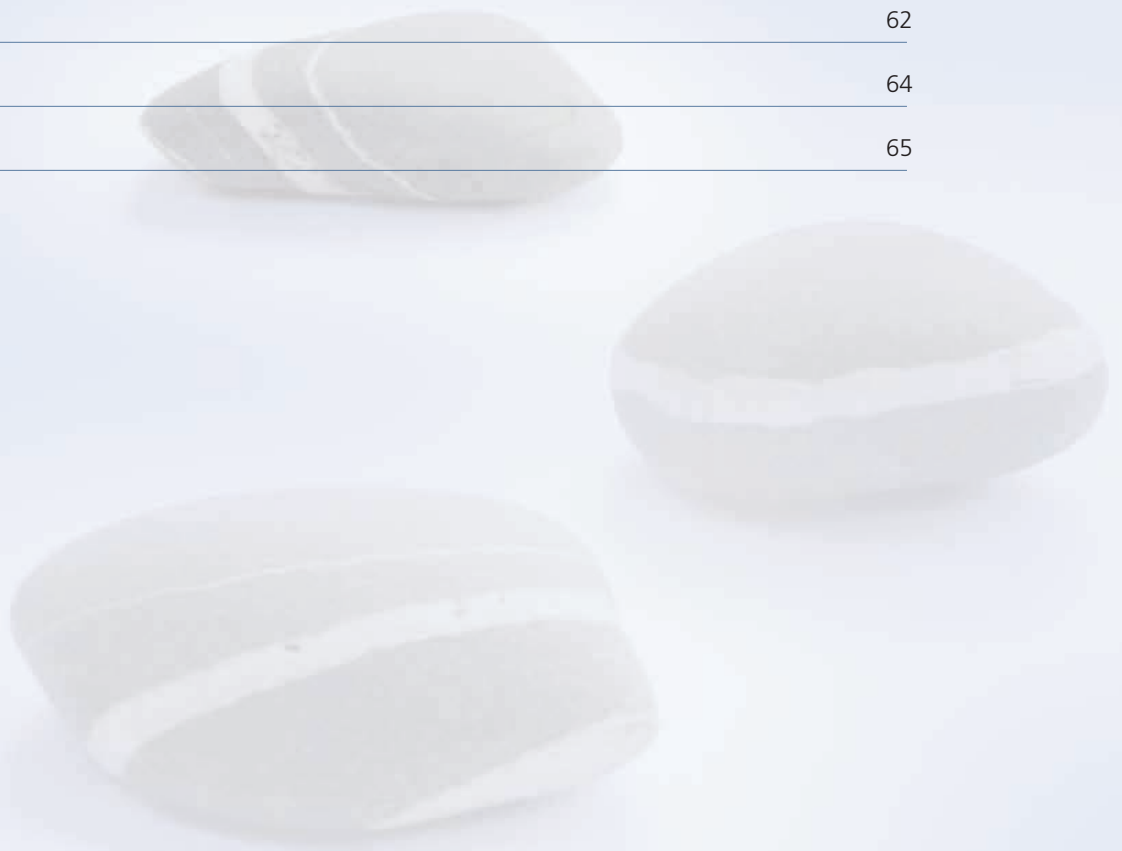
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EXECUTIVE SUMMARY

Introduction

This report presents the results of a study that investigated the role of Hospice Day Care in the care of people with terminal illness. It set out to capture the perspectives of patients and their family members and carers as they engaged with the palliative care day care service over time. The study also explored the views of service providers to more fully understand the complexities of the service.

The National Advisory Committee Report on Palliative Care (Department of Health and Children 2001) has highlighted the crucial role played by hospice day care in supporting terminally ill patients and their family members and carers, but the efficacy of palliative day care within the Irish context is largely under-researched.

This study sought to address this lack of empirical evidence and it is anticipated that this will assist in guiding and informing policy and service directions within specialist palliative care.

Palliative Care Day Care Services

The aim of palliative care is to achieve the highest possible quality of life for both patient and family, by maintaining dignity and controlling symptoms (Davies and Higginson 2005). Quality of life for patients with limited prognosis and their families and friends is a broad ranging concept that is affected in a complex way by a person's physical health, psychological state, level of independence and their relationship to salient features in their environment' (Szabo 1996).

Palliative care services are provided across a range of settings and a number of specialist palliative care services also provide day care services for patients. These services provide facilities for medical and nursing assessment and care, combined with social and therapeutic interventions provided by an interdisciplinary team (Goodwin et al. 2002).

Within palliative care day care services, a rehabilitative approach is adopted to optimize quality of life for patients and their family and friends and in this context rehabilitation may be viewed as a process of adapting to the changes that are occurring, using an active approach in managing complex symptoms and giving assistance to the patient and family to cope with end-stage disease (Hockley 1993).

An integrated model of rehabilitation enables patients to be assessed and for appropriate care to be given as their needs change with advancing disease and is considered appropriate for terminally ill people (Tookman et al. 2004). Palliative day care also potentially provides an extension of the support

available to people in their home environment (Lawton 2000) and may also increase the continuity between in-patient and home care, easing the burden of responsibility on carers (Thompson 1990).

Methodology for the study

A longitudinal approach was adopted in the research in order to capture how patients' and family members/carers' experiences and perceptions of hospice day care may change over time.

The study aims were:

- To examine the role of hospice day care in the care of patients with life-limiting illness.
- To explore patients' experiences of attending hospice day care over the course of their illness.
- To explore carers' perceptions of the contribution made by hospice day care in supporting them in caring for their terminally ill family member.

The specific objectives of the study were:

- To describe the context in which hospice day care is delivered in terms of the structure, process and outcomes of the service.
- To explore patients' experiences and perceptions of hospice day care.
- To explore carers' and family members' perceptions and experiences of hospice day care.
- To examine the perceptions and experiences of service providers regarding the contribution of hospice day care in supporting terminally ill patients and their families.
- To identify the components of hospice day care services that have the greatest impact on patients' lives.
- To explore and analyse the impact of receiving hospice day care services on terminally ill patients and their carers over time.

Data collection

This is primarily a qualitative study that adopted an ethnographic approach. Observation was made of the activities and interactions within hospice day care. Interviews with service providers, patients and family members were conducted over a period of nineteen months.

Study participants

All patients attending the hospice day care service from the commencement of the study who met the inclusion criteria—being capable of providing informed consent—were invited to participate in two interviews on two separate occasions. The first patient interview took place one month after the patient started in hospice day care, and the second interview occurred three to six months later. A nominated family member was also invited to participate in the two interviews on two separate occasions. Patient and family member interviews occurred separately.

A purposeful sample of 24 service providers were interviewed to explore their perceptions and experiences of delivering care in this context. Data collection involved a single interview with a cohort of staff from each discipline, including volunteers who provide day care activities.

A total of 101 interviews were conducted:

- 43 interviews took place with twenty patients.
- 34 interviews took place with seventeen carers/family members.
- 24 interviews took place with doctors (2), nurses (4), care assistants (4), chaplains (2), social workers (2), allied health care professionals (occupational therapists, physiotherapists) (3), complementary therapists (3) and volunteers (4).

Data analysis

Data from all formal interviews, informal conversations and observations were transcribed; line-by-line coding was employed to produce sub-categories (Coffey and Atkinson 1996; Strauss and Corbin 1998). These were grouped together to form categories that captured the main dimensions of study. A software package, INVIVO 7 computer data management and analysis package (QSR International 2006), was used to assist with management of the large quantities of data.

Ethical conduct

All research activity associated with the study was in accordance with the regulations of the University of Dublin, Trinity College Guidelines for the conduct of Research Studies

(2002). Ethical approval to conduct the study was obtained from the Research Ethics Committee, Faculty of Health Sciences, Trinity College, and from the Research Ethics Committee of the hospice where the study was conducted. The anonymity of all the participants was assured through the use of identification numbers rather than the use of names or other identifying information.

RESULTS OF THE STUDY

HOSPICE DAY CARE

A comprehensive picture of the palliative care day service emerged from observation and interviews. The longitudinal approach adopted for the research proved valuable for gaining a deep understanding of the complexities of the service and the experiences of patients and their family members and carers. This understanding emerged over time, in much the same way that the experience of being involved with these services had an incremental impact upon patients and their families and carers. The findings of the research are presented in a way that mirrors the journey that patients and their family members and carers undertake as they engage with the palliative care day care services.

Referral to the service

All patients are referred to the palliative care service from their doctor in the hospital or their general practitioner. The general method of referral to hospice day care is from the community specialist palliative care team, who referred about 80% of the patients in this study. Patients may be placed on a waiting list until a vacancy becomes available, and are prioritised for access to hospice day care according to their needs.

Some patients and their family members may be reluctant to engage with hospice day care as doing so may be seen as an acknowledgement of the progression of their illness. Family members may also be reluctant to share the care of their relative. Poor perceptions of hospices—as places where people go to die—may act as barriers to engaging with hospice day care.

'When they said I had cancer, they said "Would you go to [the hospice]?" I said "Oh, my God", that frightened me, you know, I said people die in the hospice.' (Patient 03)

The hospice day care environment

As a patient's physical condition deteriorates, social isolation can significantly increase. Hospice day care provided an environment for patients to connect with other patients and staff in a relaxed, home-like atmosphere where the same patients came each week on an assigned day.

By creating an environment reminiscent of home, they also created a sense of 'a family' through camaraderie, friendship and belonging. Most patients described coming to hospice day care as offering them a place of peace and an opportunity of getting away from the unpleasantness of their illness. There was a sense of camaraderie between patients who were undergoing similar experiences; this enabled patients to connect with each other and feel less isolated.

'We are all like one big family in here. You really get used to everyone when you are coming here for a while.' (Patient 15)

Coming into hospice day care provided patients with a social outlet to reconnect with the 'normality' they had experienced before their illness. Volunteers within the hospice day care setting facilitated a range of recreational activities.

'I feel the bubble has come back in me. I come home from day care a new woman. I am different since I started coming to day care ... I had given up but now I feel I have started living again.' (Patient 007)

Participating in the organised activities within the hospice day care setting gave patients an opportunity to connect with others in a social environment. Many patients had a shared sense of belonging because they all shared a similar connection—their advancing illness and felt that they benefited from having other patients with whom they could share their experiences.

SERVICE PROVISION

Interdisciplinary teams work collaboratively to provide holistic care for patients with life-limiting illness and support for their family members and carers to enhance quality of life. A detailed medical and nursing assessment of the patient's, their family's and carer's needs is carried out when each patient starts attending hospice day care. These assessments are ongoing and are adapted according to the patient's needs.

Members of the interdisciplinary team sought to maximise patients' physical function, promote independence and help people to adapt to their condition as their illness progressed in accordance with the rehabilitative model of care adopted. Patients may require different levels of care from a variety of professionals and services within the hospice service. Through inter-professional collaboration, many patients were able to gain some independence and continue with their interests and hobbies within the confines of their illness.

'It may be simply showing how to get up from their bed when their mobility is limited ... I sometimes show patients strategies how to conserve their limited energy.' (Staff member 09)

Hospice day care provides a range of complementary therapies that are greatly beneficial for many patients.

'At the moment in hospice day care service we have the services of physiotherapists, occupational therapists, complementary therapists, manual lymphatic drainage nurse specialists and social workers that we can offer patients.' (Staff member 014)

These therapies can alleviate difficult symptoms and improve the quality of life for the patient as well as help with difficulties surrounding altered body image as a result of the illness and treatments. They can also be relaxing for patients and can help to ease anxiety. Therapies are carefully selected, depending on the medical history and current health status of the patient.

Coordinating care

Hospice day care nurses coordinated care, both internally in the service and externally with other health care providers, to provide a continuity of care. Many patients who attended hospice day care were also receiving care from many different services throughout their illness. Nurses in hospice day care frequently coordinated care from acute hospitals; outpatient departments, community services and specialist palliative care services in order to provide continuity of care for the patient.

'We needed to get back to [hospital] for an appointment as [patient 018] was getting frequent dizzy spells. I couldn't leave him unattended as he could fall. We knew we would have to wait weeks for an appointment and he just was not well enough to wait ... the nurse rang from day care and organised the appointment.' (Carer/family member 018)

Weekly community palliative care interdisciplinary meetings allowed hospice day care nurses to discuss the needs of patients who are cared for by both care teams—the day care and community care teams, leading to a continuity of care between all the specialist palliative care services.

Supporting family members and carers

A family-centred approach to care was provided by the hospice day care. While the patient was attending hospice day care, the main carer was able to get some relief from their caring role.

Carers valued the continuity of care between different parts of the palliative care service, as this meant that any staff member from the palliative care service was familiar with the patient and their current condition, thus alleviating carer/family members' anxiety.

'I see the same people each week; they know me and I don't have to keep telling them the same things each week. I only need to tell them if there is anything new.' (Carer/family member 05)

Carers also appreciated that nurses from hospice day care negotiated and advocated on behalf of their relative. Patients and family members/carers experienced a coordinated package of care from different specialist health service providers.

Carers' needs also include the provision of knowledge and support and nurses offer telephone support to all the patients and their carers who attend hospice day care. Family members/carers and patients have access to 24-hour telephone support from the specialist palliative care service. Hospice day care organised respite care for patients, either in the in-patient unit of the hospice or in the community, to give the carer a break from their caring role. Respite beds were sometimes difficult to obtain.

A DEEP CONNECTION

Patients who attended hospice day care were allocated a named nurse who cared for them while they were in hospice day care, which facilitated the development of a trusting relationship. The relationship between patients and the nursing staff also helped nurses to establish patients' needs—these can be fluid and changeable as their illness advances. Staff anticipate many issues for patients because of their experience and expertise in caring for terminally ill patients.

'I don't think I could manage without the day care ... it has been awful and I know things are going to get worse ... but they have been there for me and I know they will be there for me ... I couldn't manage without day care. They are always one step ahead.' (Carer/family member 08)

Over the period of time that the patient attends the service, hospice day care staff become very aware of each individual's circumstances and needs. As patients get to know and trust different staff members, they began to confide their fears and worries, as some patients were unable to talk to their family. Staff facilitated discussions with patients and family members/carers regarding plans for end-of-life care.

'I see others slipping each week I come in, I see them getting weaker and I know it's happening to me too.' (Patient 13)

Day care service facilitates and supports a deepening awareness of the reality of approaching death. Spiritual care is an important aspect of the palliative care model. People may return to religious practices and rituals at the end of life. The availability of chaplaincy and pastoral care in day care facilitated a spiritual connection and preparation for patients if they wished to have this. Hospice day care provided the space to allow patients to reconnect with their spirituality and religious practice, if desired.

'It was troubling me for a long time. I have not been to the sacraments for years ... I was talking to [a staff nurse in day care] and she offered me the choice of meeting the priest ... I went to confession and it's a weight lifted off my mind ... I am so relieved now.' (Patient 015)

Day care can be a bridge between home and the in-patient unit. The hospice, a cause for anxiety and concern at the beginning of patient and family contact with the service, can become a familiar and welcoming place. The relationship between patients and the day care staff can ease anxieties that patients may have about the in-patient unit. Many patients were brought on a tour of the whole hospice and this helped to reduce anxieties and made the hospice environment a familiar and safe place.

'And now that I'm in the hospice I've seen every part of it and I'm not afraid of it ... I want to die in the hospice.' (Patient 07)

CONCLUSION

The first impression of Hospice Day Care may be that this is a welcoming and pleasant social service, with the additional benefit of health care professionals being to hand. This impression slowly gives way to a deeper understanding of what is involved.

Underneath the veneer of social activities lies a complex myriad of interventions and interactions, all of which are focused on providing holistic care for patients with life-limiting illnesses and their family members/carers. The longitudinal nature of this research rendered these differing levels more visible, in a way that research focused on perceptions and experiences at one point in time may have been unable to do.

The transition to hospice day care can be a difficult one for many patients and family members. Staff within day care managed this transition in a way that enabled most patients to enjoy the physical surroundings, the social connections and the multi-dimensional aspects of care that patients may need. Beyond this, however, staff facilitated and supported patients and family members/carers in further transitions as the illness progressed.

Managing the growing awareness of the implications of a life-limiting illness and at the same time providing the necessary supports, at a time and pace that is highly individualistic, is a challenging service.

This type of care for people with life-limiting illnesses and their family members/carers is an ambitious model of care and one that requires very considerable resources. The benefits, however, are very clear.

The skill, expertise and experience of health care professionals from a number of disciplines have been brought together in a careful and considered way to improve the quality of life for patients and their families—in ways that are very finely tuned and individually balanced.

RECOMMENDATIONS

Hospice Day Care is a key service within the range of specialist palliative care services providing comprehensive and complex support for patients and their family members and carers. Service providers demonstrate considerable skill in navigating the internal and external services and in using their experience and expertise to help alleviate fears and anxieties about aspects of death and dying as well as specific anxieties about hospice services for patients and their family members and carers.

This longitudinal study has investigated the role of Hospice Day Care in the care of patients with terminal illness; a number of recommendations are made as follows:

Increase public awareness of hospice day care

- A significant barrier to engaging with the hospice day care was a lack of awareness and understanding of the day care services. There can also be a negative perception of hospices, as solely places where people go to die. These factors may lead to reluctance on the part of patients and their family members to engage with the service, in spite of the benefits that such engagement may bring. Greater public awareness of the service and of the range of positive activities, therapies and interventions would be of benefit.

Increase resource allocation for hospice day care

- This study has shown that the range of activities, therapies and interventions were of considerable benefit to patients and their family members/carers.
- The holistic care of patients and family members needs an interdisciplinary team approach, which requires considerable resources to maintain. A lack of adequate resources could lead to a dilution of the service and its resultant benefits.

- Funding is also required to increase the capacity of the service so that a greater number of patients and their families can avail of it. There is currently a waiting list for hospice day care.
- A reliance on volunteers for the provision of recreational and therapeutic activities can cause difficulty in maintaining a consistent availability of activities. Funding is required to increase the range and number of therapies and activities.

Carer support

- Current support needs to be extended and enhanced, for example by the provision of additional respite beds. Further research is required to identify the range of needs of carers and family members and how they can be adequately and appropriately supported.
- Family members and carers who look after patients at home do so at considerable cost to themselves—emotionally, physically and socially. They may also be engaged in this role for a long period of time.
- Hospice day care currently provides a level of support for family members and carers by providing respite for one day a week, enabling carers to have some time to themselves. Hospice day care also provides respite care in the in-patient unit of the hospice when this is warranted, although availability of this can be limited.
- The provision of regular telephone support for family members and carers keeps families informed about the patient's condition and any changes that may be occurring. Twenty-four-hour telephone support is available from the palliative care service.
- Current services could be extended and enhanced, in particular by the additional provision of respite beds. Carer support groups, as suggested in the literature, may also be of benefit, but further research is needed to identify the range of needs of carers and family members and how they can be adequately and appropriately supported.

Formalise continuity of care

Further research is needed to investigate the feasibility of formalising procedures for a continuity of care across a range of external health care services.

Health service providers in hospice day care frequently support patients and their family members/carers by negotiating with a range of external health care services regarding appointments, tests and services. Continuity of care can be of enormous benefit for patients and their families at a time of considerable stress.

Many of these positive interventions, such as the prevention of unscheduled admissions to acute hospitals, are largely invisible and do not generally appear as part of evaluations and audits.

Hospice day care is ideally positioned to coordinate end-of-life care. Formal recognition of this coordinating role as part of a care or case-managed approach involving community care and institutional care should be considered. A feasibility study would highlight the benefits and challenges of providing this service.





PALLIATIVE CARE
AND SERVICE PROVISION

1

INTRODUCTION

Palliative care services are provided across a range of settings—specialist in-patient hospices, community specialist palliative care services, and increasingly by specialist palliative care teams in acute hospital settings. A number of specialist palliative care services also provide day care services for patients. There has been an increase in the provision of hospice day care over the last twenty years in the United Kingdom and other European countries (Clark 2000). These services provide facilities for medical and nursing assessment and care, combined with social and therapeutic interventions provided by an interdisciplinary team (Goodwin *et al.* 2002). Little is known, however, about the impact of such services on the patients and their carers and how effective they are in helping individuals to manage the impact and changes occurring throughout the course of their illness.

Palliative day care potentially provides an extension of the support available to people in their home environment (Lawton 2000) and may also increase the continuity between in-patient and home care, easing the burden of responsibility on carers (Thompson 1990).

The National Advisory Committee Report on Palliative Care (Department of Health and Children 2001) has highlighted the crucial role played by hospice day care in supporting terminally ill patients and their family members and carers, but the efficacy of palliative day care within the Irish context is largely under-researched. This study originated in an effort to address this lack of empirical evidence and aims to explore the role of hospice day care in an Irish specialist palliative care service. It is hoped that this will assist in guiding and informing policy and service directions within specialist palliative care.

This chapter defines palliative care and the underlying principles upon which the model is based. It outlines the development of the modern hospice movement and the evolution of the specialism of palliative medicine, internationally and in Ireland.

There are current challenges facing the provision of services for an increasingly ageing population and to non-cancer patient groups, which are documented. Achieving the best possible quality of life for terminally ill patients and their families is a central goal of palliative care; how this is measured and achieved is considered in this chapter, in addition to how this is specifically achieved and evaluated within day care services. The broader sweep of palliative care across the spectrum of care, with a variety of therapies, interventions and supports for patients and their family member/carers, is discussed.

THE DEVELOPMENT OF PALLIATIVE CARE

The World Health Organisation (WHO) has defined palliative care as ‘an approach to care that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2005, 1). Ahmedzai *et al.* (2004) expanded this definition to state that ‘palliative care is the person-centred attention to physical symptoms and to psychosocial, social and existential distress and cultural needs of patients with limited prognosis in order to optimise quality of life of patients and their families and friends’.

Palliative care is the continuing active total care of patients and their families at a time when the medical expectation is no longer for a cure. Palliative care extends to support in bereavement and the goal is the highest possible quality of life for both patient and family, as defined by the patient, by maintaining dignity and controlling symptoms (Davies and Higginson 2005).

Background

Modern-day palliative care has developed from hospice care. Hospices, as places to care for the dying, have a long history and can be documented from the fourth century with the establishment by St Fabiola of a hospice for pilgrims. Medieval hospices were dedicated to the sick and dying and the Christian burial of the dead. The Irish Sisters of Charity opened a hospice in Dublin in 1879 and in London in 1904. Hospice is now a term that describes both a place and a philosophy of care that can take place in a wide range of care settings. ‘Hospice care’ and ‘palliative care’ are terms that are commonly regarded as being synonymous (Lawton 2000, 18); however, palliative care rather than hospice care is more widely used since the development of the medical specialism of palliative medicine (MacConville, forthcoming).

In the United Kingdom the current model of hospice care is one that has developed from the work of Dame Cicely Saunders. In the 1960s Saunders and other medical professionals became disillusioned with the care of dying patients in hospitals and established St Christopher’s Hospice in London as a community ‘inspired and informed by Christianity’ (Small 1998, 170). The community was described by Saunders as ‘the kind of family that can give the kind of welcome and hospitality of a good home’ (Saunders 1965). The ideal of the hospice movement was to provide a form of extended family which sought to provide patients with a more personal form of care and which stressed the importance of including the family as well as the dying person within the remit of care (DuBois 1980).

St Christopher's quickly became a model for future developments, inspiring other groups of people across the UK to set up their own services (Lunt 1985, 753). While the hospice philosophy is rooted in a Christian tradition, Saunders was also influenced by the work of Victor Frankl (1985). Frankl developed logotherapy, which focuses on the meaning of human existence and the human search for meaning.

Saunders stated that hospices were developed outside the NHS 'in order to move back in' (Taylor 1983). St Christopher's Hospice was opened in 1967, and an outpatient department was initiated in 1969 (James and Field 1992, 1367). By 1976 Saunders wrote that 'the growth of what has become known as the "hospice movement" now shows about 20 homes for terminal care throughout the UK and a dozen Marie Curie homes' (Saunders 1976).

While it was Saunders's intention that improved care for dying people and their relatives should become part of the mainstream, the form and structures of these improvements have been shaped by a number of factors. Ideological changes in the welfare state under Thatcherism and reforms in the NHS since 1991 have brought palliative care services further into the NHS organisational framework (Small 1998, 18).

James and Field (1992) have examined the routinisation and bureaucratisation of the hospice movement in an English context. They argue that while some of the changes and reforms have come from within the hospice movement, others, such as the establishment of palliative medicine as a speciality (by the Royal College of Physicians in 1987), have led to an increase in the medical imperative to intervene, marking a move away from the earlier, more holistic, hospice model. The re-medicalisation of hospices is exemplified by the change in terminology from 'terminal care' to 'palliative medicine' and the career-based developments of doctors specialising in 'palliative medicine'. James and Field contend that in some circumstances physical care dominates over social, psychological and spiritual care (1992, 1373).

International development of palliative care

Hospice or palliative care is now present in almost every industrialised country in the world: by the mid-1990s it had been established in every continent and in 21 countries (Saunders and Kastenbaum 1997), demonstrating its global spread in a relatively short period of time.

According to a study by Voltz et al. (1997), the number of hospice programmes in the US in 1997 was roughly 1,700. In Germany the first hospice institution was opened in 1983 and at the time of the study there were 21 palliative care units and eleven in-patient hospices. In Japan the hospice idea was first introduced by Christian and Buddhist initiatives but has now been taken over by the national health system. The first in-patient palliative care unit was established in 1981. By 1995 the government had approved fourteen palliative care units and in-patient hospices.

