

From starched uniforms and capes to card carrying companions: Future challenges in Disability Nursing.

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Abstract

Disability Nurses in ADHC are taking on the challenge of providing people with intellectual/developmental disabilities similar palliative care options as those available to the broader community.

Today we will be looking at the practice of Palliative Care in Disability Nursing from our perspective as RNs working for ADHC at Summer Hill. Our focus is the practical and ethical lessons learnt, the benefits to clients and families, and the areas we are still exploring. We'll also explain what we mean by Palliative Care; how the concept developed, and how end of life experiences were managed for our clients prior to the implementation of ADHC's Palliative Care Policy.

What is Palliative Care?

In 1967 St Christopher's Hospice in London was opened by Dame Cicely Saunders. This marked the beginnings of the move towards the principals of the hospice movement and more recently Palliative Care.

In research and popular usage, the terms palliative and hospice care are often used interchangeably. The terms are, however, not the same and Palliative Care reaches beyond the immediate care of those who are dying.

The term hospice usually means a place of care. The hospice movement was a reaction against the inhumane treatment of the dying. The word hospice, originally used to describe a medieval way station for travellers, was chosen to evoke an image of sanctuary for those isolated in their dying.

Palliative care however refers more widely to a philosophy of care that can be provided for patients in a diversity of settings and for a diversity of disorders. It is not restricted to the dying phase.

Palliative care has been defined by the World Health Organisation (WHO) as "the active total care of patients whose disease is not responsive to curative treatments." In addition WHO stated that the "control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount."

Palliative care affirms life, regarding death as a normal process; neither hastens nor postpones death. It supports the patient and their family in living actively, and supports the family during the dying process, and in bereavement.

According to Palliative Care Australia: “Palliative Care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary target is quality of life.”

Palliative care can benefit patients with other illnesses where a cure is not possible and where attention to palliation will afford an improved quality of life. Active treatment from a team of skilled practitioners can optimise the quality of life, dignity and comfort for these patients.

Ethical principles guiding Palliative Care

There is often conflict due to ethical issues existing between patient, family and clinicians when decisions are being made to move to a palliative model of care rather than a curative approach.

There is a commonly held misconception that there is a relation between palliative care and euthanasia. Relatives are often unfamiliar with the normal dying process. They may require reassurance that the nutritional needs and wants of the dying diminish, patients want only enough to keep them comfortable. Artificial nutrition, NG tubes etc are more likely to distress the patient than relieve their condition. The wide held belief that dehydration and starvation are an integral part of palliative care should be banished.

There has also been a perception that the use of opioid analgesics shorten life. There is no evidence that the skilled use of these drugs in palliative care hasten death. Just as premature death may occur during other phases of the therapeutic interaction, it is possible in the palliative phase.

A therapeutic balance between symptom relief and risk of death is sought in the terminal phase. We do not seek death to alleviate suffering. To do this would be euthanasia – either voluntary or involuntary.

Communication plays a very important part in dispelling these misconceptions held by patients and families. It is important that clinicians' communication is both open and honest throughout the disease trajectory.

In Summary; Palliative Care is, at its essence, an ethical endeavour. Improving the quality of life for patients and families, relieving suffering, and supporting the identification and honouring of the patient's preferences for

treatment are centered components of ethical behaviour.

Mack's story

At Summer Hill, prior to the Palliative Care policy being introduced and implemented, when clients had a significant or sudden change in health they were transferred to hospital for treatment. This still remains the case for all clients not on Palliative Care. The following story, with identifying details changed, characterises how end of life was managed prior to the change in departmental policy.

Mack was a young man with spastic quadriplegia, fixed joints, non verbal, totally dependant for all his needs, fed via PEG and asthmatic. The two main reasons for his frequent transfers to hospital were seizures not responding to prn medication, or aspiration pneumonia, which would be a result of the seizures. If Mack was then admitted he would inevitably succumb to aspiration pneumonia while in hospital.

Mack had a very involved family; he was much loved and went home regularly for week ends. His family believed that he recognised them and his surroundings.

Since a very young child when Mack came in for Respite he was regularly transferred to hospital. This wouldn't have necessarily been the case had client been at home at the time as Mum and Dad would often decide to "ride it out".

Mack became a permanent resident and continued to have regular hospital admissions. Of course every hospital admission meant the family were then at the hospital constantly. It meant Mack was not in familiar surroundings, nor did he have familiar staff caring for him when at his most vulnerable. Hospital staff did not know the best way to care for him. A majority of nursing staff in hospitals, who most often have had little or no experience with this type of patient, can be unsure and sometimes even tend to avoid the patient. Even with the best intentions, they can fail to recognise or know how to respond to their needs. The other broader issue, of course, is that when in hospital the thinking is that it's imperative to treat. If you can treat, you should treat.

