Palliative care is an important and challenging part of a practice nurse’s role. The appropriate and timely transition of a patient to palliative care can be stressful and difficult for the patient and all those involved in their care. Referral to palliative care services is a complex process. Its importance should not be underestimated, if the fear and misunderstandings around accepting palliative care are to be minimised.

This reflective case study of a 72-year-old woman’s transition from general practice to palliative care highlights a number of the issues that can arise in this transition.

The World Health Organisation in 2002 defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual”.1

Care specific to person, not disease
Palliative care has been described as a “a form of care specific to the person, rather than the disease: care that bears no temporal relationship and where the goal is achieved of the best possible quality of life and only when life is clearly drawing to an end does the intent change to facilitating a dignified death”.2

Both these definitions encourage us to look holistically at our patients so we can provide sensitive, individualised patient and family-centred care.

This reflective case study uses the Burford reflective model of nursing, which is based on the core question: What information do I need to nurse this person and their family?3 This model recognises that assessing what is, evaluating what has been and envisaging what may be, is a combined process that will ensure we respond to our patients in an holistic way, with an emphasis on patient and family concerns.4

Jill* was 72, with a history of bilateral mastectomy for breast cancer, bowel cancer, hypertension, atrial fibrillation and type 2 diabetes. As a practice nurse in a busy general practice, I had known Jill for five years. Inoperable bowel cancer was diagnosed in early 2007, she suffered a myocardial infarction mid 2007, and further breast lumps appeared in 2008.

Jill lived alone and was a very independent, upfront person, who maintained a delightful sense of humour throughout her illness. Her immediate family lived overseas. We had developed a good relationship over the last couple of years. Jill would often share a joke with me, some a little raw, that alluded to the depth of her knowing she was reaching the terminal stage of her life. According to two New Zealand writers on palliative care, humour may help restore our inner peace and open other interpretations, so we may laugh and feel joy in the midst of trials.5

Burford’s reflective model used cue questions to determine what event brought the person to a care environment – in Jill’s case, the general practice where I worked. Jill had multiple health issues when she came to our practice but the most pressing symptoms were fatigue, shortness of breath and occasional fresh blood in her stools. Her low haemoglobin was one of the reasons for her fatigue and shortness of breath. This was monitored and blood transfusions arranged as required. Suggestions were made to plan her daily activities around peak fatigue times.

During the course of her bowel cancer, holistic assessment ensured Jill’s needs were being met and that interventions were appropriate. Part of this process was to question whether her physical symptoms were under control, and did she feel supported, physically, socially, culturally, mentally and emotionally?

The general practice team initiated home help, meals on wheels, assessment for continence services and referrals to the different disciplines. The pharmacist assisted with the administration of multiple medications by initiating blister packs. Support also came from friends, neighbours and from her involvement with her church. On reflection, although Jill received wonderful care from the practice, it was often reactive, ie in response to issues that arose, with little co-ordinated advanced planning.

As well as a very supportive GP and practice nurses, many specialists were involved in Jill’s care: a gastroenterologist, a general surgeon, a breast surgeon, a gynaecologist, a cardiologist, a gerontologist and previously an oncologist.

Referral should have been sooner
However, despite all the specialist management and Jill being very aware her tumours were inoperable, she was not introduced to palliative care until February 2008, just two months before she died. Her symptoms had been palliative for a long time, but it was only after an admission to hospital for fatigue and social reasons that she was introduced to the idea of palliative care. With so many specialists involved in Jill’s care, referral to palliative care should have been made earlier.

Doctors can find it difficult to make early referrals to palliative care for many reasons. These include being unsure of the disease process, possibility of periods of remission, inadequate communication skills or knowledge, and lack of support and time. Such delays in referral calls into question who is co-ordinating care in our multi-layered health system.

Communication issues such as non-integrated medical records and the lack of team accessibility may also delay referrals. Team accessibility means effective interaction and timely collaboration among the health professionals involved in a patient’s care, to ensure planning and decision making are effective. The patient’s personality, experiences and coping mechanisms also need to be considered when making a referral to...
Easing the Transition to Palliative Care

Early referral to palliative care enables patients and their families to gain maximum benefit from all services the hospice and interdisciplinary teams provide. The importance of a well-timed and skilful introduction to palliative care cannot be underestimated to ensure the best possible outcome for the patient.