While formal integration into health care systems is at an early stage in most European countries, the development of hospital-based palliative care services has been established in the UK since 1977; by 1996 approximately 160 hospitals had palliative care services (McQuillan *et al.* 1996). Palliative care services are now considered at different levels of ascending specialisation: level one is the palliative care approach in which the principles of palliative care can be applied by all health professionals; level two is general palliative care which, at an intermediate level, may be available from a range of health care professionals who have had some additional training and expertise in palliative care; and level three is specialist palliative care, i.e. services that are limited to the provision of palliative care—the original hospice model (NCH-SPCS 1996).

PALLIATIVE CARE SERVICE PROVISION AND DEVELOPMENTS IN IRELAND

Clarke (2006, 1) has stated that 'Ireland has a rich culture of hospice and palliative care organisations involved in the direct delivery of care, as well as in grant-giving, fund-raising, advocacy and public education'. Palliative care services began in Ireland in the late nineteenth century when the Irish Sisters of Charity established Our Lady's Hospice for the care of the dying in 1879. Owing to an overwhelming demand, a larger facility for 110 patients was built in 1886. In 1928 the Little Company of Mary established Milford House in Limerick, which provided facilities for dying patients (Ling and O'Soirain 2005). The original hospices established in Dublin and Cork became incorporated into the health service and the evolution of palliative care commenced, supported by the establishment of the Irish Hospice Foundation in 1986 as a voluntary support organisation for the development and improvement of hospice services. The Irish Association of Palliative Care was established in the early 1990s to promote the development of palliative care throughout Ireland. The Irish Medical Council approved the recognition of the specialism of palliative medicine in 1995.

Local and voluntary organisations have played a large part in the initial development of hospice services in Ireland, as has also been the case in the UK. Palliative care services were initially established around the country largely owing to the 'strong and concerted efforts of various voluntary organisations' (Department of Health and Children 2001). The role of voluntary organisations has also been specifically recognised; in 1994 the Department of Health recognised that the voluntary sector plays 'an integral role in the provision of health and social services in Ireland, which is perhaps unparalleled in any other country' (Department of Health 1994, 10).

While the role of voluntary organisations in the establishment of palliative care services is acknowledged, this has led to the *ad hoc* establishment of services nationwide, with a number of different and independent organisations working within each health board area. The relationships between these

organisations and the health boards, in terms of reporting structure, funding and issues of responsibility, can, according to the National Advisory Committee on Palliative Care, lead to 'unsatisfactory and often divisive relationships' (Department of Health and Children 2001).

The development of palliative care in Ireland

The lack of a national policy on palliative care and the diverse range of services available around the country led the Irish Association of Palliative Care and the Irish Hospice Foundation to commission a survey of Irish palliative care services in 1993 (Igoe *et al.* 1997). All adult palliative care services (24 home care services, three in-patient services and one acute hospital service) in existence at the end of 1993 were contacted. Findings indicate that the palliative care service was largely a home care-based service for cancer patients (only 2% of care patients had another diagnosis). The survey also found a wide variation in staffing levels, workload, travelling, assessment of needs and finance arrangements. A major feature identified by the survey was the difficulty of providing an adequate service to a dispersed rural population, with a large difference in costs and work patterns between urban and rural services.

Arising out of the 1993 survey, a position paper (Irish Association of Palliative Care and the Irish Hospice Foundation 1996) was presented to the Minister for Health. This made a number of recommendations for the future development of palliative care services and addressed issues of funding, structures, standards, education and training. The establishment of a national policy for the development of services and greater partnership between the statutory and voluntary health groups involved in the provision of palliative care were also recommended. More recently, a report on primary care services has proposed that specialist palliative care could be delivered by primary care providers (Department of Health and Children 2004).

The National Advisory Committee on Palliative Care

The Minister for Health and Children established a National Advisory Committee on Palliative Care in 1999 to report on palliative care services in Ireland. The National Advisory Committee on Palliative Care report (Department of Health and Children 2001) provided a comprehensive overview of the development and level of current palliative care services and set out a number of key recommendations for the future development of services in line with developments in other countries. For instance, the committee recommended that palliative care should be structured in three levels of ascending specialisation: palliative care approach, general palliative care and specialist palliative care (a development of palliative care services, outlined above, and that these levels of care should be available in each health board area (*op. cit.*, 32).

A number of priorities were highlighted, including the completion of needs assessment to define the requirements of palliative care, which in turn will inform the implementation of a national policy on palliative care. The National Advisory Committee also noted the lack of research on palliative care in Ireland and has recommended that research be undertaken, especially to evaluate the effectiveness of different models of specialist palliative care (Department of Health and Children 2001).

A baseline study (Irish Hospice Foundation 2006) was conducted to measure the extent to which the report of the National Advisory Committee on Palliative Care (Department of Health and Children 2001) had been implemented within the state. This study highlighted major deficits in service provision and outlines the challenges to be overcome to fully implement all the NACPC recommendations. It was agreed that palliative care was an integral part of the Irish health service and that patients must be given a choice of their preferred place of care. This report stated that a flexible, patient-focused service should be provided in a variety of settings. The Advisory Committee suggested the provision of a regional specialist care unit that would provide support for services, education, training and research coordinated to meet the needs of each individual area. It also suggested that an integrated model of care with comprehensive services should provide care in a range of settings that include in-patient beds, community settings, acute general hospitals, day care and outpatient services. The NACPC recommended that palliative care should be structured in different levels of specialisation and that all levels of palliative care should be available in all settings (Department of Health and Children 2001).

Current palliative care service provision in Ireland

At present the delivery of palliative care services in the Health Service Executive (HSE) varies from and within each primary, community and continuing care local health area and within each hospital network, and is either directly provided by the HSE or in partnership with the non-statutory agency (Irish Hospice Foundation 2006).

Palliative care is provided in a number of hospices, and by palliative care teams in hospitals and in the home. There are currently eight hospices in the Republic of Ireland in various parts of the country, with almost all areas having some level of community palliative care services. Each specialist care in-patient unit has specialist palliative care teams working in the community. Most of the specialist palliative care units also provide a hospice day care service for patients, with the exception of two centres that have a day care unit in the absence of an in-patient unit.

There are currently four main modes of delivery of palliative care services in Ireland.

- *In-patient hospice care*: where patients are admitted to in-patient units for complex symptom management, respite care, complex psychosocial care, rehabilitation or terminal care.
- *Hospice day care*: where patients who are well enough to travel to the day care centre receive specialist palliative care and social support from an inter-disciplinary team.
- *Community palliative care*: where a palliative care team provides an advisory specialist palliative care service to patients and families in their own homes. Doctors and nurses, with the support of social workers, physiotherapists, chaplains and occupational therapists, predominantly deliver this service. Their role is to enhance the care given by the public health nurses, general practitioners and other community services.
- *Specialist palliative care services in acute hospitals*: referral to these hospital services is generally by the patient's hospital consultant.

Future demands for palliative care provision

There will be an increasing need for palliative care service provision in Ireland. This will arise firstly from the changing demographics in Irish society and secondly from the ethical imperative to provide palliative care services for non-cancer patient groups.

Changing demographics

Like other European countries, Irish society is facing an increasingly ageing population. In the next ten years there will be a significant increase in the number of people aged over 65 in Ireland (Central Statistics Office 2006). Currently 11% of the population is over 65 years, but this figure is expected to rise to 15% by 2016 and to 25% by 2050. The prevalence of malignant and non-malignant diseases increases as the population ages.

Almost 30,000 people die annually in Ireland, and cancer is responsible for a quarter of all deaths here. According to the Strategy for Cancer Control Report (Department of Health and Children 2006), one Irish person in three will develop invasive cancer, and one in three of these will die from it. Approximately 20,000 Irish people develop cancer per annum, and approximately 7,500 people will die of the disease each year. About 60% of cancer patients die of the disease within five years of diagnosis. By 2020 the average number of cancers with the most terminal prognosis is set to double to nearly 29,000 per year. This increase will occur mostly as a result of demographic changes (National Cancer Registry 2006). The anticipated increase in cancer and in the ageing population will undoubtedly place a burden on Irish cancer and palliative care services.

The number of cancer deaths is expected to rise to approximately 9,300 by 2016. It is predicted that there will be a major increase in the common cancers (breast, lung, bowel, prostate and skin) that will receive new treatments that will reduce mortality and extend the period of time for which palliative care will be required (Department of Health and Children 2003). Patients with cancer typically experience a steady decline over a few years, with a relatively short terminal phase often lasting less than six months (Bomba 2005). There is some unpredictability as regards the terminal phase, based on the type and site of cancer. Multiple symptoms (pain, nausea, breathlessness, fatigue, weight loss) are indicators of the need for specialist palliative care services. It is likely that by 2016 approximately 6,500 people will have a need for specialist palliative care services (Irish Hospice Foundation 2006).

Extension of services to non-cancer patient groups

A current challenge for palliative care is the extension of the service to other, non-cancer, patients, which has been advocated since 1980 (Wilkes 1980). Addington-Hall and Higginson (2001) have outlined the current arguments for inclusion of other patient groups. The physical, emotional and spiritual needs of dying patients and their families are not exclusive to cancer patients, and cancer patients cannot be considered to have a monopoly on suffering (Wasson and George 2001, 240). The aims of palliative care—such as holistic care, maintaining quality of life and dignity, family and carer support—are seen as equally applicable to non-cancer patients.

A move to extend palliative care services to patient groups other than cancer and motor neuron disease has been advocated within the Republic of Ireland (Irish Hospice Foundation 2008). Services for patients with illness other than cancer, including Chronic Obstructive Airways Disease (COAD), dementia and heart failure, are currently disjointed and limited in Ireland. These conditions have been selected as suitable for inclusion in the extension of palliative care services in Ireland in a programme initiated and funded by the Irish Hospice Foundation—Palliative Care for All. It is also argued that specialist palliative care services should accept referrals based on need and not on diagnosis, and that patients, as their needs become more complex, should have equal access to all levels of palliative care.

APPROACHES TO DEATH AND DYING

The modern hospice movement and the subsequent professional development of palliative care services arose primarily from the work of Dame Cicely Saunders in the UK, as previously discussed. Alongside this development, interest in issues of mortality and the experiences of death and dying have grown considerably from the 1960s. Over the last 40 years theoretical understandings of the experiences of death and dying have been developed (Glaser and Strauss 1967; Kübler-Ross 1969; Pattison 1997; Corr 1992; Buckman 1993; Copp 1998).

Awareness of death and dying

The work of Glaser and Strauss (1967)—based on research into the organisation of dying in San Francisco Bay area hospitals—concerned the way in which awareness about death was managed and communicated. This was particularly influential in the debate on communication and awareness about dying in modern western societies, especially so within the model of palliative care. Glaser and Strauss identified four ‘awareness contexts’—closed awareness, where staff kept patients ignorant of their impending death; suspicion awareness, where patients suspected that they were dying and tried to get staff and relatives to confirm this suspicion; mutual pretence, where all parties knew that the patient was dying but did not acknowledge this, pretending that ‘everything was normal’; and open awareness, where all parties knew and acknowledged that the patient was dying and were therefore able to talk about it.

Since the 1960s there has been a considerable shift from closed awareness to open awareness. This trend is particularly evident in the United States. For instance, a study published in 1961, ‘What to tell cancer patients’ (Oken 1961), showed that 88% of doctors would not normally tell cancer patients their diagnosis. Novak *et al.* (1979) replicated this study in the 1970s and found that 98% of respondents would usually tell their patients the prognosis.

Kübler-Ross and stage theory

A key figure in the area of death and dying, particularly in the United States, is Elisabeth Kübler-Ross and there are elements of the psychological, the spiritual and the existential in her work. Kübler-Ross observed the isolation of dying patients and a lack of attention to their needs, and, like Saunders in the UK, promoted holistic care of dying people (Small 1998, 175). She developed a stage theory of dying, based on work with over 200 dying patients, and observed that, in coming to terms with a terminal illness, many patients went through stages of denial, anger, bargaining, depression and acceptance (Kübler-Ross 1970).

The stage theory developed by Kübler-Ross was very influential in understanding the experiences and needs of dying people; however, Copp (1998) maintained that Kübler-Ross’s theory gained acceptance largely because it filled a void in health care theory. Questions have also been raised about the adequacy and validity of this stage theory (Weisman 1974; Charmaz 1980; Kastenbaum 1985). A major criticism is that it is too mechanistic an approach as it fails to consider that, while in practice most dying people experience all of these stages, they may not follow any order or they may not experience all of the stages. Dying people may also move in and out of these feelings at different times or they may experience several of them at the same time.

Towards an individual perspective

Attempts to find more individualistic and fluid conceptualisations of the experiences of death and dying have been formulated by Buckman (1993), who proposed a three-stage model of the process of dying and stated that people will react to their impending death according to the way in which they reacted to difficulties in their past. Buckman’s three stages—an initial stage, a chronic stage and a final stage—viewed the emotions of patients as a gauge for understanding which stage a patient is passing through. Pattison (1977) put forward a trajectory of living and dying, also with three phases—the living dying interval, the acute crisis phase, and the terminal phase—and allied to the feelings and reactions of the dying person. His theory, however, does not take into account that dying may not always be a downward trend, as some people may experience a plateau and then enter a terminal phase rapidly. Copp (1998) has built on previous theories of death and dying to incorporate individual awareness of time and duration of dying. Her work drew attention to ‘the notion of separating body and self as a paradigm for understanding the manner and readiness of dying’ (Copp 1998, 388). Specifically, Copp conceptualised a ‘readiness to die theory’, which consists of ‘person ready/body not ready’, ‘person ready/body ready’, ‘person not ready/body ready’ and ‘person not ready/body not ready’. This model illustrates a body/person split, and adds a further dimension to understanding the process and experience of death and dying. In particular, the model highlights how hospices manage real-life situations in a conceptual way, but as this theoretical model is based on work within hospice care and with cancer patients it may not be widely applicable to other settings and illnesses.

THE PRINCIPLES OF PALLIATIVE CARE

Lawton (2000) has argued that the modern hospice movement formed part of a broader cluster of social movements that shared a number of features. There is, according to Lawton, a distinct parallel between the hospice and alternative health movements, as both advocate that the patient should be seen as a 'whole person' (2000, 14). The holistic view of the patient and the emphasis on death as a natural event have shaped and informed the principles of palliative care, which are open awareness and communication and the concept of 'total pain'.

Communication and open awareness

The modern hospice movement formulated ways to understand the experiences and needs of dying people and how they could be addressed—through communication, listening and supporting both the patient and the family. Alongside the work of Saunders, the work of Glaser and Strauss (1965) was influential in the debate on communication and awareness about dying in modern western societies, as previously outlined.

There are several reasons why open awareness about death and dying became more common and why it is currently considered very important in palliative care. Improved health care, and in particular improvements in the treatment of cancer, makes a prognosis clearer; it also means that many people spend a longer time living with incurable illness. As a result, it can be more difficult to hide the truth about a terminal illness, or at least more difficult to manage non-disclosure (Walter 1994, 32). McNamara *et al.* (1994) contend that while formalised hospice objectives do not state disclosure norms regarding impending death, open communication concerning death seems to be the 'preferred interaction between patients and nurse and a path toward a "good death"'.

In spite of an ideological commitment to open awareness and a wish for full information, there is now recognition that while patients and family have a right to full information and may wish to have this, they may be unwilling to be continually reminded that they are dying (Field and Copp 1999, 466). The consequences and implications of this position may create emotional and professional tensions which doctors and nurses must manage in such a way as to facilitate informed patient choice (*ibid.*, 465).

Open awareness in an Irish context

There are considerable cultural differences with regard to the appropriateness of open awareness about death and dying. Seale (1998) argues that the Anglo-American culture of individualism is at the heart of the growth of the patient-centred approach to relationships between health

professionals and patients. In other cultures, however, there is not necessarily the same individualism. A study conducted in Italy (Surbone 1992) argues that this idea of patient autonomy is, in an Italian context, considered as patient and social isolation. In this context the protection of the patient by the family, considered negatively as collusion or denial in awareness contexts (Faulkner *et al.* 1994), is understood as protection and as shouldering the burden of knowledge for the patient (Seale 1998, 112).

The views expressed by some Irish people regarding communication around death and dying are varied and may reflect cultural differences. An analysis of a discussion about 'breaking bad news' to terminally ill people that took place over four days in November 2003 on the daily radio chat show *Liveline* documents the responses of nineteen callers who related their own experiences and their views on the appropriateness of telling people of a terminal prognosis. This describes the way in which health care professionals delivered this news (MacConville and McQuillan 2009) and concludes that while open awareness may be an ideal of palliative care, cultural differences may make it more difficult to implement.

The concept of 'total pain'

The palliative care model is the holistic care of the patient and the family and encompasses four dimensions: emotional, physical, social and spiritual. It operates to a holistic model of pain incorporating the idea of 'total pain'—pain is present on the physical, emotional, social and spiritual levels (Baines 1990, 26). This concept was developed from the work of Saunders, who observed that once the physical symptoms and pain were managed and controlled, patients often revealed their emotional, psychological or spiritual concerns about death and dying. The concept of 'total pain' is also a development of the Gestaltian idea that a dying person's physical, emotional, social and spiritual concerns are inextricably entwined and each contributes to a 'total pain experience' (Lawton 2000, 13). It is understood, however, that physical pain often masks pain on other levels, and that emotional or social pain can exacerbate physical pain (Baines 1990, 28).

Interdisciplinary team working

The aims of palliative care are ambitious, as they include meeting multi-dimensional needs. Palliative care also provides support to the family as they experience bereavement and grief, and extends to preparing the patients and the family for the dying process and death, in addition to the management of that process. This multi-dimensional and multi-layered care is considered to be 'most effectively delivered by an interdisciplinary team which may complement and enhance disease-modifying therapy or alternatively become the total focus of care' (Higginson and Cosstantini 2008, 235).

In order to address the multi-dimensional aspects of pain, palliative care draws on the expertise of different professionals. Abu-Saad states that the goal of interdisciplinary palliative care is the provision of excellent care, taking into consideration the complexity of care provided, the utilisation of the appropriate skills provided by the team members and minimisation of fragmentation of care (2001, 21). According to Abu-Saad, the dynamic of interdisciplinary team working is one of mutuality, respect and interdependence.

PALLIATIVE CARE DAY CARE SERVICES

There has been an increase in the provision of hospice day care over the last twenty years in the United Kingdom and other European countries (Clark 2000). The aim of palliative care day care services is to improve quality of life by providing interdisciplinary holistic care and opportunities for rehabilitation within disease constraints (Corr and Corr 1992; Spencer 1998). These services provide facilities for medical and nursing assessment and care, combined with social and therapeutic interventions provided by an inter-disciplinary team (Goodwin *et al.* 2002).

The purpose of day care services is not just to maintain people but also to give them the ability to move on with normal life (Low *et al.* 2005). Palliative day care potentially provides an extension of the support available to people in their home environment (Lawton 2000) and may also increase the continuity between in-patient and home care, easing the burden of responsibility on carers (Thompson 1990). Day care services provide a range of services and activities that straddle the boundaries of social health and social care (Higginson *et al.* 2000).

Little is known, however, about the impact of such services on the patients and their carers and how effective they are in helping individuals to manage the impact and changes occurring throughout the course of their illness. Most evaluation studies of these types of services have been descriptive and have focused on identification of the services provided (Low *et al.* 2005). One such evaluation (Goodwin *et al.* 2003) found no difference in quality of life outcomes between patients using day care services and those receiving home care. A difficulty in evaluation may be that the palliative care day care services cannot be measured using existing QOL measures (Low *et al.* 2005). It has also been found difficult to evaluate ongoing services (NICE 2004).

Quality of life

The definitions of palliative care proposed by the WHO (2005) and Ahmedzai *et al.* (2004) emphasise the focus on optimising quality of life for patients with limited prognosis and their families and friends. Quality of life, however, is a difficult concept to define and measure; it has a usage across many disciplines—literature, philosophy, politics, health

promotion, medicine and the social sciences (O’Boyle and Waldron 1997). The WHO Quality of Life (WHOQoL) working party has provided the following definition of quality of life: ‘Quality of life is defined as the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person’s physical health, psychological state, level of independence and their relationship to salient features in their environment’ (*ibid.*, S20). This definition underpins the development of the WHOQoL core measure, specific editions of which are planned for various groups such as cancer patients (Szabo 1996).

A rehabilitative approach

Miller *et al.* (1980) define rehabilitation as ‘...a coordinated, inter-disciplinary program to restore an ill or disabled individual to his or her maximum capabilities in physical, mental, social, vocational and economic usefulness’ (1980, 1221). In a palliative care setting, however, it may be unrealistic to expect a restoration to economic usefulness when facing a far-advanced cancer. It may be more important to provide assistance to the patient and family to cope with end-stage disease. Hockley (1993) suggests that for patients with advanced cancer, rehabilitation may be viewed as a process of adapting to the changes that are occurring and using an active approach in managing complex symptoms. Rehabilitation is the process of ‘...helping a person to reach the fullest physical, psychological, social, vocational, and educational potential consistent with his or her physiologic or anatomic impairment, environmental limitations, desires and life plans’ (Delsia *et al.* 1998, 132). Nocon and Balwin (1998) defined the primary objectives of rehabilitation as the ‘restoration (to the maximum degree possible) either of function (physical or mental) or role within the family social network or workforce’ (1998, 23). The application of a rehabilitative model of care to service delivery in hospice day care is appropriate for terminally ill people (Tookman *et al.* 2004). An integrated model of rehabilitation enables patients to be assessed and for appropriate care to be provided as their needs change with advancing disease.

Measuring quality of life in palliative care day care services

There is a question of whether the measurement of outcomes is appropriate when judging the value of palliative care day care services (Douglas *et al.* 2000). There are limitations in using QOL measures to identify the effects of palliative care day care services, as the benefits that patients particularly value are more likely to be in the social, psychological and spiritual domains than in the more ‘traditional’ medical and more easily measurable areas of QOL and symptom control (Goodwin *et al.* 2002).

A recent study, 'Palliative day care—a study of well-being and health-related quality of life' (Andersson Svidén *et al.* 2009) sought to study the outcomes of palliative care day care. Specifically, the study focused on the health-related quality of life and emotional well-being of a group of cancer patients attending day care and a group not attending day care, over a period of five weeks. This study utilised two QOL measures: the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30) and the Mood Adjective List (MACL). The results showed higher levels of emotional well-being among those patients attending day care than those in the comparison group using the MACL, although this was not statistically significant. The study found similar levels of functioning between the two groups when measured using the EORTC QLQ-30 scale.

The authors argue, however, that there are problems with both of these measures. Palliative care day care interventions focus on achieving better well-being in spite of the deteriorating health of the patients and the EORTC QLQ-30 does not capture the complexity of emotional well-being. The authors suggest that the interventions of palliative day care are probably better assessed using a measure that is not health-related. The MACL measure was found to be more sensitive to day care interventions, as these appear to improve or maintain well-being despite the fact that functioning and symptoms remain unaffected (Andersson Svidén *et al.* 2009). These authors recommend that future studies evaluating palliative care need to consider the use of alternative study designs.

Qualitative evaluation of palliative care day care

A recent study adopted a qualitative approach in evaluating the impact of palliative care day services and was based on the experiences of patients, informal carers, day unit managers and volunteer staff (Low *et al.* 2005). This study utilised focus group discussions to explore views regarding four areas—perceptions of the benefits of palliative care day care; the impact on quality of life; perceptions of the challenges facing day care services; and the challenges in delivering the service.

Access to palliative care health professionals and the availability of these professionals in one place was considered by patients to be the main benefit of the service. In particular, most patients highlighted that they felt more comfortable in discussing certain issues with these staff rather than with, for example, their GPs, who were perceived as being too busy and not specialists in cancer care.

The ability to access these professionals provided patients with the security and peace of mind that any health problems could be dealt with. Patients also expressed a high level of trust in palliative care professionals and had confidence that they would manage any problems that arose quickly and effectively as their condition was being monitored through attendance at day care (Low *et al.* 2005).

The input of allied health professionals, such as physiotherapists and occupational therapists, was welcomed and was often the main reason for some patients to attend. Patients saw treatment from these professionals as the opportunity to improve their physical functioning or mobility (Low *et al.* 2005).

Peer support was the overwhelming benefit for most patients attending day care. In this study patients spoke about the freedom to talk and be open with one another, which they felt was limited at home as they were trying to protect their families. Most patients used day care as a forum for support and to share information; they perceived this kind of peer support as extremely positive, enabling them to cope with problems and to have some control and independence. This was especially true of patients who lived alone and had few opportunities to socialise. For this group, palliative care day care was frequently a highlight of the week, reducing feelings of isolation and offering a different outlook on life.

Patients also appreciated the opportunity to access complementary therapies, as many perceived that these provided them with a positive attitude, a feeling of well-being and increased confidence. Patients explained that the activities in day care gave them an opportunity to sit and chat together and provided them with a sense of achievement and an increase in self-esteem.

Respite was the main benefit identified by carers as this gave them the opportunity to have time to themselves, although this was of less benefit to carers who had other ongoing responsibilities, such as young children to care for. An additional benefit for carers was the support from the service in dealing with their own fears of the unknown, and they considered the service a place where they could seek advice, if necessary, from specialists who had an intimate knowledge of their family member. The study found that in centres where carer support groups had been established, carers were able to discuss their roles and the issues that were important to them with other carers in a safe environment.

In this study, the purpose of day care was seen as not just to maintain people but also to give them the ability to move on with a more normal life. This led to patients being discharged from the service when appropriate. Discharge, however, caused difficulties for patients and carers, who found it difficult to imagine life without it. In addition, volunteers were concerned that, following the withdrawal of these specialist services, patients and carers would lose their feeling of peace and calm. Day Care Unit managers in this study valued the role of volunteers and recognised the importance of their contribution, especially in the provision of complementary therapies. Managers found some difficulties, however, particularly in terms of development and in relation to awareness of professionals' boundaries.

Low *et al.* (2005) conclude that all stakeholders saw the main benefit of palliative care day care in terms of accessing specialist health professionals and providing social and peer support, and these findings are supported by other studies (Langley Evans and Payne 1997; Scheffer 1998; Payne *et al.* 1999; Holmes 2001; Hopkinson and Hallett 2001; Lee 2002; Goodwin *et al.* 2003).

A SPECTRUM OF CARE

Interdisciplinary teams, which are a fundamental part of the palliative care model, can be constituted in a number of ways but most frequently include professionals from nursing, medicine and social work. Teams may also include contributions from other disciplines, such as occupational therapy, physiotherapy, complementary therapy and chaplaincy, depending on organisational structures and resources. Within palliative care, the holistic model of care demands a broad-based interdisciplinary approach, as the previous discussion of the underlying principle of 'total pain' suggests.

Connectedness

As a holistic model of care, palliative care seeks to address the multi-dimensional needs of people with life-limiting illnesses and their families. In paying attention to the whole person, it may need to facilitate a process of connection—with elements of people's lives and/or selves that have become disconnected over time and through their life experiences. Connectedness is a fundamental human need (Townsend and Whirter 2005) and people have a need for regular positive interactions with others (Baumeister and Leary 1995). A lack of connection can impact negatively on health, adjustment and well-being (Moen 1998; Rude and Burham 1995), in addition to imparting a sense of social isolation and a lack of meaning and purpose in life (Baumeister and Leary 1995).

Connectedness is a fundamental factor in human development and is both a protective factor in preventing problems and an aid in helping to resolve inter/intra-personal concerns (Karcher 2002). Connectedness can be considered a sub-state of the broader term 'relatedness', used within the field of psychology. Hagerty *et al.* (1993) define relatedness as an individual's level of involvement with persons, objects and groups or natural environments, and the level of comfort or discomfort associated with that involvement. Furthermore, a capacity for relatedness, on individual and societal levels, can act as a health-promoting agent (Townsend and McWhirter 2005, 192).

The concept of relatedness has its origins with theorists such as Klein (1964), who built upon Freud's ideas of drives and instincts and began to consider individuals' relationships with the external world and specifically to other people.

Attachment theory (Bowlby 1969) provided a basis for studying early parent-child processes that lead to development and conduct of human relationships. Relatedness is a functional behavioural system rooted in early attachment behaviours and patterns (Bretherton and Waters 1985). Drawing on social psychology, it was proposed that in early life people express and satisfy their need for belonging through identification with and participation in the social world (Baker and Baker 1987; Kohut 1984; Wolf 1988). These social expressions are gradually organised into cognitive representations of the self in relation to the other.

Social connectedness reflects this internal sense of belonging and is defined as the subjective awareness of being in a close relationship with the social world. These relations include both close and distant relationships with family, friends, peers, acquaintances, strangers, community and society (Lee and Robbins 2000). It is the aggregation of all these experiences, which are gradually internalised by the individual, that serves as the foundation for a sense of connectedness. People with high levels of connectedness are better able to manage their own needs and emotions through cognitive processes, for example self-evaluation and self-comparison (Tesser 1991). This resourcefulness makes people less prone to low self-esteem, anxiety and depression (Kohut 1984). Individuals who are out of touch with their social world experience feelings of loneliness, isolation and alienation.

Hagerty *et al.* (1993) have devised a model to demonstrate differing levels of connectedness or involvement with other people, social situations and the environment, with an according level of comfort or discomfort. They contend that four states of relatedness are present—connectedness, disconnectedness, enmeshment and parallelism.

According to this model, people experience *connectedness* when they are actively involved with another person, object or group, and this involvement thus gives a sense of ease and comfort. *Disconnectedness* occurs when a person is not actively involved with another person, object, group or environment, resulting in unease, anxiety, loneliness and social isolation. *Parallelism* occurs when a person's lack of involvement with another person, object, group or environment is experienced as comfortable, and *enmeshment* occurs when people's involvement with others, objects, groups or environments causes both discomfort and anxiety.

Reconnecting

Lawton (2000), in her UK study of palliative care, has described the sense of isolation and disconnection experienced by many patients in hospice day care. She argues that, for many patients, their experiences of their illness and deterioration led them to a 'debasement of self' and a disengagement from the 'matrix of social relations' within which they were previously located (*ibid.*, 41). She further

contends that patients can become increasingly estranged from normal frameworks as 'their future cannot be mapped out' (*ibid.*, 42).

Hospice day care seeks to address this sense of disconnection. In addition to the provision of social activities and access to health care professionals, hospice day care services may also provide a range of therapies and interventions to assist in this process of reconnecting, if this is appropriate and desired by the patient and their family members/carers.

Physical therapies and interventions

There is a scarcity of literature examining the use of physical therapies within hospice day care service, although Santiago-Palma and Payne (2001) argue that, as disability in patients with advanced cancer often results from bed rest and neurological and musculoskeletal complications of cancer or cancer treatment, rehabilitation and palliative care are two important parts of comprehensive care for patients with advanced disease. Palliative care and rehabilitation share common goals and therapeutic approaches, with an interdisciplinary approach that aims to improve patients' levels of function and comfort. These authors argue that, while there is a scarcity of evidence in this area, clinical experience suggests that the application of the fundamental principles of rehabilitation medicine is likely to improve care. They further argue that physical function and independence should be maintained for as long as possible, not only to improve patients' quality of life but also to reduce the burden of care for the caregivers. One recent study has considered patients' experience of physical therapy within palliative care (Dahlin and Heiwe 2009) and found that it was important, enabling independence, providing relief from distressing symptoms and offering a level of support for patients. These authors contend, however, that good interdisciplinary team communication is required for the full benefits of these interventions to be realised.

While more studies are needed to evaluate the impact of physical therapies on patients with life-limiting illness, two studies have considered the experiences of occupational therapists in providing therapy for terminally ill patients. Rahman (2000) explored the perspectives of occupational therapists in their role in hospice, regarding whether they experienced a conflict in supporting the dual status of living and dying for individuals with terminal illness. While the role may appear to be in conflict with their role in relation to other patients, Rahman found that the respondents in this study felt that occupational therapy played a significant role in helping individuals with a terminal illness to live life more fully and comfortably while facing death. In addition, occupational therapists used a holistic approach in their work by addressing physical, social, emotional and spiritual aspects of care. The experience of working with terminally ill patients seemed to generate a 'personal-professional connection' between professionals and their patients in a study (Prochnau

et al. 2003, 196) examining the experiences of occupational therapists working in palliative care, with respondents finding satisfaction and enrichment in this work.

Complementary therapies

Eisenberg *et al.* (1998) contend that there is a worldwide increase in the use of complementary therapies within palliative care. Palliative care has been at the forefront of incorporating such therapies into orthodox care. Seventy per cent of palliative care units offer complementary and alternative medicine (Thompson *et al.* 2007), thus indicating the growth of complementary therapy. Therapies are seen as being an integral part of the hospice's provision and valuable as a means of introducing people to other services offered by the hospice (Penson 1998).

The development of complementary therapy in conjunction with conventional medicine can promote relaxation and emotional and psychological well-being, and can have a positive impact on the quality of life of individuals with life-limiting illness. Massage therapy, with its variety of approaches and applications, is increasing in popularity and is used with clients seeking benefits such as relaxation, feelings of well-being, improved circulation and reduction in anxiety and pain (Smith *et al.* 2009). Research conducted by the Marie Curie Cancer Care in London provides some clinical evidence of the benefits that these therapies can offer cancer patients. Results (Wilkinson *et al.* 1999) revealed a statistically significant reduction in anxiety after each massage, and patients who received aromatherapy massage also noted improvements in their disposition, physical comfort and quality of life.

Cassidy (2002) argues that the application of the four essential elements of massage—hands-on practice, touch, communication between patient and practitioner, and practitioners hoping to address the 'whole patient'—within a holistic environment promotes an interactive and relatively egalitarian therapeutic relationship.

Massage therapy represents the treatment of choice for a significant number of people '...seeking greater levels of control and empowerment over their lives' (Coulter and Willis 2004, 558). The non-specific effects of a 'quiet time alone with a caring therapist' have also been reported as contributing to outcomes of massage therapy sessions (Patterson *et al.* 2008, 174). As such, treatment outcomes are not completely biomedically based but rather may involve the psychosocial processes such as caring, comfort, communication, active participation, sense of control and being understood. Developing an understanding of the massage process, and therapeutic relationship variables such as comfort, contact, connection and caring that may, Smith *et al.* (2009) argue, collectively contribute to the culture of care, requires listening to those who use these services in order to understand their needs and perceptions.

A spiritual connection

Spiritual care is an essential element of the palliative care model, but definitions of spiritual care are difficult to pin down. The literature on spirituality emanates from a wide number of disciplines yet there is no agreed definition (Dyson *et al.* 1997; Greasley *et al.* 2001; McSherry and Draper 1998). There are, however, many related concepts that are common across disciplines, for example relationship, meaning, purpose in life, energy, and emotions such as forgiveness and hope. Connectedness is one of the most consistently identified concepts of spirituality (Burkhardt and Nagai-Jacobson 2002; Chiu 2000; Reed 1992; Sherwood 2000) and is usually understood as connectedness within oneself, with others, with nature or with a deity (Bellingham *et al.* 1989; Reed 1992; Schubert and Lionberger 1995).

The relief of suffering is one of the goals of medical care, and may become the primary goal when illness is incurable. To relieve suffering, health care providers must be skilled in treatment for pain, but they may also be called upon to attend to emotional and existential causes of suffering. Spiritual care is one way to address these needs.

Minor-Williams (2007) has observed, from her grounded theory study on the nurse–patient relationship, that at times patients present with needs emanating from deep within the person, needs that can be considered needs of the spirit. She further observes that under certain conditions—with a nurse who is competent and willing—a meaningful process evolves which not only meets these needs of the spirit but strongly impacts on the nurse, the patient or both, and promotes healing, growth and comfort. In this process there is a ‘connectedness’ in the nurse–patient relationship (*ibid.*, 1234).

As patients and families face serious illness, access to clergy and to faith communities diminishes. Strategies to meet the demand for spiritual care could include expanding the presence of clergy in health care. Nevertheless, in a study focused on exploring the types and providers of spiritual care in serious illness, Hanson *et al.* (2008) found that seriously ill patients and family caregivers experience spiritual care from multiple sources, including health care providers. For families and patients in this study, being spiritually cared for was more important than who gave that care. As the authors argue, even taking a ‘spiritual history may honour the patient’s need to be seen as more than a physical being and health care providers can learn this skill’ (*ibid.*, 913).

Religious rituals and practices are a pertinent part of spiritual care (Kellehear 2000), and some studies suggest that religion is a common coping mechanism with positive effects in relation to adjustment (Dein 1997, 295). In a study exploring the variety of understandings of spirituality in an Irish hospice, MacConville (2006) found that traditional religious practice was still very important to many of those cared for there. The presence of nuns and priests in the hospice also seemed to be

reassuring to patients and family members. Although there was an expectation that older people have a stronger religious adherence, and many did, younger people also demonstrated religious belief and drew strength from it at the time of illness. Comfort was derived from belief in an afterlife but also from the familiar rituals and language of religion, both by the person who was dying and by family members and staff. Religious practice can also be seen as activities that comfort and support people who are seriously ill as they search for meaning and for connection to what is infinite or transcendent.

Kellehear (2002) argues that the desire for transcendence has situational, moral, biographical and religious sources, and states that in each of these areas there is a need for community connection and for social action rather than simple discussion with health professionals (*ibid.*, 170). While acknowledging the importance of listening, discussion, counselling and joint reflection with professionals, he suggests that ‘the major role lies with the person with the terminal illness, with his or her self and with his or her usual social world’ (*ibid.*, 171). Spiritual needs, therefore, have a large community-based component, with friends and family, a component that is recognised within the model of palliative care.

Supporting family members and carers

Holistic palliative care includes the care of the family as well as the person with a life-limiting illness, as the WHO (2005) definition states. The provision of care and support for family members is enacted across all the domains of palliative care services—community, in-patient and day care. The provision of community specialist palliative care services helps to keep terminally ill patients at home for as long as possible (Irish Hospice Foundation 2006). Community palliative care team visits are usually weekly and may become more frequent as the illness progresses and symptoms more complex and difficult to manage. Additional assistance is available through the Irish Cancer Society-funded night nurse service. The main carers, however, are generally family members, friends and neighbours (Neale 1993).

Numerous studies have identified a clear need to support family members and carers. Caring can frequently be physically and emotionally costly and, in the case of palliative care, the level of anxiety for carers can be extremely high. Hinton (1994) states that maintaining the terminally ill person at home is dependent upon material, social and professional support being available to the carer. Family members/carers can experience mental, emotional and physical ill health, in addition to high levels of burden, when caring for an individual in the home (O’Connor and Ruddle 1998; Blackwell *et al.* 1992; O’Donoghue 2003).

Northouse and Peters-Golden (1993) state that carers who seem to be coping in their caring role and do not request services or help are assumed to have no unmet needs; thus services may only respond in crisis situations. Brown and Stetz (1999) argue that the valuable contribution that caregivers make is frequently of much longer duration than is acknowledged by health care professionals. They also suggest that collaborative relationships between family members and health care providers can be critical components of ongoing family assessment. Proot *et al.* (2003), in a study on the vulnerability of informal caregivers, argue that existing supports are not sufficient and that there is a need to identify family members caring for terminally ill persons who are at high risk of burn-out; it is also recommended that family needs in terminal care be assessed and monitored on a regular basis. The carer support groups identified as supportive in the Low *et al.* (2005) study could be a potentially positive aspect of family and carer support.

An in-depth case-study by the Canadian Hospice Palliative Care Association (Wilson 2004) found that if carers are not supported by services they may experience burn-out and long-term negative consequences. Wilson argues that 'timely care is critical to the identification of potential or existing problems, the prevention of problems, and the early and successful resolution of problems' (*ibid.*, 273). In addition to material needs, carers' needs may also include the provision of knowledge and support (Payne *et al.* 1999; Soothill *et al.* 2001; Higginson and Gomes 2002). In this regard, Cox (1993) has highlighted the benefit to carers of a specialist telephone support service. Family education and support can be a significant preventive health care strategy and can contribute to reducing or avoiding subsequent crises (Brown and Stetz 1999).

Several Irish studies have shown that family carers experience mental, emotional and physical ill health alongside high levels of burden when caring for an individual in the home (O'Connor and Ruddle 1998; Blackwell 1992; O'Donoghue 2003). An extensive study on family carers in Ireland by Care Alliance Ireland (2008) examined the health status of a random sample ($n=2,834$) of family carers. The results showed that family carers were less likely to report themselves in excellent or very good health in comparison to the general population.

Patient- and family-centred care is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships between patients, families and health care practitioners (Kovacs *et al.* 2006). This approach to care is a basic tenet of palliative care philosophy that recognises the terminally ill patient as part of a family. Family-centred care is based 'on the understanding that the family plays a vital role in ensuring the health and well being of patients' (*ibid.*, 16). The ultimate goal of patient- and family-centred care is to create partnerships between health care practitioners, patients and families that will lead to the best outcomes and enhance the quality and safety of health care for the patient (Davies 1994).

SUMMARY

This chapter has outlined the development of palliative care, internationally and nationally. Current and future needs for palliative care service provision in Ireland have been detailed. The underlying principles of this model of care—open awareness and communication about death and dying and the concept of 'total pain'—have been outlined. Quality of life issues are central in the provision of palliative care, and the difficulties of finding adequate ways to assess the impact and value of interventions with this patient population have been documented. Qualitative approaches to evaluation of palliative care day services have been reviewed, and the impact on family members of caring for terminally ill patients at home have been outlined. This chapter has also explored the spectrum of care, through a range of interventions, therapies and support, that palliative care services provide.



RESEARCH
METHODOLOGY

2

INTRODUCTION

This chapter outlines the research methodology and the methods used to conduct the study. The research design is identified and justification is offered for the approach. The study aims and objectives are outlined. The study participant population and procedural stages of data collection and data analysis are described. Ethical and consent issues are also discussed.

AIMS AND OBJECTIVES OF THE STUDY

Study aims:

- To examine the role of hospice day care in the care of patients with life-limiting illness.
- To explore patients' experiences of attending hospice day care over the course of their illness.
- To explore carers' perceptions of the contribution made by hospice day care in supporting them in caring for their terminally ill family member.

Study objectives:

- To describe the context in which hospice day care is delivered in terms of the structure, process and outcomes of the service.
- To explore patients' experiences and perceptions of hospice day care.
- To explore carers' and family members' perceptions and experiences of hospice day care.
- To examine the perceptions and experiences of service providers regarding the contribution of hospice day care in supporting terminally ill patients and their families.
- To identify the components of hospice day care services that have the greatest impact on patients' lives.
- To explore and analyse the impact of receiving hospice day care services on terminally ill patients and their carers over time.

RESEARCH APPROACH

A combination of both qualitative and quantitative methodologies was utilised. However, this is primarily a qualitative study that adopted an ethnographic approach in seeking to understand the unique experiences of terminally ill patients who attend a hospice day care service, in addition to exploring their family member/carer experiences of hospice day care and its contribution in supporting them in the care of their relative. Observation was made of the activities and interactions within hospice day care, and interviews with service providers, patients and family members were conducted. A grounded theory approach to data analysis provided the creation of key themes.

Qualitative research methodologies

This was an ethnographic study that also adopted a grounded theory approach to aid understanding and as a mechanism for sharpening the focus of understanding.

Ethnography can encompass a variety of research methods and involves an emphasis on discovery and understanding. Charmaz and Mitchell (2001, 160) advocate the use of grounded theory methods and approach to help ethnographers conduct efficient fieldwork and create astute analysis.

Both ethnography and grounded theory share common roots within symbolic interactionism and, while ethnography and grounded theory have developed differently, the two approaches can complement each other. According to Charmaz and Mitchell, 'using grounded theory methods can streamline fieldwork and move ethnographic research toward theoretical interpretation. Attending to ethnographic methods can prevent grounded theory studies from dissolving into quick and dirty qualitative research' (2001, 609), and they argue that grounded theory can sharpen the focus of ethnography.

Ethnography

Ethnography as a research method has its origins within social anthropology and it seeks to convey a cultural description of groups in society (Malinowski 1922), placing an emphasis on people's behaviour in relation to their culture and social environments. The underlying rationale of ethnography is that society and culture can only be studied from the inside by immersion of the researcher in the society under study, and it relies upon the researcher, through the process of observation, as the primary research instrument (Walsh 2001, 218). This view stands in contrast to a positivist view of social phenomena that emphasises neutrality and objectivity (*ibid.*, 217).

Ethnographic research methods include fieldwork, participant observation and other qualitative research methods. This variety of sources may be utilised in order to arrive at what Geertz (1973) has termed 'thick description', i.e. the multi-layered meanings that are present in any social action, and involves the researcher in observations of what is happening, listening to what is being said, and asking questions—in effect, collecting all available observations (Hammersley and Atkinson 2007) in a holistic attempt to cover as much territory as possible (Fetterman 1989).

Ethnographic inquiry requires the researcher to pursue and present the viewpoints of those with whom they have contact, adopting an emic framework, which presents the views and perspectives of those under study (Prus 1996), rather than imposing an etic or external framework of understanding (Fetterman 1989).

Grounded theory

Grounded theory was developed by Glaser and Strauss through their research into the hospital care of dying patients (1965). It arose from their dissatisfaction with sociological theorising that seemed generally speculative in nature, as it had not grown directly out of research. As a result, it did not 'fit' the real world and had little relevance to the people concerned (Layder 1993).

Grounded theory utilises research methods that facilitate exploration of meanings, such as observation, in-depth and semi-structured interviews and documentary evidence. Hammersley has argued that the main assumption underlying qualitative research methods is that 'the social world must be discovered and this can only be achieved through first-hand observation and participation in "natural" settings and guided by an exploratory orientation' (1992, 598). Glaser and Strauss state that, whether or not there is a previous speculative theory, discovery 'gives us a theory that "fits or works" since the theory has been derived from data, not deduced from logical assumptions' (1967, 30). Grounded theory fits well with the methodological framework for this research. It does not impose a theoretical model on the data but allows the overall pertinent themes to emerge as data are collected.

Validity and reliability in qualitative research methodology

Qualitative research seeks to provide validity and reliability through description and interpretation. Staying close to the data is a key aspect of qualitative descriptive methodology to ensure accuracy of representation, thus increasing descriptive validity (Sandelowski and Barroso 2002).

A further method of ensuring validity is the process of triangulation; this derives from surveying and navigation, in which people discover their position on a map by taking bearings on two landmarks, lines from which will intersect at the observer's position (Seale 1999, 54). The process of methodological triangulation is a method whereby 'links between concepts and indicators are checked by recourse to other indicators' (Denzin 1970; Hammersley and Atkinson 1983, 199). In this research a process of triangulation was adopted by the combination of field notes, observation and interviews, to facilitate the verification of data. An unstructured approach to observational data collection and the presentation of multiple perspectives of patients, carers, staff and the researchers' observations have enhanced the accuracy and truthfulness of individuals' responses.

The use of independent experts to review data and give expert opinion on emerging themes can enhance validity and reliability in qualitative research (Cormac 1996). The principal investigators of this study fulfilled this role as independent reviewers, given their expert knowledge of palliative care and

research issues. An expert in palliative care research conducted an additional independent audit of all the data—observation notes, field notes and interview transcripts.

DATA COLLECTION

Participant population

To obtain good-quality qualitative descriptive data, all participants in the study need to have experience of the phenomena under investigation (Sandelowski 2002). Hospice day care in this research setting offers its service to 64 patients over four days per week. All patients attending the hospice day care service from the commencement of the study were invited to participate, and those who met the inclusion criteria—being capable of providing informed consent—were approached about the research and invited to participate in the two interviews on two separate occasions.

The inclusion criteria for all participants included basic requirements of being over eighteen years of age, an ability to understand and speak English, an ability to provide written consent and a willingness to voluntarily take part in the research.

Additional criteria were for patients was to be objectively and subjectively well enough to participate in the research (i.e. the participants themselves feel well enough to complete the research and the Hospice Day Care Manager also feels that they are well enough to participate). For family members and carers to be nominated by a person attending hospice day care and a willingness to voluntarily take part in the study and for service providers to have experience of caring for people in hospice day care

The interviews

The first patient interview took place one month after the patient started in hospice day care, and the second interview occurred three to six months later in order to capture the views of the service over time and as the illness progressed. For each patient who agreed to take part, a nominated family member was also invited to participate in the two interviews on two separate occasions. Patient and family member interviews occurred separately.

Forty-three interviews took place with twenty patients; in most cases a second interview was conducted with the patient, although this was not always possible. One patient took part in three more informal conversations over time, and one patient conversed on four occasions. This approach was taken as some patients were too tired to participate in a formal interview and rich data were gathered from these informal conversations.

Thirty-four interviews took place with seventeen carers/family members; not all family members were able or willing to engage in a second interview, whilst some family members/carers had several—albeit short—interviews.

All members of the interdisciplinary team that delivered care in hospice day care were also invited to take part. Twenty-four interviews took place with doctors (2), nurses (4), care assistants (4), chaplains (2), social workers (2), allied health care professionals (occupational therapists, physiotherapists) (3), complementary therapists (3) and volunteers (4).

Qualitative data collection: four phases

There were four phases of data collection.

- Phase 1: Context-setting.
- Phase 2: Non-participant observation.
- Phase 3: Patient and family member interviews.
- Phase 4: Interviews with health care professionals and volunteers.

Phase 1: Context-setting

Phase 1 was concerned with gathering data on the activities of hospice day care, including examination of the number and nature of patient referrals over the twelve-month period prior to the commencement of the study. Details on all newly referred patients over the last year were also collected. Documentary research is a well-established method of research and has the advantage of being convenient and unobtrusive (Bowling 1997).

Demographic information on twenty patients and their carers was collected to contextualise the qualitative analysis (see tables 1 and 2). This provides information on the twenty participant patients and their carers.

Table 1 Age and gender of patients

Age	No. Male	No. Female
35-39	0	1
40-44	0	0
45-49	0	1
50-54	1	0
55-59	0	2
60-64	0	4
65-69	2	0
70-74	0	3
75-79	1	1
80-84	1	2
85-89	1	0
Total	6	14

Table 2 Age and gender of family members and carers

Age	No. Male	No. Female
30-34	0	1
35-39	1	0
40-44	1	1
45-49	1	0
50-54	0	2
55-59	0	1
60-64	1	0
65-69	3	2
70-74	1	1
75-79	0	1
80-84	0	2
Total	8	11

Documents in the form of information sheets, booklets, published newsletters, service philosophies and patient records were included in the data collection to contribute to the landscape of enquiry, alongside observation and interviews.