Holistic Assessment
Careful holistic assessment of a range of factors such as age, life experiences, spirituality, social and family networks, coping ability, mental and emotional status, and physical effects of the illness should influence the way this transition is approached.

Unfortunately, Jill’s referral to palliative care occurred when she was terminal, following her final admission to hospital. We, as her general practice, were not informed of this—the information had somehow fallen through the system. Jill informed me several weeks after her last hospital admission that hospice nurses were visiting her at home weekly and had been since her discharge.

A lack of communication between physicians, health professionals and patients can be detrimental to advanced care planning, and poorly co-ordinated care may increase confusion and difficulties for the patient and family.

An earlier, appropriately paced introduction to palliative care would have helped Jill’s and her family’s understanding and acceptance of palliative care. For many patients and their families, “palliative care” is often misunderstood as imminent death. To accept palliative care requires an understanding of what it is. A timely, paced referral in the earlier stages of Jill’s disease may have demystified the meaning of palliative care and broken down some of the associated barriers, thereby enhancing her quality of life. This was particularly important in Jill’s situation, as her family was living overseas, making regular access more difficult.

But once she had transitioned to palliative care, moving forward was possible. Once the strain and resistance to the concept of palliative care disappear, the way is then open for constructive planning.

Although many health professionals were involved with Jill’s care, a co-ordinated, multidisciplinary approach only occurred at a very late stage. The interdisciplinary care was fragmented. Each discipline contributed to aspects of care, but decisions were made independently, meaning treatments were offered that broke Jill into parts: breasts, bowel and heart.

Communication, holistic assessment, and co-ordinated care and planning occurred only after she was referred to palliative care. But this did not happen immediately and we, at the general practice, found out only by chance. An assessment and care package was implemented which included the GP, hospice doctor and nurses, a counsellor and social worker to offer support and assistance. Earlier referral to palliative care may have ensured Jill received the support and benefits of these services at a more appropriate time.

Good communication is paramount in providing seamless care and reducing patient and family stress, while the interdisciplinary team approach is pivotal to palliative care, with the emphasis on collaboration and not duplication of different services.

Despite the difficulties with the timing of Jill’s referral to palliative care, the fact the general practice was not informed and the lack of co-ordination of the many aspects of her care, once the care package was in place, she did receive well-planned, holistic care. Jill died peacefully in the hospice two months after her original referral to palliative care.

Transition Not Ideal
Jill’s transition from general practice care to palliative care was not ideal. It raised a number of issues, notably a lack of co-ordination of her care. When that care encompasses primary, secondary and tertiary services, co-ordination can be complex. When patients are referred to palliative care, it is essential the general practice is informed, as it can continue to play an important role under an integrated, co-ordinated model of care.

Who should take responsibility for referral and co-ordination of care in our complex, multi-layered health environment? The primary reason doctors refer patients to palliative care is for symptom management, especially pain control. Nurses, however, primarily refer to palliative care for emotional needs and support. This reinforces the benefits of working in a multidisciplinary team, with each discipline complementing the other, to enhance the well-being of the patient.

Review of Care
By using the Burford model, I was able to review our care of Jill as practice nurses, identify gaps, and determine ways we could plan care more effectively in the future. The model gives a framework to assess patients from an holistic viewpoint and identify strategies best able to assist them through their journey, driven by their individual needs and requirements. Reflecting on our practice as nurses allows us to evaluate what our responses are to patients, to anticipate possible developments and work towards resolution. Such reflection on our nursing care also identifies gaps in our practice knowledge, thus creating opportunities for continued research and education, an essential part of our nursing practice.

Jill’s experience highlighted the importance of timely referral, paced to the individual’s needs. To achieve this, care must be co-ordinated and planned with excellent communication, if members of the multi-disciplinary team are to work effectively and collaboratively. The practice nurse is ideally suited to play a pivotal role in promoting effective communication and collaboration, to ensure the palliative care patient receives the best possible care.

* Names, dates and some references have been changed to protect the identity of the patient.

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