Phase 2: Non-participant observation

The main data collection tool for phase 2 of the research was observation. The involvement of the researcher-as-observer in the setting may vary. For example, Adler and Adler (1987) note that researchers are increasingly shifting towards a greater involvement in the settings they are observing. These membership roles are classified as complete, active or peripheral. In relation to observing the context in which day care takes place, observation by the researcher in a peripheral membership role was considered to be the most appropriate. In this role the researcher is known to be observing the clinical setting while remaining separate from the care team. When combined with other methods, observation produces rigour as it provides the natural setting or context against which data collected using other methods can be compared. Adler and Adler (1994) suggest that this combination enhances consistency and validity.

One hundred hours were spent in non-participant observation over a nine-month period in order to observe the practices and activities that occur in the hospice day care service. During the observation phase, all patients attending the hospice day care service were informed about the research: the hospice day care manager distributed study information literature and the researcher made a personal approach to all present on each of the days, explaining the project and requesting permission for attendance at the various activities the following week.

Permission to observe activities in hospice day care was obtained from the individual leading the activity and the patients taking part. The researcher spent time observing all the activities in the day care centre, shadowing those individuals who deliver activities, attending day care centre meetings, and recording and maintaining field notes of these observations. During this data collection period many informal conversations were held with patients and their family members. Extensive field notes were written after each period of observation.

Phase 3: Patient and family member interviews

All newly referred patients who started attending hospice day care from December 2006 and who met the inclusion criteria were invited to participate in two interviews on two separate occasions. The hospice day care manager distributed a written information sheet and acted as the gatekeeper regarding suitability for inclusion in the research. Once written confirmation from potential research participants was received, these patients were contacted directly and the study was explained in more detail.

For each patient who participated, a nominated family member was also invited to participate in two interviews on two separate occasions. Patients and family members were interviewed separately. A schedule of interviews—patients, family members and carers and service providers is detailed in table 3).

Table 3 Schedule of interviews

Participant Type	Number of Participants	Total Interviews	
Service providers in Hospice Day Care Nurse Manager Nurses Care assistants Doctors Chaplaincy Social worker Allied Health Care Professionals: Physiotherapists, Occupational Therapists, Complementary Therapists Volunteers	24	24	
Hospice Day Care Patients	20		
		Formal Interviews Informal Interviews	13 7
Family members/carers	19		
		Formal Interviews Informal Interviews	13 6
Total number of interviews Service providers			24
Total number of patient interviews			40
Total number of family member/carer interviews			38
Total number of interviews			102

The interview process

Patient case notes were accessed with consent in order to obtain demographic and medical data. This avoided the need to obtain this information during interactions with the patients. Access to patients' notes also ensured an awareness of key information prior to contacting patients or carers to arrange follow-up interviews.

Individuals attending hospice day care are uniquely situated to provide important insights about themselves and the processes of care at the end of life (Barry and Prigerson 2002; McPherson and Addington-Hall 2004), informing research and contributing to improved services for dying patients and their loved ones (Kelly *et al.* 1999; Patrick *et al.* 2003). Data collected by means of interviews encourage patients to voice their concerns and make suggestions for improvement of the service.

Qualitative methods are able to elicit more meaningful consumer and user perspectives of a service (Blaxter 1995). Older consumers and their carers in particular may have lower expectations and be satisfied with a service that is less than ideal (Owens and Batchelor 1996). Patients may also be fearful that any criticism would affect present or future care (Nolan and Scott 1993; Brooker 1997). As the researcher was not a member of the care team, this gave the patients freedom and security to be openly critical of any aspects of their care.

The first interview generally took place within four weeks of the patient starting in hospice day care. The rationale for the timing of the first interview was to understand and explain the uncertainty regarding starting attending hospice day care, and patients' and carers' experiences of engaging with the hospice day care service. It was intended that the second interview would be completed some three to six months after the patients began attending hospice day care. The timing of the interviews had to be flexible, however, owing to changing circumstances. While the formal interviewing of patients on two separate occasions was envisaged in order to capture patients' and family member/carers' experience of hospice day care over time, this was not always possible owing to patients' changing health status. Frequently a patient's health might decline suddenly, and some patients became too unwell to participate in a formal interview, although many informal conversations were held with patients while they attended hospice day care.

Conduct of the patient interview

Patients were interviewed in their own homes, at hospice day care or at an agreed, accessible venue, at a time of the patient's choosing. On commencement of interview, consent was again requested and it was reiterated that they were free to withdraw from the study at any point and that their care would not be affected in any way. Written consent was obtained from all participants.

Semi-structured interviews were used to collect data from the patients who were attending hospice day care. Interviews were conducted as a conversation about the patient and their experiences of hospice day care, with the schedule being used at the end to check that issues were addressed. The draft interview guide was modified in response to emergent data. Subsequent interviews were informed by ongoing data collection and analysis.

Thirteen patients were formally interviewed on two occasions, while seven patients were interviewed once, with the follow-up interview taking the form of an informal conversation. All formal interviews were recorded digitally and were transcribed professionally. Notes were taken by the researcher after the informal conversations and were later transcribed by the researcher.

Conduct of the family member/carers interviews

Data collection involved an interview with the family member/carers after the patient's first visit to day care at one month (baseline), and a second interview after 3–6 months, following the rationale developed with the patient interviews. The majority of the carers were interviewed in their homes, but some were interviewed in a neutral location and others were interviewed in the hospice. Nineteen carers were recruited. Thirteen were formally interviewed on two occasions while six were interviewed once, with the follow-up interview taking an informal conversational approach.

It was difficult to arrange a time for interview with some family members/carers because they were busy caring for their relative, as the patient's condition could change very quickly and they could deteriorate very suddenly. This informal approach was taken as some family members were too busy to participate in a formal interview, and rich data were gathered from these conversations. The formal interviews were recorded digitally and transcribed professionally. Notes were taken by the researcher after the informal conversations and were later transcribed by the researcher.

Phase 4: Interviews with health care professionals and volunteers

The total staff complement (including part-time staff and volunteers) in hospice day care is 65. Data collection involved a single interview with a cohort of these staff from each discipline, including volunteers who provide day care activities. A purposeful sample of 24 service providers were interviewed to explore their perceptions and experiences of delivering care in this context. These interviews were recorded digitally and transcribed professionally.

DATA ANALYSIS

Data interpretation and analysis involve making sense out of what people have said and what is observed, looking for patterns, putting together what is said in one place and what is said in another place, and integrating what different people say overall. The analysis of qualitative data is a complex process of establishing ideas about analysis when the data are still being gathered and often they are viewed as forming part of the same process (Patton 1990). The purpose of data analysis is to preserve the uniqueness of each individual's experience of the phenomenon while permitting an understanding of the meaning of the phenomenon itself to emerge (Streubert *et al.* 2003).

Approach to data analysis

All data were analysed using grounded theorising, which Hammersley and Atkinson (2007, 159) define as 'a way of working with data in order to generate and develop ideas'. The data collection and analysis was a cyclical process, with both occurring simultaneously. All formal interviews with patients, carers and staff were recorded and subsequently transcribed. Written notes were taken of informal conversations and observations and these were subsequently typed up after a period of fieldwork. These field notes were read and re-read, and this guided subsequent observation sessions in the field. Throughout the data collection a reflexive diary was maintained in order to record the researcher's personal views about the phenomena being explored. This is in accordance with the reflexive relationship that an ethnographer is urged to maintain throughout the fieldwork and analytic stages in order to extend rigour (Hammersley and Atkinson 2007; Lofland and Lofland 1995).

Process of data analysis

Data analysis was initially conducted manually, and a software package, INVIVO 7 computer data management and analysis package (QSR International 2006), was used to assist with management of the large quantities of data. Data from all formal interviews, informal conversations and observations were transcribed and inputted into the computer. Line by line coding was employed in the production of sub-categories. This first level or open coding (Coffey and Atkinson 1996; Strauss and Corbin 1998) involves coding everything that seems relevant and allows similar areas to be grouped together into sub-categories. The data are read and re-read to get a deeper sense of meaning, and are examined to see different or similar things. These sub-categories were grouped together to form categories that then captured the main dimensions of the issues observed and the areas discussed in the interviews.

After the principal categories were established, second level coding or axial coding was undertaken. This process

established connections between categories and sub-categories. Continuous comparisons were made between '... words, sentences, paragraphs, codes and categories', the purpose of which was to identify similarities and differences in the data (Bluff 2005). In this process, the data were dissected and put back together in a different way (McCann and Clark 2003). In the end, level three coding was conducted, whereby all the categories and sub-categories were united to form themes (Charmaz 1990; Bluff 2005).

ETHICAL CONSIDERATIONS

There are general principles that guide the conduct of any research. These can be considered in terms of duty towards participants and protection of the rights of participants (Murphy and Dingwall 2001). These principles have been stated as: non-maleficence—that researchers should avoid harming participants; beneficence—that research with humans should produce some positive and identifiable benefit and not be carried out simply for its own sake; autonomy—that the values of research participants should be respected; and justice—that all participants should be treated equally (Beauchamp *et al.* 1982, cited in Murphy and Dingwall 2001).

These guiding principles apply irrespective of whether qualitative or quantitative methods are used, although the practice of these principles can be complex in conducting qualitative research. Murphy and Dingwall have specifically addressed the practice of these ethical considerations in ethnography. They argue that while the risks associated with ethnographic research are not of the same order as, for instance, biomedical research and administration of drugs or new treatments, ethnographic research is not risk-free and its potential for harm should not be lightly dismissed (2001, 340).

The ethical principles of non-maleficence, beneficence, autonomy and justice can be directly applied in qualitative research to issues of informed consent, the right to privacy and protection from harm, which are the ethical concerns that social researchers have traditionally addressed (Denzin and Lincoln 2003, 89).

Ethical principles

Informed consent

The purpose of informed consent is to ensure the privacy and welfare of those taking part in research and to offer a choice concerning participation in the study (Arksey and Knight 1999, 133). Underlying the principle of informed consent are two issues: that individuals are competent to make rational and mature decisions, and that their agreement to participate in the research is voluntary (Homan 1991).

The right to privacy

The right to privacy encompasses the central issue of confidentiality. Confidentiality is about not disclosing the identity of the research participants and not attributing comments to individuals in ways that can identify those individuals and the institutions with which they are associated (Arksey and Knight 1999, 132). All reasonable efforts should be undertaken to preserve anonymity, such as using code numbers for interview transcripts or assigning different names to interviewees and disguising the location of the study by using a fictitious name (*ibid.*, 134).

Protection from harm

Participating in research is not a neutral experience, and while it may not be a negative one it can raise uncomfortable questions and issues. In-depth interviews aim to go beneath superficial responses to obtain meanings that individuals assign to events and the complexities of their attitudes, behaviours and experiences (Bowling 1997, 336). Interviews are also a way to access the perspective of the person being interviewed and to find out from them things that cannot be directly observed (Patton 1990), and can facilitate the exploration of the meaning of individual experience.

Arksey and Knight have outlined a guide to good practice when asking sensitive questions in qualitative interviews. They state that interviewers need to be sensitive to the needs of interviewees and to let the interviewee lead in choosing whether to introduce especially distressing issues or when to draw back. Interviewers need to listen, be supportive and encouraging, and empathise with the interviewee. These guidelines for good practice also state that interviews should end on a positive note and, if appropriate, information concerning local agencies to approach for guidance, support and help may be offered (*op. cit.*, 113).

Ethical considerations in palliative care research

The need for research and critical evaluation was recognised at the foundation of the modern hospice movement. The main aim of research in palliative care is to identify ways in which the quality of life for patients and their families may be improved (Richards *et al.* 1998, 399). Understanding the experiences of dying people and those who care for them is important in an effort to improve care. Randall and Downie (1996) have stated that all kinds of research involving human subjects are likely to raise ethical problems but that research in the palliative care field is especially sensitive.

Interviewing terminally ill patients

One aspect of research within palliative care that raises particular ethical problems concerns interviewing patients or

their relatives. A central ethical question in palliative care is whether it is fair to expect people who are terminally ill to give up their valuable time for research. Many researchers have stated that there have been enough studies based on interviewing dying patients to discount a view that these patients should not be interviewed at all. David Field (1995) cites considerable evidence for this view: Hinton 1980; McDonnell 1989; Cartwright and Seale 1990; Higginson *et al.* 1990; Kellehear 1990; Dand *et al.* 1991; Field *et al.* 1993; Spillar and Alexander 1993; and Townsend 1993. Research has shown that dying people welcome the opportunity to tell their own story, even if this is difficult, uncomfortable or painful (Kellehear 1989), although Kellehear (1999, 72) has also argued that research is always about 'interfering with people' and the responsibility for researchers is to minimise this disturbance. The ethical task for researchers is to enable these voices to be heard in a way that causes the least intrusion.

Ethical conduct of this research

In line with the ethical considerations of informed consent, the right to privacy and protection from harm, a number of procedures were implemented during this research. Ethical approval to conduct the study was obtained from the Research Ethics Committee, Faculty of Health Sciences, Trinity College, and the Research Ethics Committee of the hospice where the study was conducted.

Informed consent

The Irish Council for Bioethics states that people's beliefs and opinions must be respected and that they must be allowed to decide for themselves whether they want to be involved in any piece of research. In order to achieve this, all potential respondents were given all the information about the study, including the benefits and the possible risks. Careful consideration was given to this information to ensure that it could be read and understood by a variety of people from a variety of backgrounds. The researcher's contact details were provided in case any of the potential participants wished to make contact.

It was envisaged that the potential participants in this research would be well enough to take part because they are able to attend hospice day care activities; through the use of the hospice day care manager as a gatekeeper and of inclusion and exclusion criteria, only potential participants who were capable of providing informed consent were approached about the research. It was considered that the hospice day care manager was in the best position to assess the individual's capacity to understand the purpose, benefits and risks of the research.

Informed consent was not seen as a static concept. It was seen as a process that was adhered to rigorously so that informed consent was sought at every stage of the data collection process (both observation and interviews). The voluntary nature of participation in the study was also highlighted on the information sheet and verbally to the potential participants. Participants who decided to withdraw from the study were free to do so without any penalty.

Confidentiality

During the research, the hospice day care manager acted as a gatekeeper to the research sample. Although the manager knew which patients were given information about the research, she did not know whether the potential participants were actually observed or interviewed. Therefore there was no linkage between the reported findings and the individuals who were observed or interviewed by the researcher, as a coding process was utilised. The researcher also omitted any names or locations mentioned by the interviewees. The hospice day care manager is a registered nurse and is bound by a code of conduct in relation to issues pertaining to confidentiality of privileged information (An Bord Altranais 2000).

Protection of research participants

The participants' well-being was at all times given priority over the research study. Firstly, potential participants were advised not to participate in the research if they felt that it might have a detrimental effect on their health or if they thought that it might cause them unnecessary upset or distress. By utilising a gatekeeper and strict inclusion and exclusion criteria, the chance of this happening was minimised. The researcher is an experienced qualified oncology nurse who was mindful at all times of the vulnerability of these patients, given the nature of their illness. Throughout the observation process every effort was made to minimise intrusiveness.

The researcher used clinical judgement in consultation with the nursing staff from the hospice day care service to further ascertain the health status of the patients prior to engaging in the interview process. If participants became distressed during the interview, the interview was stopped and the researcher utilised clinical skills to assess whether further intervention was required. When appropriate, and with the permission of the participant, the researcher referred the situation to the manager of the hospice day care unit.

All information retrieved was stored on coded forms. The participants' names do not appear in the research report in any form. Access to the data was password-protected and the research was stored in accordance with the Data Protection Act 2003. No individual person or location will be identifiable from the study findings.

SUMMARY

This chapter has outlined the research methodology, the research methods used, the approach taken to analysis and the ethical conduct of the research. The research methodology was predominantly qualitative, although some measure of quantitative data was collected and is presented. The research methods utilised were a combination of documentary data, observation and interviews with patients, family members/carers and service providers. The analysis was a thematic analysis and was completed using a combination of manual and computer-assisted analysis methods.

THE PALLIATIVE CARE
DAY CARE ENVIRONMENT

3

INTRODUCTION

This chapter, and the two that follow, present the findings of the research. This was a longitudinal study—conducted over a period of nineteen months—an approach that greatly aided the understanding of the complexity of palliative care day care service. In particular, it helped an understanding of how, over time, the relationship between patients and family member/carers develops and deepens. The way in which these findings are presented mirrors this process—the initial contact with the service and the initial impressions of the social and physical environment are presented in this chapter. The following chapter explores the perspective of service providers and explores the complex nature of interdisciplinary working, while Chapter 5 documents the way in which the interdisciplinary approach to care combined with the physical, social and therapeutic aspects of the service all work together to facilitate and support people on their individual journeys. There have been a number of studies that have examined the role of hospice day care (Corr and Corr 1992; Spencer 1998; Lawton 2000; Goodwin *et al.* 2002; Higginson *et al.* 2000) but little has been published on the experience of patients and their carers over time in a hospice day care setting. The recent study by Andersson Svidén *et al.* (2009) attempted to measure changes over time, but the quality of life measures adopted proved inadequate to capture the complexity involved. The qualitative approach adopted in evaluating the impact of palliative care day care services and the experiences of patients, informal carers, day unit managers and volunteer staff' (Low *et al.* 2005) provides some comparison to this current research, although the Low *et al.* study utilised focus group discussions rather than interviews to explore views at a particular point in time. This study is unique in that it serves to explore patients' and carers/family members' perceptions over time. Data were collected between December 2006 and June 2008.

REFERRALS TO PALLIATIVE CARE DAY CARE SERVICES

The specialist palliative care centre where this research was conducted offers three distinct services to patients and their carers/family. It provides care to the patients in their own home through the community palliative care team. The day care service allows patients to attend the hospice on a weekly basis, and the in-patient unit provides full-time care for the management of complex symptoms and psychosocial problems, as well as care in the terminal phase of a patient's illness.

All patients are referred to the palliative care service by the patient's doctor in the hospital or their general practitioner (GP). The community specialist palliative care service comprises two teams of nurses, doctors, social workers and chaplains, with the support of other professionals as required. Patients are cared for at home, with the community palliative care team providing an advisory role to carers/family members and the patient's GP. The general method of referral of patients to the hospice day care service is from the

community specialist palliative care team, who referred eighty per cent of the patients in this study.

The community palliative care team are usually the first point of contact for the patients within the hospice services. Many patients recalled the first visit they had from the community palliative care team to their home.

'The doctor came to my house, she sat down there [gesturing to a chair] and she just talked and listened ... she was in no rush ... She went through everything ... it was like I was the only person in the world and I felt she listened to me ...' (Patient 002)

'The nurses called to the house and they brought a calmness to the house; they listened to my mother ... they are really lovely, every one of them.' (Family member 004)

When the community palliative care team become involved with patients, they inform patients and their families of the types of services that the hospice offers. After a period of time of involvement with the patient they may offer hospice day care service to patients whom they feel would benefit from the service.

'I would suggest day care to patients that I felt had complex needs, maybe for symptom control but also, because of the nature of where they were in their illness, they would have very limited social outlets. They wouldn't be able to go out any more, maybe they lack social activities that they were able to do before. Also, people whose relatives you'd consider would be doing an awful lot of caring and would be sometimes quite burdened by that caring, and therefore you'd see day care as an opportunity for them to have a little bit of a break.' (Community Specialist Palliative Care Nurse 02)

After a patient is referred to the hospice day care service, their name is placed on a waiting list until a vacancy becomes available. At the weekly community palliative care interdisciplinary team meetings all hospice day care referrals are discussed with a hospice day care nurse. Patients are prioritised for access to hospice day care according to their current needs.

Many patients spoke about their fears and worries about coming into hospice day care, some of which were based on their previous knowledge or experiences of hospice services.

'When they said I had cancer, they said "Would you go to [the hospice]?" I said "Oh, my God", that frightened me, you know, I said people die in the hospice.' (Patient 03)

'Aw, that's only for people who are really bad. We thought you had to be dying to go to day care. We hadn't a clue, only listening about other people.' (Carer/family member 08)

Many patients did not take up the initial offer of a place in hospice day care and a process of encouragement usually occurred. This initial encouragement came from members of the community specialist palliative care team.

'Certainly at the first interview I would never push it so I would be sowing the seed about day care if I felt it was appropriate for them, encouraging them but not putting pressure on them. Maybe just asking ... some people would need time to think about it. Then in a follow-up visit, the nurses would maybe then do the referral or say "Yes" or sometimes, for some people, it's no definitely, not at all and those people will never come. You have to respect that.'

(Community Specialist Palliative Care Nurse 02)

'Sometimes we use a carrot to entice the patient to come into day care. We might offer them the opportunity to see the physiotherapist as this service can be very difficult to access or it may take a considerable length of time before the patient can be seen.'

(Community Specialist Palliative Care Nurse 03)

Staff described why they encouraged patients to attend hospice day care. Within hospice day care the collaborative approach adopted by a range of professionals working together can enable patients to function to the maximum of their ability. Nursing staff were also aware that most patients enjoyed the many benefits from attending once they started in hospice day care.

Many family members or carers also encouraged their relative to attend hospice day care, as the service provides a social outlet for the patient and for a break for themselves from their caring role. As the patient's physical functioning declined, many carers found it increasingly difficult to care for their relative. Carers spoke about needing time away from their caring role.

'Well, I was anxious that [husband] come to day care, to give me a break ... I am not getting any younger ... I feel I need a break.' (Carer/family member 16)

One of the underlying principles of the hospice philosophy is family-centred care, which includes caring for the family alongside the patient (Kleubler et al. 2008). Allowing the patients to come to hospice day care permitted the carer to be sustained in their caring role, as the hospice day care team was caring for their relative. Sometimes the patient made the decision to come in order to give the carer/family member a break.

'I came here partly because I wanted to give my wife a break from me ... we've been thrown together a lot, very closely together; we've never been this close. I feel it's a great thing for her to get a break. She's gone off into town now.' (Patient 09)

While many family members encouraged their relative to attend hospice day care, in other cases there was sometimes a reluctance to allow them to attend. Carers experienced an internal struggle, as on the one hand they felt they needed a break from caring but on the other hand they felt that they were letting their relative down by handing over their care to someone else.

'We are very private people, we are a very private family, and this cancer has made us all vulnerable; we are dependent on others ... we would always have done things ourselves, it is hard starting to hand over your loved one to someone else.' (Carer/family member 18)

A number of patients who were referred to hospice day care never attended. Staff discussed this non-attendance as possibly being the result of anxiety and fear of engaging with the hospice day care service. A staff member spoke about why she felt many patients were reluctant to attend.

'People have a fear of coming to day care, an understandable fear. People have a fear of spending time within the hospice because in some ways it's probably an acknowledgement of the state of their disease and where they're heading ultimately.'

(Staff member 08)

Starting in day care

The first day of hospice day care was a milestone for the patients. It represented an acknowledgement of their illness on some level. A patient's spouse describes this first day.

'I think for a lot of people the term hospice would have worrying connotations; the fact that you had accepted, the fact that you were entering as a day care patient would, I would say, have marked a huge milestone in the reality of your condition. [My husband] didn't really want to come. He wanted to be quite detached from it but I think he thought it really wasn't for him. Somehow, I think he thought it was for the others.' (Carer/family member 08)

Carers also described what it was like for them when they were coming into hospice day care for the first time. A husband talked about his first impression when he accompanied his wife to day care on the first day.

'Very impressed—the layout, the way the people deal with you, very professional, make you feel relaxed from the time you walk into them. That's very hard to do ... they just bring you with them, come into the room and all this—hands-on type of approach, it's fantastic. I was very impressed myself now. That was my first time in it.' (Carer/family member 08)

In order to ease the patients into hospice day care, staff make a special effort to make them feel welcome but not overwhelm them. They welcome the new patient to hospice day care and greet them by name. Introductions are made to other patients, and staff show them around and inform them of the activities that take place within day care.

'Initially we try and make their first day a welcoming day and get them used to the environment ... we [have] got great facilities in it ... the facilities are here for people and I like to think that every person that comes would benefit from it.' (Staff member 01)

The experiences that patients had on the first day had an impact on whether they would continue to attend hospice day care. One patient described what it was like on the first day and what she felt when she came in to hospice day care.

'I was a bit quiet on my first day because I didn't know anybody. I think I was only about half an hour sitting and someone sat beside me and we started talking and that was it, you know. And you're made so welcome up here when you come.' (Patient 07)

ENABLING A CONNECTION

Environment and atmosphere are two important aspects that enable patients to connect with others in a social setting. Hospice day care facilitated patients to become actively involved with other patients attending on the same day by providing a physical environment that was home-like in appearance. In addition, hospice day care staff created an atmosphere that helped patients to relate to and interact with each other, further encouraging connectedness.

Patients interacted with other patients and staff in a social manner and numerous activities were provided within the day care setting. Many factors combined to contribute to a pleasant and relaxed environment and an atmosphere that facilitated patients to connect with each other.

The physical environment

The Design and Dignity Guidelines (Irish Hospice Foundation 2008) state that the physical building where end-of-life care is provided should be instrumental in supporting high-quality care. The impact of space and environment upon behaviour has been theorised within both the anthropological and the sociological literature—buildings and architectural spaces are designed to shape and reflect the interactions that take place within them (Buttimer 1980, 24). When space is bounded and shaped it exerts its own influence and can define its own action (Ardener 1981). Nevertheless, the participants within that space determine its nature.

In keeping with the philosophy of palliative care, considerable thought and planning were put into the creation of attractive premises promoting a certain ethos and atmosphere. The hospice day care service is located in an attractive, bright, new, purpose-built building extending over two floors. Its modern architecture is bright and airy, with pleasant décor and floor-to-ceiling glass in parts. The use of quality materials and furnishings combines with attention to detail and colour to present a bright, attractive and well-thought-out interior. The inspiration of the religious order that run the service is evident in various religious statues and photographs that serve as a reminder to people of faith and spirituality.

The ground floor contains a spacious entrance lobby with a large desk at the side for the hospice day care secretary. This is the first point of contact for people entering the hospice day care and the caring attitude was evident through the welcome accorded to everyone. This seemed to foster a sense of belonging and inclusiveness and helped to lessen anxieties. On entering the main lounge each patient is welcomed and greeted personally by name by a member of hospice day care staff. Many patients are given a hug when they are leaving the day care facility. This personalised approach helps to foster a sense of individualised care and to create a sense of belonging and connectedness.

The large day care lounge and dining room has direct access to a patio area that contains wooden seating. The use of landscaping and garden features can be restful and uplifting for patients. Cohen *et al.* (1998), in a study of terminally ill cancer patients' determinants to improve quality of life, found that patients valued access to nature and the outdoor environment. Many patients in this study enjoyed being able to view natural scenery as it helped them to connect to nature and gave them a sense of comfort and well-being.

'Before I got sick I was an avid gardener. I loved gardening, I found it relaxing. In here I can admire the lovely garden and it reminds me of the pleasure I got from gardening.' (Patient 08)

The dining area, to the side of the large lounge area, contains a large dining table with chairs where patients sit together to eat their midday meal. A small kitchen near the dining area houses facilities for tea-making and the preparation of light snacks. Food can be an important symbol within social relationships and the sharing of food in a communal setting serves to create relations of equality and connectedness (Goody 1982; Delphy 1984). Patients were served a light snack in the morning after arrival and again before they left for home in the evening. Eating together and sharing a meal is seen as a social activity and several patients referred to being 'one big family' in day care.

'We are all like one big family in here. You really get used to everyone when you are coming here for a while.' (Patient 15)

The lounge is a bright and airy room, with one complete wall featuring glass from floor to ceiling, allowing patients and staff an unobstructed view of the elevated garden outside. A fireplace dominates one wall in the main day room. This is generally lit before the patients arrive and it helps to create a warm, homely atmosphere. A wooden cabinet at the side of the fireplace holds the compact disc (CD) player and CDs. Beside the fireplace are two cuddly toy dogs, placed on footstools on either side of the fire. The design and layout of the furniture attempts to evoke a sense of homeliness.

There is a hairdressing area in an alcove off the main lounge, with a volunteer hairdresser in attendance several days a week. It has facilities for washing, drying and styling hair and was a hive of activity when the hairdresser was present. Cancer patients may experience many changes to their hair as a result of chemotherapy and radiation treatments and advancing illness, and this may have a negative impact on their self-esteem. Many patients, both male and female, regularly used this service while they were in attendance at the hospice, and many mentioned that having their hair styled or cut made them feel good about themselves. A lady with ovarian cancer who had her hair styled by the hairdresser was observed coming into the main lounge area to join the other patients for lunch. She was greeted by some of the male patients, who cheered and called out to her. Her demeanour changed and she gave a large smile to acknowledge their compliments, which seemed to boost her mood and may have given her an increased sense of well-being.

Facilitating levels of connection

Hospice day care provided an environment for patients to connect with other patients and staff. The lounge seating is arranged in a horseshoe shape around the fireplace. Space is left alongside this seating to accommodate patients in wheelchairs. Most patients sit in the same seat each week while they chat to other patients. The seating is arranged so that it facilitates group activities. The seats are close enough to each other so that those patients with limited mobility or who may tire easily do not have to negotiate a large space if they wish to talk to other patients.

Most of the patients sat in the central area of the lounge, but some were content to sit at the periphery and view what was happening from a distance. Hagerty et al. (1993) have conceptualised this form of behaviour as a form of relatedness of connection. The term 'parallelism' can be used when a person does not become involved with others in the group or the environment but still experiences a replenishment of emotional and physical health. One male patient spoke of how he was happy to bring his book to hospice day care and sit alone to read it. He was content and comfortable with his aloneness.

'I am happy to sit here and read my book and nobody says anything to me.' (Patient 12)

Some patients also demonstrated other elements of the related states: for example, some stayed at the edge of the group. This was usually an indicator that they did not want to contribute to the conversations or activities that occurred in the centre of the room. Hagerty et al. (1993) have conceptualised this type of behaviour as enmeshment.

'I did not wish to join the group setting and sit around chatting.' (Patient 012)

Disconnectedness was also in evidence; Hagerty et al. (1993) describes a state of 'disconnectedness' as when patients are not actively involved and consequently experience discomfort and anxiety. Some patients may feel restricted by their physical appearance and the bodily odours that may result from incontinence or from their wounds. These individuals usually choose to sit apart from the main group. In this study one particular patient exhibited this type of disconnectedness owing to his physical appearance and the presence of a large malodorous wound. This man said that he attended hospice day care only to have a bath and have his wound dressing changed—it was apparent that he was uncomfortable being present in hospice day care and was consequently anxious.

'I started coming in here to get my dressing carried out. It is very painful and they need to give me something for the pain first and then I have a bath before they put the dressing back on. It takes nearly two nurses and a carer to do it all. That's why I came.' (Patient 07)

Although patients may become disconnected owing to their illness, hospice day care can help to facilitate connectedness. Lawton (2000) suggests that 'social death' is determined by the 'unboundedness of the body' with problems like incontinence and other symptoms of terminal illness. Hospice day care welcomed people who no longer had control of their bodies. Ninety-seven per cent of patients who attended hospice day care during 2007 had a diagnosis of cancer. As their cancer advanced, they experienced physical weakness, breathlessness and lethargy, which restricted their mobility. This curtailed many patients' independence and meant that many were confined to their home and were dependent on others for self-care and social interaction. It was difficult for these patients to maintain social contact with friends or neighbours, especially if they lived alone.

'Many patients are on their own at home a lot ... they can have cabin fever, become unwell, become mood low; all that contributes to becoming socially isolated, not mixing with other people or family, and patients feel they can't get themselves out of this hole, because of their illness.' (Staff member 04)

As patients' physical conditions deteriorated, social isolation could significantly increase—it was apparent from visits to the homes of some of the patients that many spent long periods of time confined to a restricted space because of their symptoms.

'One lady I visited at home was confined to a limited space because of her illness. Her life revolved around one corner of her living room. Her space included a large chair, a commode and a table. She attempted to move in this confined space. Her table contained a drink, a remote control for the television, her prayer book and rosary beads.' (Researcher observation from home visit)

Additional information and observation gathered in the research suggests that patients who lived alone in restricted space were often unable to engage in social events and to maintain friendships, as many of these were built on sharing activities and interests. Many patients spent long periods at home confined to a room or a chair and had limited social interaction with others. This may have caused patients to become disconnected from their families and friends as their illness progressed. Some may experience a sense of 'social death' (Mulkay 1993), with increasing feelings of diminishing importance to the lives and concerns of other people, and of no longer being an active participant in the affairs of daily life. Hospice day care gave patients an opportunity to reconnect socially with other people.

A lady with breast cancer spoke about how she was unable to go out because she was in a wheelchair and had limited energy to negotiate social outings. Day care gave her an opportunity and a reason to go out.

'You know in the week, being stuck in bed or in a room you know. So at least this way you know you can get out.' (Patient 010)

Hospice day care provided an outlet for patients to interact with other people and provided a new social group where members have the experience of an advancing illness in common. Patients were better able to relate to other patients about their illness experience. This closeness to others which hospice day care provides facilitated a social support network and association with peers. Another patient spoke about how she benefited from interacting with other patients and staff members.

'Yeah, you can, you can sit down and if you had a bad day or a bad week you can have a chat with them and you know you have a laugh, you know. There is always someone here you can chat to. And they are all sociable now, you know, and then the helpers, them girls, there's not one that you can say is not nice.' (Patient 007)

One patient related that she had not been out of her house for a nine-month period.

'I haven't been out of the house in over nine months before I started coming here and the only time I get out is every Monday, which I love. I look forward to it, and I'm starting to kind of bring myself about and feel much better in myself and meeting the people who are fantastic and the nurses and the helpers.' (Patient 001)

Hospice day care provided patients with the venue where they could form friendships with other patients. There was certainly a sense of camaraderie between patients who were undergoing similar experiences and this enabled patients to connect with each other and feel less isolated.

The social atmosphere

Social connectedness was partly facilitated by the environment but, as Ardener (1981, 13) suggests, '...whilst space can define action, the presence of individuals in space determines its nature'. The prevailing atmosphere created by the staff set the tone for staff and patient interactions within this environment.

All staff members and volunteers in hospice day care contributed to providing an atmosphere of calm and relaxation. It was also clear that the intention was to create an atmosphere in which the patients felt a sense of belonging and that they were not an inconvenience or a nuisance. This was evident from the way people spoke about what they did in day care. For example, one volunteer driver spoke about transporting patients from their homes to day care and stated:

'I feel it important to make the patient feel that they were not an inconvenience or they were to be made feel they were rushed or being hurried ... I don't like them to believe that they have to fuss or hurry or anything of that nature.' (Volunteer 023)

Coming into hospice day care allowed patients to forget about their illness and enjoy a few hours experiencing pleasurable activities. Staff and patients regularly used humour to create a convivial atmosphere. Humour also helped patients to connect with each other and with staff within the hospice day care setting. Although the positive effects of humour on physical health are not yet firmly established, there is evidence concerning its significance in health care relationships (Doyle *et al.* 2004). Deane and Gregory's (2004) research in an in-patient palliative care unit suggests that humour was significant in establishing, enhancing and maintaining supportive relationships. One patient spoke about the atmosphere that she experienced while attending hospice day care.

'It also gave an opportunity to patients to talk and enjoy fun with other patients and staff. It is a happy place, there is lots of fun and laughter, I am happy to have had the opportunity to have come here.' (Patient 017)

'It is a happy place, it's a very happy place and it's hard to explain why; on one level you think ... well, maybe people are coming in here to get away from their illness and there is massage and getting the hair done and the nails done and you feel good, your whole body image. People are saying, "You're looking well".' (Staff member 03)

Patients and carers also commented on the overwhelming niceness of all the staff they met in hospice day care. Being nice or good is a central unwritten value in palliative care (Aranda 2004) and is strongly linked to the religious origins of palliative care. While Street (1995, 30) refers to the 'tyranny of niceness' as 'being nice, not making a fuss, smiling a lot, speaking in a sympathetic voice ... and always putting the other person first', many patients felt that the staff were genuinely interested in them and their families.

'And he found the staff terribly nice and just living life at a different kind of pace. I think he found that was very nice.' (Carer/family member 007)

'Surreal—that's the only word I can think of. At first I thought this cannot be true, everyone being so nice, but now I feel they are genuine and they are interested in me.' (Patient 012)

Most patients described coming to hospice day care as offering them a place of peace and an opportunity of getting away from the unpleasantness of their illness. While it could be argued that this is a form of denial, many patients wanted to switch off and not think about what was happening to them. The atmosphere created in hospice day care allowed patients to forget about their illness and enjoy living each day—in keeping with the hospice philosophy (Saunders 1965). Patients frequently identified with the 'sick role' at home. While this may relieve them of their responsibilities (Parsons 1951), coming into hospice day care allowed them the freedom to have a new identity as well as providing a social outlet to reconnect with a past life of the 'normality' they experienced before their illness.

'I feel the bubble has come back in me. I come home from day care a new woman. I am different since I started coming to day care ... I had given up but now I feel I have started living again.' (Patient 007)

'In here they include you in everything; I feel I have started living again since I started here. I have come out of myself.' (Patient 01)

Day care allowed patients to reconnect with others in an atmosphere that was unlike what they experienced at home. Attending hospice day care gave them some 'time for themselves'. Many patients described hospice day care as being 'like heaven'.

"This is my oasis ... this is my space, a place for me ... Oh I just love it, I don't know, you just have to see it.' (Patient 001)

Hospice day care provided an atmosphere where they were not defined by their illness but by their individuality, and for some of these patients this was the only time that the illness did not define them since their terminal diagnosis.

'Well, you really don't talk about your illness when you are in here.' (Patient 018)

'I think in here they can just be themselves. Many of the patients that's come to day care call it a piece of heaven. To me what they mean is—the peace in themselves—of being who they are, their pain, their sadness, their joy.' (Staff member 015)

Recreational activities

Patients were frequently unable to continue with their hobbies or activities that they once enjoyed as their illness progressed. For many this meant that they had become disconnected from their circle of friends and companions. Volunteers within the hospice day care setting facilitated a range of recreational activities. These included art sessions, music, singing and bingo, which occurred on different days. Participating in the organised activities within the hospice day care setting afforded patients an opportunity to connect with others in a social environment. Care assistants and volunteers were available to assist patients if they were feeling unwell and unable to participate themselves, given the limitations imposed by their illness. For example, one lady who had a brain tumour with weakness in one side of her body and diminished sight was now unable to play bingo in her local club. She enjoyed being able to participate with help in the bingo sessions in hospice day care.

'I enjoy the bingo. I haven't been able to go since I got sick, I used to go three nights a week ... they make it fun in here and sometimes I play. I can't see the numbers that well and I am unable to mark the numbers as I can't hold a pencil any longer. One of the girls in here plays the bingo for me ... so even when I can't play, I feel I can join in, they always try and include me.' (Patient 005)

'Now, you try to keep them all together, you would often get like "is the bingo on?" and they sit down, and some days they are not well enough to play and then you play their game for them.' (Staff member 012)

Underlying the palliative care philosophy is a belief that the arts can enhance the personal living and environment of patients (Bailey et al. 1990). Many patients who attended hospice day care participated in the art sessions. Most were apprehensive at first about trying something new, but under the guidance of the art teachers many patients enjoyed the experience. For many this was an opportunity to be involved in something creative that allowed them to express themselves in a way they had not done before. The atmosphere in the art room enabled patients to participate in creative activities in a relaxed, supportive environment; sometimes there was very little conversation as individuals were absorbed in their own work, and at other times there was a lot of chat and laughter, with patients providing mutual support.

'I never painted before so decided I would do a painting for some of my family and now I am doing my second one.' (Patient 013)

'My painting is in the hospice calendar for next year, all my sisters have bought the calendar.' (Patient 05)

There were many activities on offer within the day care service. Staff tried to include everyone, if they wished, in the group activities. Some patients felt tired and were happy to sit or read the paper without being disturbed. They did not feel pressurised to talk to others if they did not wish to do so.

'We have started playing cards; you have to see what the whole group wants because you can't exclude people, which we don't do. There might be a person that doesn't like cards, so you just say "Would you like a cup of tea?" and they can sit back and watch, but we bring them into the group, they don't have to play it but they can sit and watch, and they enjoy that.'
(Staff member 012)

Staff recognise that they offer patients a choice to participate or not in activities, but were also aware that even though patients are offered choice it might be difficult for them to refuse.

'We try and offer patients a choice of what they wish to participate in. Sometimes I feel some patients feel they have to do what's on offer.' (Staff member 01)

Creating a family

The approach in hospice day care enabled the provision of services in a relaxed, home-like atmosphere where the same patients came each week on an assigned day. By creating an environment reminiscent of home, they also created a sense of 'a family' through camaraderie, friendship and belonging.

'There's a sense of camaraderie in here.' (Patient 018)

Many patients had a shared sense of belonging because they all had a similar connection—their advancing illness. This gave patients a connection with each other and they often referred to this as 'all being in the same boat'. Patients also felt that they benefited from the presence of other patients with whom they could share their experiences. Some of the younger patients formed friendships and ties with older patients and often sat together in the smoke room. The initial topic of conversation was their own families, and the patients seemed to like and look forward to meeting other patients, whom they now referred to as 'their friends', each week.

'Well, I meet my friends when I come in here, I look forward to meeting them each week.' (Patient 005)

Making sense of the life that has been lived can be an important part of coming to terms with a terminal illness. Many patients did this by talking to others and were helped by being given the space and opportunity to tell their story. This sharing of stories also allowed them to connect and seemed to help reduce anxiety and fear.

'It's nice to be able to sit with others and chat. We sometimes just talk about what we did in the past and relive old times gone by.' (Patient 023)

SUMMARY

This chapter has considered the palliative care day care environment in which this study was located. It explored both the physical environment and the social atmosphere of day care and the process and experience of referral to the service. It also examined the ways in which connections between patients, carers/family members and service providers are facilitated through multi-faceted activities and social interactions.



SERVICE
PROVISION

4

INTRODUCTION

The aims of day care include social contact and support and maintaining people at home within their own medical support systems, as well as assessing and managing pain and symptoms. There is a focus on getting the balance right between a social service and a medical one.

In the palliative care day care in this research, a rehabilitative model of care was adopted to enhance the quality of life for patients, their carers and family members. A rehabilitative model of care uses a collaborative approach and encompasses a range of professionals working together to observe and monitor the changing needs of patients, as outlined in Chapter 1. Whilst rehabilitation aims to restore an ill or disabled individual to his or her maximum capabilities, in a palliative care setting it may be more important to give assistance to the patient and family to cope with end-stage disease. Hockley (1993) suggests that for patients with advanced cancer, rehabilitation may be viewed as a process of adapting to the changes that are occurring and using an active approach in managing complex symptoms.

This chapter explores the processes of interdisciplinary working and the impact this has on multi-dimensional levels for patients and carers/family members. It explores the management of internal and external links with the specialist palliative care services, hospitals and community health care professionals, and considers the nature and extent of carer/family support.

INTERDISCIPLINARY TEAM WORKING

A central component of the palliative care philosophy is the interdisciplinary team (Randall and Downie 1996). Interdisciplinary teams provide a unique forum for creative problem-solving, especially if every member's contribution is genuinely solicited and respected (Parker 1994). Meetings are held regularly as a means of communicating and discussing patients' care. In this day care service, staff meetings occurred at the beginning and end of each day.

An interdisciplinary team provides specialist palliative care within the social environment of this hospice day care. Access to specialist palliative care staff to manage complex symptoms is available, and a supportive environment is provided for patients as they try to adapt to their changing situations. Patients derived support from having regular access to skilled staff and other terminally ill patients who were in a similar situation in order to help them cope with the stress of adjusting to their situation.

The hospice day care interdisciplinary team is composed of nurses, doctors, care assistants, pastoral care team, physiotherapists, social workers, occupational therapists and complementary therapists. An interdisciplinary approach is considered best practice within the palliative care model, as

it is recognised that all disciplines have an essential contribution to managing patients' and their families' care at end of life (Billings *et al.* 2003; Doyle *et al.* 2004).

A detailed medical and nursing assessment of the patient's, their family's and carer's needs is carried out when each patient starts attending hospice day care. This forms the basis for establishing a good patient–professional relationship. These assessments are ongoing and were adapted according to the patients' needs.

'All patients are assessed medically when they start in day care; it gives a comprehensive holistic picture of all the patients' needs.' (Staff member 018)

The needs of patients change as their illness progresses, and a nurse assessment is undertaken for each patient every week; this is an opportunity for nursing staff to get a clear picture of how the patient is and highlights whether there is a need for further formal medical, psychological or social assessment.

'I think the nursing side of it is very important because their medication can be very important, some people can be very confused about their tablets and it's an opportunity for them to have a conversation with the nurses with regard to what tablets they take when, and it's also an opportunity for the nurse to see if the patient is becoming slightly confused? Is there a need for a pillbox, where they put their tablets in for the week, which can be done for them, to ensure that they are taking the correct tablets at the correct time.' (Staff member 20)

Patients may require different levels of care from a variety of professionals and services within the hospice service. For example, if their health problem is related to mobility or breathlessness, intervention by a physiotherapist may be required for optimum patient care. At other stages symptoms may become more complex and a medical consultation would be requested.

'At the moment in hospice day care service we have the services of physiotherapists, occupational therapists, complementary therapists, manual lymphatic drainage nurse specialists and social workers that we can offer patients.' (Staff member 014)

Initially some of these complementary therapies had been provided by volunteers and overseen by the day care nurses. The main focus originally was on relaxation. As the benefits became evident, however, the service moved to provide a number of full-time professional positions in order to ensure reliability of the service for patients.

'It was first set up with the volunteers, ... we looked after a broad range of symptoms, backache at that stage, mobility problems, what we would do then was massage them, and even breathlessness, we worked with people from a relaxation point of view, and then it became very evident after a while, first of all from a volunteering perspective, we weren't able to rely on the volunteer to come in every week, so it wasn't really a reliable service.' (Staff member 14)

Rehabilitation in practice

Nurses in hospice day care coordinated the care from the interdisciplinary team to help to restore the patients to their maximum capability. Members of the interdisciplinary team sought to maximise patients' physical function, promote independence and help them to adapt to their condition as their illness progressed. To enable patients to live and enjoy living each day, they were encouraged to do as much as possible within their limitations. This is in keeping with the underlying philosophy of palliative care of offering support using a team approach to address patients' and their families' needs as they approach the end of their life (Ferrell and Coyle 2006). This is also one of the fundamental principles of rehabilitation, where interventions can impact on function and symptom management in terminally ill patients (Santiago-Palma and Payne 2001). A member of the interdisciplinary team stated that

'It may be simply me showing how to get up from their bed when their mobility is limited ... I sometimes show patients strategies how to conserve their limited energy.' (Staff member 09)

'Some patients may have problems with fine motor movement and they may need adaptation to their cutlery to enable them to eat.' (Staff member 010)

Through interprofessional collaboration many patients were able to gain some independence and continue with their interests and hobbies within the confines of their illness. A good example of this effective collaboration is illustrated by the case of one 70-year-old female patient (Patient 02) who lived alone and was attending hospice day care. As her illness progressed, she experienced deterioration in her health and was finding it difficult to continue working in her garden, which was a lifelong interest from which she had gained immense pleasure. She expressed a desire to continue to work in her garden. She experienced pain and lymphoedema, which was managed by the day care nurses and manual lymphatic drainage nurse specialists.

Her home environment and garden were assessed by an occupational therapist. Aids were provided to enable her to adapt the home environment. In addition, advice was given on the use of specialised garden equipment that would help her to continue to work in the garden without the need for

repetitive bending. This lady was also reviewed by the physiotherapist, who demonstrated and prescribed some gentle exercises for the patient to practise on a daily basis. A back support was provided for her to wear while gardening. This patient continued to work in her garden with the help and support from the hospice day care team.

The patient spoke about what it meant to her to be able to continue working in her garden, thanks to these interventions by the hospice day care staff:

'I love my garden. It gives me a lot of pleasure and I feel relaxed when I am gardening. Now I can still look after my flowers and get pleasure from them.' (Patient 02)

This interdisciplinary collaborative approach by a variety of health care professionals helped this lady to retain control over some aspects of her life, to remain at home and continue her lifelong hobby. By so doing, it addressed more than physical functioning as it also sought to enable this patient to continue an activity that gave her life meaning and purpose. Gourdji et al. (2009) have found that palliative care patients value 'doing what they always do', and that doing these things that brought structure to their lives provides them with comfort and security, helps preserve their identity and keeps them connected with life and living.

This interprofessional collaboration illustrates the way that the majority of patients received care from different specialist palliative professionals within the hospice day care setting. The level of care varied according to the patients' needs, however; depending on specific needs, different professionals had input into the patients' care at various stages in their illness. There was regular communication between team members to discuss patients' current requirements.

Managing the needs of patients

A daily interdisciplinary meeting is held in hospice day care in order to arrange the physiotherapist, occupational therapist and complementary therapist appointments that day for individual patients. This appointment schedule is flexible as some patients' needs may have changed and this may not become evident until they arrive into hospice day care at 10.30 a.m. Their health may have declined and they may have more urgent needs that require attention. All staff were adaptable in their approach to accommodate the patients with the most urgent needs. As many of the patients tire easily, appointments were scheduled to allow patients time to rest between appointments.

'Each morning we have our meeting. Today it was about our Tuesday clients ... who's seeing who, so that the girls [nurses in hospice day care] would know when they could get to see their clients. One of the professionals said one of the clients last week had everybody and by the time the afternoon came, they were exhausted, so you're trying to prioritise whether they really need OT, physiotherapy and complementary therapy in the one day. The majority of them [patients] wouldn't come in until half past ten, so you're trying to fit them in between half ten and half twelve. If they're gone to art, going to Mass, you're trying to slot in everything, so you really only ever get them for two hours in the morning.'
(Staff member 06)

Managing the needs of patients requires considerable flexibility on the part of the interdisciplinary team. This flexibility is fundamental when caring for terminally ill patients whose needs may change rapidly and is managed through effective communication and a commitment to seamless care.

A TRIANGLE OF CARE

Holistic care of patients is a fundamental element of the palliative care model. In this day care centre, the holistic care of all the patients is considered in relation to palliative care not only from the specialist service but also from other external health care providers. The hospice day care nurses coordinated care, both internally in the service and externally with other health care providers, to provide a continuity of care for their patients. A coordinated and family-centred approach to patients' care can support patients and their families as they come closer to death (Hanson 2004), and in this study care and support was also extended to informal carers and family members.

Many patients that attended hospice day care were also receiving care from many different services, including acute hospitals, outpatient departments, community services and specialist palliative care services throughout their illness. Nurses in hospice day care frequently coordinated care from all of these services to provide continuity of care for the patient. As patients become more unwell, the community palliative care team also become involved in caring for the patients and visiting them in their own homes. If a patient's condition deteriorates, he/she may be admitted to the in-patient unit in the hospice for symptom control, respite care or terminal care.

Managing internal specialist palliative care services

Communication, both formal and informal, within a team is a major factor in successful service delivery (Jones 1992). Weekly interdisciplinary team meetings were led by the hospice day care manager to discuss and plan all aspects of the patients' care. This facilitated the flow of information between different providers of care within the hospice day care team. Staff discuss patient issues with each other, thus benefiting from other team members' experience and expertise.

Each week the care of a cohort of day care patients is discussed with the interdisciplinary team members. This allows all the disciplines to have their specialist input into the care of each patient. Following this discussion, any changes to patient care are documented and an action plan is outlined. The interdisciplinary team discussion concerning the difficulties that a carer is experiencing, as her husband requires more care as his physical health deteriorates, is detailed as follows:

'It's becoming too much for her on her own trying to manage him on her own day and night. He really cannot be left on his own as he gets dizzy and he might fall.'
(Staff member 013)

'Is there anyone at home with her?' (Staff member 010)

'We did mention it before and she felt they were too busy. I was talking on the phone last week and I was asking her how were things at home. She is very reluctant to complain and tries to struggle on. I think we will ask the community palliative care nurse to do a visit this week just to give her a bit of extra support. I think we need to be looking at trying to put in some supports for her.' (Staff member 03)

The holding of weekly community palliative care interdisciplinary meetings also allows hospice day care nurses to discuss patients who are cared for by both care teams—the day care and community care teams. This allows the flow of information between all carers; problems can be identified and discussed and potential solutions explored, leading to continuity of care between all the specialist palliative care services. All discussions and treatment plans are documented in the patient's case notes. Carers seemed to value the continuity of care between different parts of the palliative care service as this meant that any staff member from the palliative care service was familiar with the patient and his/her current condition. This helped to alleviate carer/family members' anxiety.

'I see the same people each week; they know me and I don't have to keep telling them the same things each week. I only need to tell them if there is anything new.'
(Carer/family member 05)

Systematic assessment and documentation of patients' needs, problems and concerns along with professional observations were recorded in chronological order in the patients' case notes. The hospice provided patients with a 24-hour, seven-days-a-week telephone support service for carers/family members.

Managing links with external health service providers

Many patients require access to outpatient clinics in the acute hospitals at regular intervals during the course of their illness. Carers appreciated that nurses from hospice day care advocated and negotiated the health service on behalf of their relative.

'We needed to get back to [hospital] for an appointment as [patient 018] was getting frequent dizzy spells. I couldn't leave him unattended as he could fall. We knew we would have to wait weeks for an appointment and he just was not well enough to wait ... the nurse rang from day care and organised the appointment.' (Carer/family member 018)

It can be difficult for very sick patients to be waiting for long periods of time for appointments. As the nursing staff assess the patients each week, they are very aware of their current health status and realise that some patients with a short prognosis cannot wait a number of weeks for an appointment. Nursing staff from hospice day care often ring the outpatient clinics to talk to the doctor or specialist nurse about the particular patient and their particular needs, and were frequently able to organise an early appointment for the patient.

Nurses informed other care providers of changes in the patient's condition and current treatments. As a result, patients and family members/carers experienced a coordinated package of care from different specialist health service providers. For example, one day care patient—a 79-year-old lady—had increased growth of her tumour, which was close to a main artery. Hospice day care staff arranged an early appointment for this patient. A detailed medical update on the patient's current condition was sent to the specialist radiation clinic. This allowed this lady access to further radiation therapy in a timely manner. She was seen by the radiation specialist and had radiation treatment carried out within a week of presentation at the clinic. Had the appointment had not been organised in this way, the patient may not have accessed the radiation treatment as quickly and she may have experienced a major bleed that would have necessitated her arriving as an emergency to the accident and emergency department of the acute hospital.

Many of these positive interventions carried out by hospice day care staff, such as the prevention of unscheduled admissions to acute hospitals, are largely invisible and do not generally appear as part of evaluations and audits. While

much of this negotiation and advocacy for the patient within the day care service may be invisible, there is considerable communication by telephone and fax messages between hospice day care nurses and acute and primary care services to facilitate continuity of patients' care. Crawford (2002) states that a challenge for specialist palliative care teams is to support primary carers, such as general practitioners and generalist community nurses, in caring for patients. Good communication, which takes time, is needed to establish roles and responsibilities between different care providers.

'We work very closely with the community services, the public health nurses, and the patients' GPs ... we are in contact with them regularly.' (Staff member 01)

Most patients that attended hospice day care had frequent visits to outpatient departments for follow-up care, palliative radiation or palliative chemotherapy. Several incidents were observed of patients being scheduled to attend clinics in other specialist services without tests or scans being carried out, or the results of scans or X-rays not being available.

'Often you'd find, say, somebody has an appointment to see their oncologist, and a CT scan is planned but the scan is two weeks after the appointment, so there's no point going for the appointment, and maybe by changing the appointment date, they have the scan, the results are there. It's just trying to save them hassle like this when they are so unwell.' (Staff member 03)

Without these kinds of interventions on behalf of the patient by the day care staff, patients might attend the appointment unnecessarily. Many patients were not aware, or were too unwell to know, that they needed to have these tests carried out prior to the appointment. Nurses frequently negotiated the health service facilities on behalf of the patients or their carers.

Family-centred care

The hospice day care provided a family-centred approach to care that was in accordance with the underlying tenet of the philosophy of palliative care (Kovacs 2006). While the patient was attending hospice day care, the main carer was able to get some relief from their caring role. Palliative care day care nursing staff were aware that caring for a close family member over an extended period of time can be costly—physically, emotionally and economically. They encouraged relatives to use the time that their relative was in day care as time for themselves, and to do something that would allow them to get out of the house.

'We say to the carer we will take care of your relative for one day a week ... The carers need the break sometimes more than the patient ... we know the family really needs a break ... they can have cabin fever, stuck in the house all day every day. So we encourage the relative to use this day for themselves as families need it.' (Staff member 04)

As health declined, many patients felt that they were a burden to their main carer. Becoming increasingly immobile, more dependent and requiring more assistance are indicators that patients use to describe when they feel they are becoming a burden (Chochinov 2009). Coming in to hospice day care allowed the patients to feel that they were giving their carers a break from them.

'I don't want to be any trouble to any one else.'
(Patient 04)

'It's nice if I can come in here and give her a chance to go out with her sister or whatever and have a day off, it's a break for her from me.' (Patient 012)

Carers spoke about caring for their relative as a 24-hours-a-day, seven-days-a-week job. Carers experienced tiredness, fatigue and exhaustion as a result of always being on call with very little time for themselves. Caring for a person approaching the end of life can place a heavy burden on the physical, emotional and mental well-being of carers (Payne *et al.* 1999).

'At times, things get out of control and things get on top of you ... I suffer. It's the mental strain of it, I think is what really gets to you.' (Carer/family member 18)

Hospice day care staff are aware that the task of caring for a terminally ill patient is tiring and can be exhausting, leaving the carers feeling tired and isolated.

'They knew things were difficult at home, they suggested getting a carer into our home to help.'
(Carer/family member 08)

Some carers would have liked their relative to attend hospice day care for more than one day a week.

'Sometimes I wish he could go in another day, as it's really difficult at times. A second day in day care would help me a lot.' (Carer/family member 012)

Some patients did attend hospice day care two days a week. This option was offered to a minority of patients as resources are limited, although nursing staff did so when possible in an attempt to help sustain the carer in continuing to care for their relative at home.

'Well since [her husband] started coming the second day, things have been so much easier.' (Staff member 08)

'Yes, sometimes we offer some patient a second day in day care if we feel it would help their situation, but we are limited in the number of people we can offer a second day in hospice day care to.' (Staff member 012)

Carers' needs also include the provision of knowledge and support (Payne *et al.* 1999; Sothill *et al.* 2000; Higginson

and Gomes 2002). Andershed (1999) states that if carers are informed about issues about which they are concerned they are more likely to be enabled to continue to journey with their relative. Over the extended period of this study, it was clear that staff in hospice day care provided information to carers based on their expressed need or desire to hear the information.

'And you're building up that relationship and the trust with the carer as they are at home doing the care and you need to check out how they are too.'
(Staff member 04)

'I think the more symptomatic the patient is, the more care they may need, maybe more information, but it's very individualistic and we base our interventions on what their needs are at a particular time.'
(Staff member 010)

As the physical condition of patients deteriorated, many families needed extra support and reassurance. Hospice day care nurses usually anticipated this, as they had regular contact with the patient and were aware of changes that were occurring with the patient in their home.

'His physical condition has weakened. I would say that if he gets any pain or ache, if it's urgent, I know I could call here or he could call here, and they will look after whatever it is.' (Carer/family member 08).

As patients' needs increase, there is a need for extra support for carers to help them to continue to care for their relative at home. Nursing staff negotiated with community services to access this care, as the Health Service Executive funds an agreed number of hours' help in the home from a paid carer, and this is organised by the public health nurse.

'We try and organise home care packages for the carer to continue to care for their relative in their home. Sometimes this is not easy to get the level of care for people that they require.' (Staff member 010)

Respite care

Staff spoke about getting to know their patients' families very well, and how this knowledge of individual patients' circumstances helped them to pre-empt the occurrence of crises. This acknowledgement by hospice day care staff of what the carer was experiencing was viewed as helpful by relatives. Many carers were finding it very difficult to care for their relative and were in regular contact with the hospice day care nurses. One carer talked about her distress when caring for her husband who had pain that was difficult to relieve.

'I absolutely was nearly crying yesterday hoping they would take him in [referring to the in-patients unit] and I think [a day care staff nurse] must have felt the vibes from me because I said to her "Nothing would give me more pleasure than for him to come here [to inpatient unit], because I know you know if he's in pain. I won't be waiting to see if he's in pain and then give him a tablet, which is not going to work for another hour". The day care staff are fantastic, I think they just know what's happening with him and with me.'
(Carer/family member 012)

Respite care is often a means of giving carers a break in order that they may continue their caring role at home. Staff organised respite care for patients either in the in-patients unit of the hospice or in the community to give the carer a break from their caring role. Respite beds for patients were sometimes difficult to obtain.

'We have two beds here in the hospice for respite care; people may come in for a rest if they're, you know, their family or themselves just need a break from home, and the family is getting very tired looking after the loved one at home.' (Staff member 01)

'We also try and help to organise respite care in a nursing home in the community but respite beds in the community are very difficult to access.'
(Staff member 04)

Telephone support

Carers also felt isolated as they were confined to their home when caring for their relative. They valued the telephone contact with the hospice day care nurses, which allowed them to discuss their relative with someone who understood and knew their relative's current condition. They also appreciated that the nurses showed interest in and concern for the carers' own well-being.

'When they ring asking how he is, they always ask "and how are you?" They always think of me too.'
(Carer/family member 012)

Some carers and relatives would have liked more support for themselves.

'I would like more access to formal counselling for myself but I know their resources are limited.'
(Carer/family member 05)

'I would like some support for my family, especially my father, as I know nobody has spoken to him. I know that my mother is their patient but I would like to be able to access more psychological support from the hospice.'
(Carer/family member 014)

Nurses spend a lot of time offering telephone support to the patients and their carers who attend hospice day care, even though they are not physically present in hospice day care. Nurses are aware of the pressure that carers are experiencing and this telephone contact is viewed as an important means of offering carers support. The nurses may potentially be offering support to all 64 patients who attend hospice day care, as well as to all their carers.

'I don't think I could manage without the day care ... it has been awful and I know things are going to get worse ... but they have been there for me and I know they will be there for me ... I couldn't manage without day care. They are always one step ahead.'
(Carer/family member 08)

SUMMARY

This chapter has explored the way in which the health care professionals in this palliative care day care service operate in order to provide a complex interdisciplinary and multi-dimensional service. It has considered how interdisciplinary team working functions and the impact this has on the care of patient and carers/family members. A triangle of care exists in which service providers manage the internal links within specialist palliative care services and the external links with health care services in hospitals and the community, and also provide a range of supports for carers/family members.

FACILITATING
AND SUPPORTING

5



INTRODUCTION

The previous chapters have described and documented the range of services provided by the palliative care day care service. The complex, and frequently invisible, levels of support available from health care providers have also been considered, in addition to the significance and impact, for patients and carers/family members, of engaging with the day care service.

This study explored patient and carer/family members' experiences and perceptions of palliative care day care services over time. The benefit of this research approach is that the relationship that develops with and between patients, family members/carers and the palliative care services can more clearly be seen. What became apparent was the deep knowledge and experience of the specialist palliative care health care providers and how this was sensitively yet rigorously applied to each aspect of care.

Whilst specialist palliative care providers bring considerable experience and expertise to their care of patients, carers and family members, there was an understanding and awareness that for each patient and their family this was a unique experience. In a sense, the broad outline or direction of the way ahead was clearly visible to health care providers from their own professional experience, yet an understanding of the uniqueness of this journey seemed always present. The interdisciplinary approach to care, combined with the facilities, the physical environment, the atmosphere and social activities (described in Chapter 3), and the therapeutic and spiritual support all work together to facilitate and support people on their own individual journey.

TRANSITIONS

Transitions—the process of change from one place or state to another—are very much a feature of the lives of patients and carers/family members in this study. The initial diagnosis of cancer was the beginning of a journey involving many transitions; a significant transition is one from hope of a cure to receiving a terminal prognosis. A referral to palliative care services heralds this change and this can be a difficult time for patients and their family members. Moving into the physical space of the hospice can also be difficult, as documented in Chapter 3. Most patients in this study were apprehensive about making the transition from community palliative care to the hospice day care setting.

Changing needs

The changing nature of care corresponds with the changing nature of the disease. Hospice day care services responded to meet these changing needs in a myriad of ways. Twycross (1997) identifies the most common physical symptoms of advancing cancer as including pain, nausea, anorexia and dry mouth, as well as psychological aspects such as worrying,

feeling sad, feeling nervous, difficulty sleeping, feeling irritable and difficulty concentrating. Many discussions between patients and staff were related to symptom control and the various medications that were being taken to help alleviate these symptoms.

'Most cancer patients really will have a problem with pain, nausea, energy and weight loss. Most patients experience these symptoms and need help with alleviating or controlling these.' (Staff member 01)

For many patients with progressive disease, their uncontrolled symptoms can affect both their quality of life and their coping mechanisms when dealing with subsequent illness and death (Higginson 1997). As the cancer advanced, many patients experienced both physical and psychological changes while attending hospice day care. This required the nurses in hospice day care to continually assess and monitor the patients' changing symptoms and to adapt the care they delivered accordingly. Patients attending day care are allocated a nurse to care for them. The nurse gets to know the patient very well and they develop a relationship over time.

Nurses in hospice day care use their experience, skills and judgement when assessing and managing these patients' complex symptoms. A description follows of the detailed assessment and management plan for an 80-year-old patient who had a diagnosis of rectal carcinoma. He was a single gentleman who lived in a nursing home and he had been coming to hospice once a week for the previous six months.

'Today, for example, we had a gentleman who came in, he has rectal carcinoma and he has a nagging pain... I can see his condition deteriorating remarkably over the last couple of weeks, I would think that his opiates [a group of medications that are used for pain relief] need to be increased and I would imagine in the next week or two that he may not be fit to travel to day care. You know, being transported from where he's living to here can aggravate the rectal trauma that he has and this causes increased pain. So it may be [that] soon that he needs to be staying in the nursing home he's in and the home care nurse from the hospice will visit him.'

I will be suggesting to the staff in the nursing home that he'll be given more opiates. I have arranged for the occupational therapist to see him today to review him getting maybe a valley cushion [a cushion that is used to relieve pressure on the rectum when a patient is sitting], which hopefully will help ease some of his discomfort. She will be doing that this afternoon.' (Staff member 05)

Patients' symptoms of pain, nausea, fatigue and breathlessness were continually assessed and managed on an ongoing basis by nursing staff. Patients' needs were assessed when they attended hospice day care and, in consultation with medical staff, appropriate medication was prescribed and its effectiveness was monitored on an ongoing basis.

Patients' responses to medication were monitored through follow-up phone calls by the hospice day care nurses to the patient or to their carer/family member.

'The nurse changed my tablets and things are a little bit better. They usually ring me the next day at home after they have changed my medicines.' (Patient 12)

Nurses systematically assessed each patient every week as their physical and psychological symptoms changed. Based on their assessments, nurses made changes to the patients' medication regime as necessary, in consultation with the palliative care doctor and the patient's general practitioner. Patients were aware that the nurses monitored their needs and were happy that health care professionals and allied health professionals were available in hospice day care to meet and review them on a weekly basis.

'Each week I come in here, they look over all my systems from head to toe.' (Patient 09)

Carers/family members also derived comfort and support from the level of care patients received in day care; having access to different health care professionals was highly valued.

'It is great when he [her husband] goes into day care each week. He is seen by the nurses and any other staff they feel he needs. He has been seen by the physiotherapist, occupational therapist and the doctors.' (Carer/family member 12)

Complementary therapies

In addition to the social activities available in palliative care day care, a range of complementary therapies was offered to patients. These were provided by professional health care staff and by some volunteer therapists.

Kennett (2001, 63) states that frequent responses to complementary therapy are comments such as 'It was the only thing that made me feel human again'. Complementary therapies can enable patients to connect with themselves and their bodies, which can increase self-esteem and reduce anxiety. In this study patients looked forward to their weekly session with the complementary therapists. Many spoke about the benefits, and pleasure, they got from receiving the various therapies.

'I feel so relaxed while getting the therapy and when I go home I have a really good sleep.' (Patient 05)

'I hope I have a massage today. I look forward to the massage. It is the best part of the day.' (Patient 13)

Therapies are carefully selected according to the medical history and current health status of the patient.

'It depends on two things. We first would interview the person, and we would get their full history, their medical and surgical history, and that would for us dictate what therapy we would use, in some instances. For example, I would have their age, their diagnosis and their prognosis and whether they had had chemotherapy or radiotherapy; they are the basic things I need to know. Why do I need to know them? Because, for example, if somebody is in the middle of chemotherapy or radiotherapy it's going to dictate how long I'm going to spend with them. Obviously somebody that's in active treatment, they are going to be a little bit more tired, so in that instance I will definitely cut down on the length of time I spend with somebody.' (Staff member 14)

There is close collaboration between disciplines to optimise the treatments that patients receive and to ensure a balance between addressing symptoms and relaxation.

'From a team approach, they also may be seeing some of the other care professionals such as occupational therapy or physiotherapy, so they in turn would need to know how long I'm going to spend with them, and that will dictate how long they will spend with them, because the person ... we want to get a fine balance with somebody when they are coming in here, we want them to enjoy themselves, to feel relaxed, and obviously from a symptom point of view we will work with that, but it's trying to get the balance right between all of the professionals and their input.' (Staff member 14)

Complementary therapies offer patients the opportunity to relax and switch off.

'I have often said to people ... "Do you want to talk about things today? Is there anything you need to talk to me about?" and they said "No, I just want to have my massage", and that's fine, and we talk about what was on the telly last night or whatever. It's giving people the option ... they know it's here if they want to talk about things. It's just meeting people where they're at, it's their agenda, it's not my agenda.' (Staff member 14)

Many patients were initially apprehensive about receiving complementary therapy. For some there was unfamiliarity with complementary therapies, although there was a willingness to try these therapies as they were being offered by the hospice.

'"What's that, what is complementary therapy?" I mean someone who's 70 years of age and they're willing to open up because this is a safe haven and it's something that's ok, it's under the umbrella of the hospice so it's acceptable. There are men here who have never been touched in their lives by another human being, or a woman, and we're working with them. I had an old man last year ... and he looked after his mother, I think his mother was dead eleven years, and I don't think he had another person touching him since then.' (Staff member 06)

Staff also found that patients who enjoyed the therapies would encourage other patients to try them.

'You can just see it happening, I suppose in places like the smoke room, where you would have the regulars that would make their way in and be chatting and you might come in on it if you were going upstairs for therapy; you can hear them chatting and discussing their diagnosis, and I suppose that's where complementary therapy comes in, it's a point of conversation for people. They recommend it to each other once one person has had it.' (Staff member 014)

Therapies such as Reflexology and Reiki were available for patients in addition to massage. Reflexology is considered a good introduction, as patients do not have to remove any clothing. It is good for relaxation, and patients tend to breathe more easily and are less anxious when relaxed.

'So what is reflexology good for? We would say it's good for relaxation ... it's a very good introduction, it's very relaxing, people would fall asleep during the treatment, working on the feet, they don't have to remove any other clothing, and good for constipation, good for anxiety, because we find that when people are relaxed they are less anxious and they can breathe a lot easier.' (Staff member 14)

For some patients these therapies seemed to have extremely beneficial and profound effects.

'One man, yesterday, wheelchair-bound—just about can walk, but here he doesn't, he's in his chair, an electric chair—and he said last week he had reflexology and he was on the bus for an hour on the way home ... he could feel the benefit of the treatment that he had because his neck and his shoulder weren't as sore on the journey home, and that he was able to cope better with the discomfort of being on the bus. He was out with his son at the weekend and he was in and out of the van for three hours and he was able for that, sometimes he wouldn't be able for it. Reflexology is something that would work with the whole body but you're only working on the foot.' (Staff member 06)

This complementary therapist went on to give an example of how a Reiki treatment benefited one patient in quite a profound way.

'I'll just give you one example of [Reiki]—there was one man last year who came in and he was really ill, somebody said "he was dying on his feet and can you do something with him". I said "Well, not an awful lot" ... "Could you even be with him?" ... So I literally worked from his head down and I just held him ... he was very ill and he was on the chair lying back ... when you're doing it, you almost top and tail the person just to balance them. He turned round to me afterwards and said "That was lovely, would you mind putting your

hand on my tummy", and I did and he said, "No, will you put it on literally underneath the shirt", and I did. So I sat there and there was great fire I would call it, and that's where there was discomfort.... so afterwards, I said "I'll leave you there and whatever else", so he lay, and I came back down to find him sitting up eating his lunch and he had dessert and seconds.

He said to me that it was the most powerful thing he'd ever experienced in his life ... Now he did die three days later, but he had less discomfort in those three days before he died.' (Staff member 06)

Altered body image

Some patients were apprehensive about receiving complementary therapies. For some this apprehension was related to the alterations to their body as a result of treatments for the illness—for example, radical surgery such as a mastectomy—and sometimes people didn't wish to expose their bodies. Some patients had an altered appearance as a result of drug treatment, and some may have become disconnected to their physical selves because of the changes that had occurred in their body owing to cancer.

'We would feel that our aim is very much taking into consideration that the patient has been through a lot of clinics, a lot of operations, a lot of surgery, have been diagnosed with cancer and if they are attending here they are palliative, so maybe their lifespan is probably shorter than they would have expected because of this, so we kind of zone in on the whole body image, I suppose, side of things if they've had surgery, we try through the different therapies we try and work with their body image if they've had a poor body image.' (Staff member 14)

Many patients were very self-conscious about these body changes, although they often became comfortable as the relationship with the therapist developed.

'We would find that they would end up talking a lot about their tumour site; it might be evident through the surgery or the marks on their body. Or, as in a mastectomy, the fact that that is very evident as well, a lot of them find that their body image is affected. [If] they've lost their hair, we would maybe do a head massage, that wouldn't happen the first day because they may have a wig on and you mightn't even know that they'd got a wig. By the second or third week we find that they might just throw off the wig and they would welcome maybe a head massage. So, it's kind of ... what I'd say we do is building up a trust with somebody.' (Staff member 14)

COMMUNICATION

Communication is fundamental to understanding the patients' and families' needs, and for patients and their families to voice their concerns. 'Communication is the foundation upon which assessments are ascertained, goals of care are developed, and relationships are established' (Steinhauser et al. 2000, 420). Ferrell and Coyle (2006, 286) have outlined four basic elements to communication—imparting information; listening; information-gathering; and presence and sensitivity—which may occur concurrently.

Staff in the hospice day care setting used many of these elements of communication. Patients who attended hospice day care were allocated a named nurse who cared for them while they were in hospice day care, which facilitated the development of a trusting relationship.

The relationship between patients and the nursing staff also helped nurses to establish patient's needs—these can be fluid and changeable as their illness advances.

'I feel so tired, I am getting weaker ... I have diabetes now as I'm taking the steroids and I am not sure if it's that or not. I need to ask them that today.' (Patient 20)

Fahnestock (1999) has suggested that nurses can use a variety of strategies to help address concerns that patients may have, perhaps about what to expect regarding their decline in health and their involvement in decision-making.

'Any kind of talking to people is counselling, listening and you're talking and you're giving them support, you know ... emotionally and psychologically, and we do a lot of talking in here.' (Staff member 07)

Some patients could discuss their own impending death based on this trusting relationship with the nurse. A patient spoke about how she initially did not want to talk to the nurse about her death:

'They said I could talk if I wanted to, but I said I didn't want to talk.' (Patient 05)

Some weeks later, while this lady was speaking with her hospice day care nurse, she instigated the conversation about her impending death.

'But then I asked [the day care nurse] what would it be like at the end? And she said that I would get more tired and more sleepy. I would start sleeping a bit more every day.' (Patient 05)

Good communication is of specific importance in end-of-life care, as the physical, emotional and spiritual condition of the patient may make communication more difficult (Faulkner and Maguire 1994). Seymour et al. (2006) suggest that discussions about advanced care planning should happen before acute and disabling events occur. Being able to discuss issues about impending death and make preferred

arrangements in advance can be reassuring for patients.

'The fact that my body is going for research ... it was worrying me, that was the one thing that I wanted to have sorted out so that was on my mind, like. When I came here and I was able to talk to [name of nurse] about that she explained everything to me. And she said she'd have a further talk with me again as well. And that reassured me.' (Patient 02)

Anticipating for patients

Staff were often able to anticipate many issues for patients because of their experience and expertise in caring for terminally patients. One staff member commented how she may observe changes occurring for patients but there is also a need to allow the patients to decide what they wish to do.

'As you see things changing, you may need to introduce ... "Have you thought about this, or what do you think?"', and often they've read up on things, or they might know things. Although we know what's ahead, we're on the journey with people and it's getting the balance between pointing what they need practically—an example is bringing the bed downstairs. It's a huge thing for people; they don't want to bring the bed downstairs, because it disrupts the house. They mightn't have the room downstairs ... a lady had the bed in the kitchen because there was nowhere else and that disrupted the whole house.

The whole thing of ... "I must be bad now if they're telling me to bring the bed downstairs" and the whole disruption that would cause.

So it's often a negotiated thing, you might say to someone one week ... "I think you're having difficulty on the stairs, would you consider bringing a bed in?"... "No way, no way." The next week ... "How are things?" "Well, I'm struggling." ... "Well, have you thought about that?"... "No"... and then the next week "I'm going to bring the bed downstairs". It's maybe getting the idea in someone's head and then when they're ready to do it, they will—whereas other people will say no, that's fine too, you know they're never ready. It's people's choice.' (Staff member 03)

Advocating for patients

Nurses played a key role in advocating for patients' wishes and preferences and communicating these to family members and other health care providers. Staff made an effort to get to know patients and their families. Over the period of time that the patient attends the service, hospice day care staff become very aware of each individual's circumstances and needs. As patients get to know and trust different staff members, they begin to confide their fears and worries, as some patients are unable to talk to their family.

'I can't talk to my family, I can't, I'm afraid to open up to them, I'm afraid I give them pain unnecessarily.' (Patient 18)

'Some patients open up to a member of staff about what their concerns and worries are; they probably tell their husband and their family one thing, but then they're probably holding an awful lot in that they can't express to the immediate family, and then if they come in here, they'd have the social worker, the nurse, the carer, whoever they choose to talk to. I think that's a great relief for anybody; there can be little deep things that they can never get out, but they can do it here.' (Staff member 12)

Many patients also found it difficult to discuss the issue of their death with their own families. Nurses were particularly helpful in acting as an advocate for patients regarding their wishes and preferences when the patients felt unable to have these discussions themselves with their families. A conversation, detailed below, shows the nurse using an open approach to allow the patient to discuss her desired end-of-life care.

'Have you thought about where you'd like to be at the end?' (Staff member 02)

'I'd rather not think about it.' (Patient 05)

'Ok, ok.' (Staff member 02)

'Well, I'd like to be at home if I could.' (Patient 05)

'Ok, ok. Does [daughter] know what you would like?'

(Staff member 02)

'Well, no.' [Silence] (Patient 05)

'Would you like me to talk to them?' (Staff member 02)

'Yes, yes, I would.' (Patient 05)

Listening

Listening was used by many of the staff to allow the patients to tell their story in their own words. Being allowed to tell their story from their own perspective in a safe environment was a source of comfort and was therapeutic for many patients. According to Tschudin (1995), listening is the beginning, middle and end of helping. Facilitating story-telling can stimulate a process of life review that contributes to a patient's sense of meaning in their life (Frankl 1985). A member of staff illustrates how she facilitated story-telling within the hospice day care setting.

'I would listen to the story over and over again and it was just her whole pain is what she was communicating, and the fact that she knows she is terminally ill, it was bringing up things from her past, an issue that happened, that she cannot forgive herself for ... and it is dragging her down. So, anyway, I tried to think of some way that would help her to move from this awful place. You know, it is about letting her express it and to be in it, but in some way maybe to be able to move on a bit from it, because it actually was making her life such a misery, you know, she was just so down.' (Staff member 21)

GOING DEEPER

On a surface level, hospice day care seems a happy place with lots of talk and laughter, but it is also a place where patients' health is declining as they approach the end of their lives. Many patients were aware that fellow patients in hospice day care were unwell and that their health was deteriorating. Patients were often reminded that many of their friends were no longer attending day care.

'I see others slipping each week I come in, I see them getting weaker and I know it's happening to me too.' (Patient 13)

'The nurses would say that they died and they would mention that. I find that can distress him more, not that he would mourn their loss because he wouldn't have known them personally enough, but the fact that it's a reminder that they're not here for a party, it's not a Tuesday club. They're all on the same journey, that's the sad part of it, it's not going to last forever, it is journeying onwards, so that's a little distressing.' (Carer/family member 09)

Patients conversed among themselves about patients who had attended hospice day care and who had since died.

'My husband would come home and say four people that he had known since he started in day care are now dead and they're not coming any more; they seem to talk about it [patients who had attended day care and who had since died in the in-patients unit] among themselves and talk about going "upstairs".' (Carer/family member 08)

When patients who had attended day care died, nurses acknowledged their death formally. A nurse gives a short remembrance reflection in the main lounge, with the day care patient group, to acknowledge the patient's death. The patients seem to know and sense when this is about to occur. Patients may find this difficult, as it raises the question of when this reflection will be done for them. Some patients quietly leave the room; others look down at the floor.

The calm atmosphere created by the staff in hospice day care seemed to allow patients the peace and time to slow down. A patient's wife remarked on the tranquillity of the hospice, which helped her husband move at a different pace.

'I would say he probably liked the taking of time out ... there is a tranquillity here that's very nice and I think all of that helps, I think the slowing down in pace and the calmness.' (Carer/family member 08)

The illness itself allowed time for preparation that some patients were grateful for.

'Often you'd find elderly people would come and say to me "I've been blessed with this, that I haven't had a heart attack or something like that, that I have this time to make my amends and ask for forgiveness and clear the path that God has given me". I had one particular man, "I've been graced that I've got this and that I'm going to be prepared now when I do die".'
(Staff member 06)

Spiritual care is an important aspect of the palliative care model. As already discussed in Chapter 1, definitions of spirituality can be difficult to pin down, although there is an acceptance that spirituality can be considered a search for existential meaning.

'I see spirituality as a very, very big part in the whole care of a person when they come here. I see it as a very valuable contribution to the service and to the whole care of the patients and often it is hard for me to put it into words what we do to facilitate it. It's about trying to facilitate the patients to find peace, it could be like meditation ... a lot of the time it can be about silence.'
(Staff member 21)

There are also considerable overlaps between religious and spiritual needs and desires (Speck 1998). This is especially so in an Irish context, where spirituality and religion are more closely bound together (MacConville 2006). As that study suggests, people may return to religious practices and rituals at the end of life. Hospice day care provided the space to allow patients to reconnect with their spirituality and religious practice, if desired. For some patients their terminal illness and deteriorating health has returned them to their religious practice.

'Well, he [patient 05] wouldn't be particularly religious. He attends Mass at Easter and Christmas. But I find since he started coming to day care he comes to Mass on the two days he attends day care. Maybe it's his way of dealing with his mortality ... In day care he has the opportunity to do these things.' (Carer/family member 05)

Patients may have practices and rituals that they wish to maintain because of their values and beliefs. Many patients described how their illness had interfered with their usual practices.

'It's great, I can get to go to Mass in here. I have not been able to go for the last few months ... It doesn't matter now if I can't go on Sunday.' (Patient 01)

Some patients were relieved that they could deal with unresolved issues from their past. They wished to return to their religion's sacraments and they requested to speak with a priest within the hospice services.

'It was troubling me for a long time. I have not been to the sacraments for years ... I was talking to [a staff nurse in day care] and she offered me the choice of meeting the priest ... I went to confession and it's a weight lifted off my mind ... I am so relieved now.' (Patient 015)

The availability of chaplaincy and pastoral care in day care facilitated a spiritual connection and preparation for patients if they wished to have this.

'A lot of the time it can be sitting beside someone who is anxious and very, very ill ... it can be about silence and about trying to be there, and that might not seem very much, but I am convinced that when [patients] ... are very, very sick ... there is something about being really, really present to that person, praying quietly with them as they prepare for their death and I see a great value in that.' (Staff member 21)

A FAMILIAR PLACE

Attending hospice day care offered the opportunity to become familiar with the hospice. Whilst at the time of referral many patients and their carers/family members expressed anxiety and fear of the hospice, as documented in Chapter 1, over time people became familiar with hospice and the service.

'And now that I'm in the hospice I've seen every part of it and I'm not afraid of it ... I want to die in the hospice.'
(Patient 07)

Day care was seen as a bridge between home and the in-patient unit—a middle ground or an 'in-between place' (MacConville, forthcoming). Some patients who were already in the in-patient unit in the hospice also came to hospice day care on their regular day, and patients who attended day care were anxious to hear what the in-patient unit was like.

'It's [the in-patient unit] like a hotel. The staff are lovely. The meals are lovely and you really don't want for anything.' (Patient 22)

Hospice day care nurses are in regular contact with patients and family members and, as patients get physically weaker, they discuss the changes they are seeing in the patient. Whilst many patients may initially have wished to remain at home for end-of-life care, as their physical health declined many expressed a desire to receive end-of-life care in the hospice in-patient unit.

The day care staff are very familiar with the patients and their condition, as they have been assessing them over time. This means that they are in a good position to assess a patient's need for admission, if necessary, to the in-patient unit for terminal care. Bed meetings are held each morning in the in-patient unit. A member of staff from the day care team attends the meeting, and if they have a patient who requires admission they list that person for a bed.

'I can see things are changing for her. I think we need to plan to look for a bed for her in the unit.'
(Staff member 04)

The relationship that has developed over time between patients and the day care staff can reduce concerns that patients may have about the in-patient unit. Many patients were brought on a tour of the whole hospice and this helped to reduce anxieties and made the whole hospice environment a familiar and safe place.

'[Day care nurse] took me on a tour of the hospice itself and I am happy to come here to die.' (Patient 02)

SUMMARY

This chapter has considered the transitions involved for patients and their families as their illness progresses. It has considered the ways in which the day care service facilitates and supports a deepening awareness of the reality of approaching death. While service providers draw on a wealth of experience and knowledge of what lies ahead for patients and their families, they respond to the individual and frequently changing needs of each patient. The relationship that develops over time helps to foster trust and familiarity between patients, family members and the palliative care service. The hospice, a cause for anxiety and concern at the beginning of patient and family contact with the service, can become a familiar and welcoming place.

A MYRIAD OF
STEPPING STONES

6



INTRODUCTION

This study has sought to examine the role of the hospice day care service in the care of patients with life-limiting illness and their families. Specifically the research set out to describe the context in which hospice day care is delivered in terms of the structure, process and outcomes of the service and to examine the perceptions and experiences of service providers regarding the contribution of hospice day care in supporting individuals with life-limiting illnesses and their families.

The study also sought to explore patients' experiences of attending hospice day care over the course of their illness in addition to family members/carers' perceptions of the contribution made by hospice day care. The research was conducted over a period of nineteen months in order to provide an understanding of patients and family members/carers' experiences and perceptions of hospice day care over time. This longitudinal aspect of the research provided the opportunity to talk with patients and family members/carers after they had experience of the hospice day care service. In addition, the lengthy period of observation greatly aided a deeper understanding of the complex interactions and interventions undertaken by hospice day care health service providers on behalf of the patients and their family members/carers.

Chapter 3 described the physical and social environments of day care and the variety of activities and services that are available for patients. It was clear from the research that hospice day care provided a warm and welcoming environment; nevertheless, engaging with the day care service in the hospice in the first instance can be a difficult step to take for many patients and their family members/carers.

Holistic care of the terminally ill person is a fundamental part of the model of palliative care and also encompasses care of the family. By its nature, holistic care requires an interdisciplinary approach, and Chapter 4 has examined the workings of interdisciplinary teams in practice. This level of care involves attention to needs across a spectrum of domains, i.e. holistic care, in order to improve the quality of life for patients and their family members/carers. Health care providers in hospice day care managed not only the holistic care of individual patients but also complex interactions with internal specialist palliative care services and external health care services, reflecting the nature of interdisciplinary working, in addition to providing respite and telephone support for family members/carers.

Chapter 5 examined the way in which health care providers in hospice day care facilitate and support patients and family members/carers through a number of transitions and changes—by anticipating the needs of patients and advocating on their behalf. The significance of these interactions and interventions were not apparent at the outset, in much the same way that patients and family

members/carers have little understanding of the benefits of the service when they first engage with it. Over time these benefits become apparent for many patients and their family members/carers, as they also became more visible to the researcher.

This chapter draws together the findings of this research and discusses the complex weave of physical, social, philosophical, practical and professional aspects that comprise the holistic care of patients and their family members/carers in hospice day care.

PROVIDING A SAFE HAVEN

From its foundation the hospice movement has sought to provide 'the kind of family that can give the kind of welcome and hospitality of a good home' (Saunders 1965, 2). Lawton (2000) noted that, even given the temporary nature of the day care pilot scheme in her UK study, funds were made available to make purchases to create a 'home-like' appearance (including rugs, lamps, cushions, floral crockery) and to furnish the day room with easy chairs, settees, a large fireplace and a Welsh dresser displaying decorated plates (*ibid.*, 54)—all of which bears a resemblance to the day care centre in this study.

While many care facilities are now designed to create a home-like atmosphere in order to reduce the feelings of fear and isolation that traditional health care facilities can induce (Godkin 1980), the need to manage patient and family members/carers' fears about hospice make this particularly pertinent. It is clear that within the day care service in this study considerable attention was given to the physical and social environment in order to create a home-like atmosphere

Crossing the threshold

The day care service provided by the hospice aimed to accommodate as many patients as possible, although there was always a waiting list for access to the services places. The majority of referrals to the service came from the community palliative care team in the hospice, and although they clearly identified people who may be helped by the service, not all patients and families wished to avail of this opportunity. As was evident from conversations with members of the community specialist palliative care team, some families never attended the service although they had a referral. Staff felt that this could be due to fear and anxieties about being in the hospice, as this was an inherent acknowledgement of the state of their disease. Family members may struggle between wishing to retain a degree of privacy while at the same time recognising that a diagnosis of cancer can bring a level of public exposure. Family members may also be reluctant to relinquish the care of their family member. As one of the respondents stated, '*it is hard starting to hand over your loved one to someone else*' (family member/carer 18).

In MacConville's (forthcoming) exploration of relationships and place within palliative care, the move to the day care service acted almost like a 'stepping stone' towards the in-patient unit of the hospice, a step that some patients may be unwilling to take. In spite of an increasing public awareness about palliative care, many of the patients referred to the hospice were of an age that may still have ideas of hospices as solely places where people go to die—'*I said people die in the hospice*' (Patient 03)—rather than as places where skills, expertise and facilities exist which can radically improve a patient's quality of life.

Little is documented that specifically considers the referral to hospice day care or the transition process that this involves; Schofield et al. (2006), however, in a review of the literature relating to the changes that patients and their families experience when they move from the acute services and initially engage with the palliative care services, found a number of relevant themes. These mainly involved the preparation and timing of discussions, identifying the information needed, responding to patients' emotional responses as well as carefully introducing palliative care services.

The findings from this study suggest that members of the community palliative care team helped a transition to hospice day care services by informing patients and families about the wide range of services available in hospice day care and not just concerning symptom management. An opportunity was also given to patients and their carers to visit the hospice day care service to see the facilities on offer. This approach follows strategies suggested for the transition from acute care to palliative care (Schofield et al. 2001; Clayton 2005).

Managing the transition

It is understandable that there can be a level of reluctance to engage with palliative care services as, notwithstanding the rehabilitative approach of palliative care, and hospice day care in particular, there is no doubt that hospices are concerned with the management of terminal illness. Hockey (1990) has argued that there is a threshold between life and death that the hospice movement manages through a framed encounter, and Frogatt (1997) suggests that hospices may be regarded as liminal spaces as they are structured to manage the process of dying. Frogatt further states that 'access to the hospice care involves crossing a boundary which marks the entry into a liminal space' (ibid., 128). Crossing the threshold, therefore, can be a considerable step to take for patients and their family members/carers and involves a substantial transition.

Within the context of palliative care, transition can refer to the individual's passage through one set of hopes and expectations to another (Davies et al. 1995). Although patients were initially very apprehensive about attending hospice day care, once they were engaged with the service many patients in this study moved from a state of anxiety and

fear to experiencing hospice day care as being the 'highlight of their week'. Many of the patients, and indeed the family members/carers, were impressed by the hospice on their first visit and spoke of feeling relaxed when they saw the physical setting and of being made to feel very welcome by staff.

The day care staff were acutely aware of the significance of this transition; considerable effort was made to make people feel welcome and to familiarise them with the building and facilities in the knowledge that a patient's experience of the first day would have an impact on whether they would continue to attend hospice day care. It is clear that staff paid considerable attention to getting the balance right—being welcoming without being overwhelming—a balance that can be difficult to achieve.

Reaping the benefits

Hospice day care provides a close monitoring of the physical condition of patients in addition to a range of social and therapeutic activities and interventions. The access to specialist health professionals and social and peer support were considered by Low et al. (2005) to be the key factors contributing to a perceived improvement in a patient's quality of life, increased confidence and self-esteem, a feeling of well-being, a reduction in social isolation and a new outlook, as previously discussed.

This is also reflected in the findings from this study, where patients were referred to hospice day care services for a variety of reasons, such as symptom management, support for family members and carers or to ease social isolation. Patients in this study also valued the opportunity to have their symptoms monitored by health care professionals, and for some patients this was the main reason for attending the service. For example, the physical condition of one patient required intensive attention from the nursing staff in order for dressings to be changed and for a bath to be taken, a level of attention that is not easily available outside of specialist health care services.

Living with a terminal illness can lead to patients experiencing increased loneliness and social isolation, which may result in a disconnection with their families, peers and communities (Mulkay 1993; Lawton 2000). Many patients in this study experienced some degree of social isolation, such as being unable to take part in their former social activities or to attend church services, resulting in a disconnection from normal social activities and exchanges. For many patients, attending hospice day care provided the opportunity to re-engage with social activities such as card games or bingo, to attend a hairdresser or to go to Mass, and were valued as a restoration of some sense of normality.

Becoming connected

Considerable effort was made in both the physical and the social environment not only to create a homely physical setting but also to encourage a sense of connectedness with staff and with other people attending the service. Lawton (2000) has described a range of informal strategies in which staff, volunteers and patients engaged to create, within the day care setting in her study, a 'safe retreat' (*ibid.*, 36). Within this 'safe retreat' patients claimed that they both felt and were treated like 'normal people' (*ibid.*, 36), which frequently contrasted with their experiences outside of the centre. Some of these informal strategies involved staff, volunteers and patients all sharing a meal together during the day; sharing food in a communal setting can help to create social connection, as previously discussed (Goody 1982; Delphy 1984).

Lawton's findings mirror much of what was found in this study, where the efforts to create a relaxed, home-like atmosphere also resulted, for many patients, in a sense of belonging and camaraderie. This sense of camaraderie was reinforced by the connection that patients had with each other—their advancing illness—and they often referred to this as 'all being in the same boat'. Similar sentiments were expressed by day care patients in the Lawton (2000) study—'we are all kindred spirits. We look out for each other here' (*ibid.*, 63).

Cancer is a common disease that can cause varying problems, depending on the site of the body that is affected. Many patients with complex symptoms are now referred earlier to palliative care. These patients are now surviving longer and may have higher levels of disability as a result of receiving more intense and prolonged treatments (West 1993). Hospice day care can offer a support system for patients to normalise their life and live actively for as long as possible (Neale 1992). Patients may feel guilty about being ill and may see themselves as a burden to their family, friends and the community as they become more dependent and immobilised (Proot *et al.* 2003). Associated with this may be feelings of being useless to themselves and to others, which may cause these patients to feel undervalued and to have lowered self-esteem (Chochinov *et al.* 2007).

Many studies of end-of-life care have identified the importance for patients of being treated with dignity (McNamara 2004). Within this hospice day care environment, staff displayed kindness, warmth and compassion to all patients, who were treated with dignity and empathy. The level of care and attention that patients and their family members and carers received from staff in this study also reinforced a sense of belonging and a feeling that the staff were genuinely interested in them and their families. Again, this level of care on the part of health care professionals involved in the day care service is echoed in the Lawton study: 'the patients here are very special ... people come here to be loved and cared for. It's being able to offer this that makes our work so rewarding' (Lawton 2000, 62).

The task of staff working in hospice day care involves creating an environment in which people with terminal illness can continue to find meaning and purpose in life (Kennett 2001). This environment can help clients to access their own resources in coping with terminal illness. Herth (1993) identified four categories of hope-fostering strategies within the context of terminal illness—relationships; humour and reliving memories; inner strength; and goal-setting.

Hospice day care in this study was seen to fulfil many of these aspects for the terminally ill patient through companionship with other patients and participating in activities, all of which were helpful in increasing patients' feelings of well-being. Patients also had an opportunity to relive past experiences with their peers, enabling them to reconnect with their past and recall what they achieved before their illness. Humour and laughter can be signs of normality and joy (Holden 1993) and it was clear that day care was seen as a place of pleasure, enjoyment and fun.

Balancing social and physical needs

Palliative care day care services aim to manage patients' pain and symptoms, which can frequently be difficult and distressing, as well as meeting other needs that patients and their family members/carers may have. Singer *et al.* (1990) have outlined that as patients approach their impending death their primary concerns include receiving adequate pain and symptom management, avoiding prolonged dying, achieving a sense of control and strengthening relationships with loved ones.

In this study a range of palliative care professionals were available to address issues of symptom management, in addition to the provision of a range of social and therapeutic activities and interventions. A number of studies of hospice day care services suggest that patients value the social dimension of hospice day care rather than the medical domains (Faulkner *et al.* 1993; Wilkes 1999; Kennett 2000; Lee 2000; Hopkins and Hallett 2001; Goodwin *et al.* 2002; 2003). The Low *et al.* (2005) study found, however, that from the perspective of patients the main benefit of the service was the access to palliative care health professionals, particularly as these professionals were available all in one place. It was also clear from the Low *et al.* study that the relationship established between patients and health professionals within the day care service facilitated discussions about their illness, providing a sense of security and peace of mind.

This study, in utilising a longitudinal approach, highlights that both aspects of the service—social and medical—are important and articulate with each other to provide a holistic service for patients. The various social activities provide a sense of normality for patients and assist in developing relationships—with other patients and also with staff. As relationships develop, a high level of trust can be engendered—with the staff and the service—that in turn can

render patients more open to a range of interventions, such as availing of the complementary therapies, which can have a therapeutic effect. Patients in the Low *et al.* (2005) study also expressed a high level of trust in palliative care professionals and had confidence that any physical (or other) problems would be addressed, as the service monitored them closely.

In many cases, in order for patients to enjoy the social aspects of day care, their physical symptoms, such as pain, nausea or fatigue, need to be addressed. Thus both models of service delivery, the social and the medical, are needed to maximise the benefits of the service for patients and family members/carers.

The majority of patients attending day care service enjoyed, and appreciated, both aspects of the service. Not all patients wished to participate, however, or to have a high level of involvement with the social aspect. Some patients, as presented in Chapter 3, were content to sit on the periphery of social activities or just to avail of the access to the specialist palliative care health professional services for symptom management. In maintaining a balance between the social and medical models, this is a further aspect that needs to be individually adjusted and fine-tuned to meet the needs of each individual patient.

HOLISTIC CARE IN PRACTICE

Many patients with advanced cancer have complex physical and psychological symptoms that cannot be dealt with by one discipline or care team (Jarrett *et al.* 1999). Interventions by specialist palliative care teams have been found to have a greater impact on patients in comparison to standard health care interventions—better symptom control, an increased satisfaction of patients and carers, a reduction of time spent in hospital, resulting in more time spent at home, and an increased likelihood of patients achieving their desired place for dying (Hearn and Higginson 1998). There is also a high level of consumer satisfaction with palliative care (Wilkinson *et al.* 1999).

In this study, both patients and their carers expressed satisfaction at the care they received from various members of the palliative care team, finding staff flexible and responsive in their approach and able to adapt to their changing needs as their health declined. Holistic care of the patient and family is the corner stone of the philosophy of palliative care. The practice of holistic care, however, involves multiple interactions between interdisciplinary team members in addition to internal and external health care providers. As such it is a complex model, and while the benefits can be clearly seen, many of the intricate workings of this holistic model are not so easily visible.

Interdisciplinary care

The WHO (1990) identifies palliative care as an approach to care that supports patients to live as actively as possible until death. An interdisciplinary approach to care is necessary in order to address and respond to the many needs of the patients and their families. No single team member has the range of skills needed to address the changing needs of these patients over time. To provide high-quality symptom control requires all disciplines to work collaboratively (Kuebler *et al.* 2005).

In this study, the day care service was nurse-led and managed, as are the majority of palliative care day care teams (Ingham and Coyle 1997; Davies and Higginson 2005). This interdisciplinary day care team also included doctors, occupational therapists, physiotherapists, complementary therapists, chaplains and social workers. In seeking to holistically address the multi-dimensional needs of patients and their family members/carers, there is a need for very considerable and coordinated interactions with and between team members.

In seeking to address individual needs and to improve quality of life for patients and their families and carers, members of the interdisciplinary team adopted a rehabilitative approach, as documented in Chapter 4. A broad definition of rehabilitation is 'a coordinated, interdisciplinary program to restore an ill or disabled individual to his or her maximum capabilities in physical, mental, social, vocational and economic usefulness' (Miller *et al.* 1980, 1021). In a palliative care setting, however, it may be unrealistic to expect a restoration to economic usefulness when faced with advanced cancer. Instead, as Hockley (1993) suggests, rehabilitation for patients with advanced cancer may be viewed as a process of adapting to the changes that are occurring, and Hockley advocates an active approach in managing complex symptoms.

Within a rehabilitative model of care, a collaborative approach envisions a range of professionals working together to observe and monitor the changing needs of patients (Nocon and Baldwin 1998). In this study, the benefits of such an approach, for example with the patient who was assisted in returning to her gardening activities, clearly can have a profound effect on quality of life for patients. This approach requires very considerable resources, however, in addition to excellence in team working and communication.

From the results of this study it is evident that palliative care day care is ideally positioned to provide a rehabilitative approach to care, and in this instance does so very well. The rehabilitative approach, using the interdisciplinary skills and expertise, can address patients' physical, psychological, social and spiritual needs and thus can have a very positive impact within an environment that acknowledges individuality and the need for flexibility.

Towards a continuity of care

Continuity of care has been defined as a 'consistent access to care with few interruptions in staff or service provision regardless of location' (Wilson 2004, 23). Nevertheless, a combination of modern advances and medical knowledge and technical advances may lead to a fragmentation of care (Byock 2006). Structural elements of the health care system and delivery models also make continuity of care difficult to achieve (Byock 2001). These factors can lead to a reduction in the quality of care that people receive (NICE Guidelines 2004). The typical patient encounters multiple health care services and organisations, each with its own policies and procedures, which can give rise to a considerable degree of stress (Conkling 1998). Patients may also experience numerous caregivers and physical surroundings.

Continuity of care requires a shift to a patient-centred approach to care delivery and as such fits within the palliative care model. Coordinating end-of-life care from one access point has been recommended in the End of Life Strategy (Help the Hospices 2007) and is considered fundamental for improving the quality of life for patients, family members and carers.

In this study, the day care service health professionals sought to provide a continuity of care on a number of levels. Firstly, within the specialist palliative care services it was arranged that the same team members cared for patients attending hospice day care each week, thus enhancing continuity of care and developing a familiarity that played a part in reducing anxiety for patients and their carers. Secondly, staff also managed the interfaces between the other aspects of the specialist palliative care service—the community palliative care service and the in-patient service. When required and available, day care patients may avail of community palliative care services, respite care and/or in-patient services.

The day care service also sought to minimise the fragmentation of service that many patients may experience in their ongoing contact with external health care services. Staff frequently acted as advocates for patients: for example, rearranging appointments in hospital and coordinating care from primary care providers. In effect, the hospice day care acted as a bridge between specialist palliative care, acute hospitals, community services, informal carers and the patient's home, with the patient being the central focus.

Beyond the patient: supporting family members and carers
The 2001 Health Strategy advocates primary care as the central focus of the delivery of health and personal social services in Ireland. Primary care provision is viewed as the most appropriate way in which to meet up to 90% of all health and personal social service needs (Department of Health 2001).

Studies in the UK have found that most people state a preference to die at home (Townsend *et al.* 1990; Karslen and Addington-Hall 1998; Higginson 2003), and this is equally true in Ireland (Tiernan *et al.* 2002; Irish Hospice Foundation 2004). In Ireland, current policy is directed at trying to increase the proportions of deaths that occur at home, and care packages have been developed to enable people to continue to be cared for at home (Department of Health 2006). While this policy is laudable, there is little recognition of the problems that patients and their informal carers may confront in accessing help and support during a final illness (Payne 1999).

The provision of community specialist palliative care services or home care services helps to keep terminally ill patients at home for as long as possible (Irish Hospice Foundation 2006). However, the degree to which palliative care needs can be met successfully in the home environment is also dependent upon the close involvement and availability of an informal carer for the dying person (Gomes and Higginson 2006). Informal caregivers in end-of-life care are generally the family members, friends and neighbours of people who are dying (Neale 1993).

Caring can be physically and emotionally costly and, in the case of palliative care, the level of anxiety for carers can be extremely high. Family members/carers can experience mental, emotional and physical ill health, in addition to high levels of burden, when caring for an individual in the home (O'Connor and Ruddle 1998; Blackwell *et al.* 1992; O'Donoghue 2003). In an extensive study of carers in Ireland (Care Alliance Ireland 2008), the health status of a random sample of family carers in receipt of a state carer payment was examined. This research showed that family carers were less likely to report themselves in excellent or very good health in comparison to the general population. Furthermore, an in-depth case-study by the Canadian Hospice Palliative Care Association (2004) found that a lack of services and support for carers can result in burn-out and have long-term negative consequences.

Patient and family-centred care is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships between patients, families and health care practitioners (Kovacs *et al.* 2006). This approach to care is a basic tenet of palliative care philosophy that recognises the terminally ill patient as part of a family. Family-centred care is based 'on the understanding that the family plays a vital role in ensuring the health and well-being of patients' (*ibid.*, 16). The ultimate goal of patient- and family-centred care is to create partnerships between health care practitioners, patients and families that will lead to the best outcomes and enhance the quality and safety of health care for the patient (Davies 1994).

Multi-tiered support

Maintaining the terminally ill person at home can require a complex mix of material, social and professional support being available to the carer (Hinton 1994), which may also include the provision of information (Payne *et al.* 1999; Soothill *et al.* 2001; Higginson and Gomes 2002). Family members and carers provide a significant amount of personal, as well as medical, care (Payne *et al.* 1999; Aranda and Hayman-White 2001; Thomas *et al.* 2002). In dealing with increasingly complex care, carers are known to employ a variety of coping strategies, varying from denial to normalising the caring situation (Rose *et al.* 1997, 126). These coping strategies may include finding some way to find time for themselves (Hull 1992). In addition, gaining information from health professionals is considered to be a helpful coping mechanism (Martens and Davies 1990).

In this study, staff in hospice day care supported family members and carers in a number of ways. Firstly, staff had regular contact with family members/carers through meetings and telephone communication. This weekly communication with the hospice day care nurses gave carers an opportunity to express their concerns and needs, and more frequent telephone contacts were made if the patient's condition warranted this. This regular communication allowed staff to be aware of any potential or actual problems that carers might experience. The provision of telephone support, as was the case in this day care service, has considerable benefits for carers (Cox 1993). Wilson (2004), in a review of end-of-life care in Canada, states that 'timely care is critical to the identification of potential or existing problems, the prevention of problems, and the early and successful resolution of problems' (*ibid.*, 24).

A second level of support was provided by the specialist palliative care service, as patients and family members had access to a 24-hour telephone service. This service, manned by experienced hospice nurses, was of great benefit to carers and patients and a key resource in supporting family caregivers. In addition, the day care service also assisted carers in accessing care packages from local Health Service Executive centres, as many carers can also be dependent upon material support being available (Hinton 1994).

Family members and carers can also experience a high level of anxiety whilst caring for their terminally ill relative or friend—they frequently can suffer more anxiety than the patient (Higginson *et al.* 1990; Hinton 1994). Access to respite care is essential in order for carers to continue in their role (Grunfeld *et al.* 2004). In this study, when patients attended the day care service it provided a welcome, although short, break for family members/carers. Hospice day care staff also negotiated respite care for patients in the in-patient unit of the hospice or in other nursing homes in the community to give the carer a break from the strain of caring. This was not always possible, however, as respite care for patients was not always readily available or accessible.

BENEATH THE SURFACE

The initial engagement with the palliative care day care services can be difficult for patients and their family members and carers, as previously discussed. The interwoven social and medical models of the day care service work together to create an environment in which most patients feel comfortable, secure and part of a social community, in spite of initial reluctance or misgivings.

For patients and their family members and carers, the main thrust of the palliative care day care service may seem to be the provision of a social programme of activities, with the additional benefits of access to health care professionals. But while this may seem to be the case initially, the longitudinal nature of this research helped to make visible the very considerable, and complex, work that lies beneath this surface.

In this study, patients remained in day care for as long as they were able, and were not discharged from the service unless they chose to withdraw or to curtail their own involvement, as some patients in this study chose to do. Some day care services studied elsewhere, for example in the Lawton (2000) and Low *et al.* (2005) studies, discharged patients from the service after a number of weeks. Although staff in these services, and volunteers in particular in the Low *et al.* study, found discharge of patients difficult, patient contact with the services was generally of short duration. Staff, and patient, difficulty with discharge from these services was also highlighted in the Douglas *et al.* (2003) study of five day care centres around London.

A growing awareness

This difference in policy enabled a deep connection to be made by patients with the staff and the service, and by staff with the patients and family member/carers. The longitudinal nature of this study also facilitated a deep connection over time on the part of the researcher and assisted in making visible the nature and extent of this relationship. For patients, and by extension their family members and carers, the extended contact with the day care service in this study enabled a shift from a surface level of engagement—with the social activities—towards a deeper realisation of their impending death and the preparations that might be necessary.

'It's not a Tuesday Club'

The social connections that were developed in the day care service amongst patients who attended on the same day were a source of much comfort and enjoyment for most patients. Friendships were made and for a while some sense of normality was regained. Given the nature of the service, however, it is inevitable that patients will, over time, become too unwell to continue to attend, or may die whilst still attending day care or on admission to the in-patient unit in

the hospice. Learning of the deaths of other patients can be difficult for patients in day care, bringing an awareness of their own mortality.

In the Lawton (2000) study, the original policy of the service was to formally inform those attending day care of the death of patients. It was planned to do this by allocating a time when the whole group could reminisce together about the deceased person and light a candle to mark their passing. In practice, according to Lawton (2000), the news of a patient's death was managed in such a way as to minimise damage to the day care 'alternative reality' (*ibid.*, 70), and patients were individually taken to one side by staff and informed about the death. Lawton further notes that on a number of occasions a bereavement counsellor was brought in to discuss the death privately in a separate room with patients who were particularly close to the person who had died (*ibid.*, 70). Lawton argues that this practice served to keep the topic of death at the fringes of the group in day care.

The day care service in this study took a contrasting approach to the deaths of patients who were attending, or had attended, the service. As documented in Chapter 5, many patients were aware of their own and other patients' declining health. As one respondent said, '*I see others slipping each week I come in ... and I know it's happening to me too*' (Patient 13), and it was clear that patients spoke amongst themselves about others who had attended the service and who had since died.

Staff formally acknowledged the death of patients who had attended the service, giving a short remembrance reflection in the main lounge, with the day care patient group. There was no doubt that this was uncomfortable and difficult for some of the patients attending the service, with some leaving the room or staring at the floor. Some patients were upset by the personal loss of someone they had come to know, and others by this reminder of their own illness and prognosis.

It is interesting to note that in the Lawton study (2000), while no formal acknowledgement of deaths was made, a number of patients left the service after several deaths had occurred in quick succession. It was, as Lawton remarks, as if the 'alternative reality' was undermined as patients found the reminders of their own mortality too distressing (*ibid.*, 71). The difference in approach may signal an important cultural difference. In Ireland there can be a greater public acknowledgement of death, and recognised rituals to deal with it (Larkin 1999; MacConville, forthcoming 2010).

Notwithstanding these cultural differences, it was clear that the formal rituals to acknowledge the death of patients served as a reminder to others attending day care of their own journey, and while this reminder was not always a comfortable one, it may ultimately be a helpful one. As one relative recounted, it was a reminder that all the patients in day care were 'on the same journey ... it's not a Tuesday Club'.

Formal and informal preparations

Contact with the day care service over a period of time facilitated a process of preparation that some patients were willing to engage with, either formally or informally. It is interesting to note that other studies on day care services make no explicit references to the preparation, either formally or informally, for death and dying. This is not to say that this does not occur within these settings, but perhaps the longitudinal nature of this study has made these aspects more explicit. As previously discussed, good communication is of specific importance in end-of-life care, as the physical, emotional and spiritual condition of the patient may make communication more difficult (Faulkner and Maguire 1994).

Few people have discussed their preferences for end-of-life care with a family member or friend. In the absence of open discussion about death, it can be difficult to broach the subject with people as they are approaching the end of life. Often conversations about death are avoided in families until a crisis arises. This can lead to inadequate advance care planning, and patient preferences are not honoured. If there has been no discussion in advance, it may be difficult to facilitate patients' preferences for place of end-of-life care and for place of death (Emmanuel and Singer 2000). As Seymour *et al.* (2006) suggest, discussions around issues of advanced care planning should take place before acute and disabling events occur.

Being able to discuss issues about impending death and make preferred arrangements in advance can be reassuring for patients. Staff at hospice day care were ideally positioned to discuss individual patients' preferences, and in this research it was clear that this could be facilitated by any member of the interdisciplinary team. These end-of-life discussions may occur on a regular basis and could be initiated before the patient's condition deteriorated, as this impending deterioration could affect the patient's capacity to communicate their wishes (Froggat *et al.* 2009).

The benefits of being able to discuss, and in some cases to formalise, arrangements was documented in the preceding chapters; for example, one patient intended to leave her body for research but was unclear how this was to be done. A trust in the day care staff and an established relationship helped in resolving this issue, and left the patient feeling reassured about the necessary arrangements and also that her wishes had been heard and acknowledged.

Staff frequently anticipated matters and advocated on behalf of the patients, particularly with regard to issues about death and dying that may be difficult to talk about with family members, such as a preference for dying at home. In one case the staff anticipated this issue early enough for it to be raised with the patient's daughter, allowing enough time for preparation for both the patient and the family members.

The established relationship with day care also provided the opportunity for staff to anticipate changes that might be happening for the patients and to make preparations with both the patient and the in-patient unit. Day care patients were familiarised with the whole hospice over their period of time in day care, a familiarisation that frequently removed or lessened some of their initial fears of the hospice. In addition, as was previously documented, staff in day care attended a daily bed meeting in the in-patient unit that enabled them to list one of their own patients for admission, subject to availability of accommodation.

Stepping-stones

Day care service has been described as a stepping-stone to the in-patient unit of a hospice (MacConville 2004), but in this more detailed study it is more accurately described or understood as a series of stepping-stones—to a myriad of places.

Spiritual care is an important aspect of the palliative care model. While definitions of spiritual care can be difficult to pin down, as discussed in Chapter 1, spirituality can be considered as care for the whole person, and helping patients to find some level of peace is a core part of the whole model of palliative care—enacted in day care as much as in other palliative care settings. Nevertheless, the uniqueness of each individual and of each individual situation demands a unique application of such care and a mindfulness of each individual exercising choice at any or all stages of their illness. For many patients, engaging with the day care service facilitated a process of differing levels of connection and disconnection.

In a sense, just as the initial entry into the service may have presented its own difficulties, moving across the stepping-stones that are hospice day care can also be a difficult process and can involve another set of disconnections and connections. One of the benefits of this holistic model of care is the attention that can be paid to the individual nature of the steps required. These steps come in many shapes—including connecting with religious beliefs, past experiences, resolving unresolved business or simply finding a level of peace and calm.

In the MacConville (2004) study, one respondent described the hospice under study as akin to 'stepping into a slow-moving stream' (*ibid.*, 136). A similar sense of a place apart, or at least of a different pace, was described by one of the family members in this study. Describing the benefits of day care, this lady stated that her husband appreciated the ability to take 'time out', as he found that the tranquillity, calmness and different pace all helped.

Elderly patients spoke to staff about appreciating their illness, as it brought with it a time for preparation and an opportunity to '*clear the path that God has given*' (Staff member 06). The multi-dimensionality of spirituality and

spiritual care reflects the importance and significance of interdisciplinary team working, and chaplaincy is a core aspect of this. For many patients, access to chaplaincy services within day care was of particular benefit, and this was especially the case for some patients for whom long-standing unresolved issues were a cause of anxiety and considerable stress. For others, it may be the opportunity to re-engage with religious practice—as many did in day care—that brings its own peace.

For still others, the whole model of holistic care, enacted as it is in hospice day care, provides a secure and stable footing. The sense of being familiar with the place and in the place and of being part of a 'family' within day care are all aspects that are facilitated and supported by the experience and expertise of the staff and the model of interdisciplinary team working. All of these aspects can have profound meaning for patients and their family members/carers. Bringing together the interwoven aspects—social, cultural, physical, emotional and spiritual—of care into a holistic whole provides a place of safety and reassurance from which to proceed, safe enough for one patient to state that '*I am happy to come here and die*' (Patient 02).

SUMMARY

The realisation on the part of one of the respondents that Hospice Day Care was 'not a Tuesday Club' encapsulates the nature of hospice day care and captures the reality that the service provides care on a number of levels—from the superficial to the deep. The first impression may be that this is a welcoming and pleasant social service, with the additional benefit of health care professionals being to hand. This impression slowly gives way to a deeper understanding of what is involved. Underneath the veneer of social activities lies a complex myriad of interventions and interactions, all of which are focused on providing holistic care for patients with life-limiting illnesses and their family members/carers.

The longitudinal nature of this research rendered these differing levels more visible, in a way that research focused on perceptions and experiences at one point in time may have been unable to do. The transition to hospice day care can be a difficult one for many patients and family members. Staff within day care managed this transition in a way that enabled most patients to enjoy the physical surroundings, the social connections and the multi-dimensional aspects of care that patients may need. Beyond this, however, staff facilitated and supported patients and family members/carers in further transitions as the illness progressed. Managing the growing awareness of the implications of a life-limiting illness and at the same time providing the necessary supports, at a time and pace that is highly individualistic, is a challenging service. This type of care for people with life-limiting illnesses and their family members/carers is an ambitious model of care and one that requires very considerable resources. The benefits, however, are very clearly to be seen in this research. The skill, expertise and experience of health care professionals from a number of disciplines have been brought together in a careful and considered way to improve the quality of life for patients and their families—in ways that are very finely tuned and individually balanced.

CONCLUSION
AND RECOMMENDATIONS

7

CONCLUSION

This research set out to examine the role of hospice day care in the care of patients with life-limiting illness. Both qualitative and quantitative methodologies were utilised. This was, however, primarily a qualitative study that adopted an ethnographic approach in seeking to understand the experiences of patients with a life-limiting illness and their relationship with hospice day care. The research also set out to explore the experiences and perceptions of their family members/carers and the views of service providers regarding the role of hospice day care.

Palliative care aims to provide holistic care for patients with life-limiting illnesses and their families and carers, and has been defined by the World Health Organisation as ‘an approach to care that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2005, 1). Underlying this philosophy are the fundamental principles of open awareness and communication about death and dying and the concept of ‘total pain’—an understanding of pain on multi-dimensional levels.

The philosophy and principles that underpin this model of care are translated into the practice of palliative care. Addressing multi-dimensional needs requires an interdisciplinary approach across a range of domains—in the patient’s home, in the specialist in-patient unit of the hospice, and in hospice day care. Focusing on the frequently changing needs of patients with life-limiting illnesses and of their families at a time of very considerable stress is challenging and complex.

The practice of hospice day care embodies the philosophy and principles of palliative care and does so in ways that are not easily seen at first glance. The longitudinal nature of this study, over a period of nineteen months, helped to make the reality of this practice more visible. On a surface level, it may appear that hospice day care provides a pleasant social interlude for patients, with health care professionals on hand to respond to any problems they may be experiencing. This allows family members and carers to have some respite from caring and some time to themselves. Hospice day care does provide all this, and more.

It became clear, over the period of time, that hospice day care acts like an anchor for patients and family members at a time when they may feel cut off from the ‘matrix of social relations’ (Lawton 2000, 41) and are attempting to cope with the realisation that their ‘future cannot be mapped out’ (*ibid.*, 41). Health care professionals in hospice day care know this landscape, and can use their experience and expertise to individually fine-tune and balance numerous complex interactions and interventions, anticipating needs and advocating on behalf of patients and their families.

Many patients can experience considerable social isolation. For some this is a daily reality, as they live alone and may no longer be able to engage with normal social exchanges and activities outside of their own home. For others there can be a sense of isolation and disconnection even in the midst of family and friends.

Connection and disconnection is a feature of the course of life-limiting illnesses and it can be difficult for patients and their family members and carers to navigate and find their footing through this. Hospice day care professionals acted as experienced guides through the series of transitions that this process involves. From the outset, many patients found it difficult to cross the threshold of the hospice, a crossing that was skilfully managed by the staff. Once crossed, day care staff assisted patients in reconnecting on a number of levels—physically, socially, emotionally and spiritually. Reconnection was facilitated and supported on a physical level through the range of physical and complementary therapies and interventions, and on a social level through the range of activities and social interaction, which also provided an emotional reconnection by creating a sense of belonging and camaraderie. All the interventions and activities are individually focused and finely balanced.

Inherent in the process of disconnection and reconnection are further disconnections and reconnections. A spiritual reconnection was also experienced by many patients; for some this was aided by the opportunity to take part in religious services and ceremonies, for others it was the opportunity to find meaning in their experiences, while still others found a reconnection in the peace, tranquillity and security that day care provided. For many patients, day care provided the time, space and support to prepare for what lay ahead, whatever that might be.

RECOMMENDATIONS

Hospice Day Care is a key service within the range of specialist palliative care services providing comprehensive and complex support for patients and their family members and carers. Service providers demonstrate considerable skill in navigating the internal and external services and in using their experience and expertise to help alleviate fears and anxieties about aspects of death and dying as well as specific anxieties about hospice services for patients and their family members and carers.

This longitudinal study has investigated the role of Hospice Day Care in the care of patients with terminal illness; a number of recommendations are made as follows:

INCREASE PUBLIC AWARENESS OF HOSPICE DAY CARE

A significant barrier to engaging with the hospice day care was a lack of awareness and understanding of the day care services. There can also be a negative perception of hospices, as solely places where people go to die. These factors may lead to reluctance on the part of patients and their family members to engage with the service, in spite of the benefits that such engagement may bring. Greater public awareness of the service and of the range of positive activities, therapies and interventions would be of benefit.

INCREASE RESOURCE ALLOCATION FOR HOSPICE DAY CARE

This study has shown that the range of activities, therapies and interventions were of considerable benefit to patients and their family members/carers.

The holistic care of patients and family members needs an interdisciplinary team approach, which requires considerable resources to maintain. A lack of adequate resources could lead to a dilution of the service and its resultant benefits. Funding is also required to increase the capacity of the service so that a greater number of patients and their families can avail of it. There is currently a waiting list for hospice day care. A reliance on volunteers for the provision of recreational and therapeutic activities can cause difficulty in maintaining a consistent availability of activities. Funding is required to increase the range and number of therapies and activities.

CARER SUPPORT

Current support needs to be extended and enhanced, for example by the provision of additional respite beds. Further research is required to identify the range of needs of carers and family members and how they can be adequately and appropriately supported.

Family members and carers who look after patients at home do so at considerable cost to themselves—emotionally, physically and socially. They may also be engaged in this role for a long period of time.

Hospice day care currently provides a level of support for family members and carers by providing respite for one day a week, enabling carers to have some time to themselves. Hospice day care also provides respite care in the in-patient unit of the hospice when this is warranted, although availability of this can be limited.

The provision of regular telephone support for family members and carers keeps families informed about the patient's condition and any changes that may be occurring. Twenty-four-hour telephone support is available from the palliative care service.

Current services could be extended and enhanced, in particular through the additional provision of respite beds. Carer support groups, as suggested in the literature, may also be of benefit, but further research is needed to identify the range of needs of carers and family members and how they can be adequately and appropriately supported.

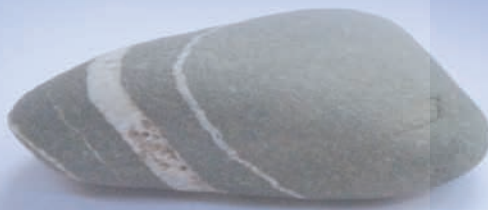
FORMALISE CONTINUITY OF CARE

Further research is needed to investigate the feasibility of formalising procedures for a continuity of care across a range of external health care services.

Health service providers in hospice day care frequently support patients and their family members/carers by negotiating with a range of external health care services regarding appointments, tests and services. Continuity of care can be of enormous benefit for patients and their families at a time of considerable stress.

Many of these positive interventions, such as the prevention of unscheduled admissions to acute hospitals, are largely invisible and do not generally appear as part of evaluations and audits.

Hospice day care is ideally positioned to coordinate end-of-life care. Formal recognition of this coordinating role as part of a care or case-managed approach involving community care and institutional care should be considered. A feasibility study would highlight the benefits and challenges of providing this service.



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