Eventually Mack was admitted to hospital several times over a short space of time and each time was sent home after being stabilised. He was finally sent in again and was admitted. He remained in hospital for a couple of weeks. Family were constantly by his bedside. A staff member visited each day for a couple of hours to be a companion. His mother would continually ask for our staff to be there more often as "they know how to move him, how to position

him, how to wash him, how to brush his teeth, how to care for him, they know him” etc.

In those couple of weeks Mack had only been sponged in bed. He had not had his hair washed as there was no way of doing that. Hospitals do not have the specialised equipment that we have for showering, positioning or transferring between wheelchair and bed. This then places an added stress on the client who is not only in unfamiliar surroundings but is also being moved, positioned and cared for differently by people they do not know.

Mack's condition continued to deteriorate. His mother was becoming more distressed because of his condition, and she continued to ask for one of our staff members to be with him all the time. We provided this to the best of our ability, but it was not always possible for someone familiar to be there for more than a few hours each day.

The family made a decision with the support and advice of the treating specialists to stop all treatment. Two days later Mack passed away in hospital with his family by his side.

Later, when his mother came to Summer Hill to collect his possessions, both she and our senior staff felt somehow uncomfortable talking about Mack's passing and her grief. The unavoidable reality was that as nurses we had not been there for Mack or his family when they all perhaps needed us the most.

This story is typical of what happened to Summer Hill clients prior to the policy change. Sometimes we were with our client in hospital, sometimes their family was, and sometimes, they died alone.

All three presenters here today have had personal experience with caring for a loved one in their final stage of life. While our experiences are very different, we all agree that having that person at home in their familiar surroundings was very comforting for the person being cared for and made it easier for other family members. It meant life could go on as “normal” for everyone and the PC person was part of that, instead of being isolated in the unfamiliar surroundings of the local hospital.

In 2004, CDDS wrote a report *Palliative care in people with congenital or acquired intellectual disability and high nursing support needs* for ADHC and in its recommendations said

“where possible keep the person in his or her own home”

“involve a palliative service as soon as possible....”

Out of this report ADHC Palliative Care Policy and Procedures was developed and rolled out in 2005. This gave us an opportunity to implement

very soon afterwards as we had two clients who met the criteria.

Palliative Care in Practice

The goal of this paper is to reflect on our personal professional experience in delivering Palliative Care, particularly the issues that we worked through and what we've learnt along the way.

At Summer Hill, Palliative Care Plans (PCPs) are established by following the departmental guidelines. Reports are obtained from involved specialists (neurology, respiratory etc) and informal discussions are held with both the family or legal guardian and all service providers. If there is general consent to proceed, the consultant physician makes a referral to the local Palliative Care team who assess the client. A formal meeting is then held, with all parties invited, at which the PCP is drawn up and signed by all. That plan is regularly reviewed at meetings attended by the parents/guardians, the Palliative Care RN, the client's GP and senior nursing staff.

The clients at Summer Hill are quite unique in having both significant congenital or acquired intellectual disability as well as high nursing support needs. Consent remains an ongoing major ethical issue for our particular group of clients. A whole paper could be written on this topic alone. In terms of our daily practice and decisions regarding Palliative Care, our most important ethical principles were firstly, "above all, do no harm" and secondly, "always consult and discuss with stakeholders when decisions need to be made".

Clients' day to day management became ongoing dialogue between the GP (who visits at least once a week to generally review as well as re-sign the "not for resuscitation" order), the client's family or guardian, the senior RNs and other service providers such as the visiting Palliative Care RN, the OT, the dietician and the physiotherapist. The role of the senior RN includes establishing and maintaining dialogues between various parties with different perspectives leading to decisions all can agree with.

An early example would be the visiting PC RN's recommendation that a client's gastric feed volume be reduced and the visiting dietician who believed this was not necessary. By facilitating a dialogue between the two, decisions were made that both agreed would maintain comfort. Over time consensus between the two became the norm as each understood much better the other's perspective.

Another example would be the PC RN recommendation for a client in his final days that all feeding cease. Had he been an oral feeder, his state of

consciousness would have made providing nutrition impossible except by medical means, which would not have happened in a hospice setting due to the nearness of death. This client's parents however were quite distressed by the removal of the feed tube. Water, administered at a very slow rate, caused the client no discomfort, and eased the distress of his parents. This decision met our ethical requirements to “do no harm” and to “always consult with stake-holders over decisions”.

Palliative Care brought with it a change in our basic thinking about our nursing practice. A focus on immediate comfort being more important than long-term benefit was easy when it came to a decision about removing splints that a client had never really liked. It was much harder when it came to decisions about gastrostomy feed regime reductions. The ongoing dialogues between ourselves and the GP, the dietician and the Palliative Care RN had wider consequences.

Over time we developed a protocol for reducing feed regimes when a client is on antibiotics, particularly when they have respiratory infections. While we've noted a significant reduction in referrals and admissions to hospital for aspiration pneumonia since this practice began, a direct causal link is difficult to prove because other factors are impossible to rule out.

Certainly our views have changed. Immediate comfort versus long-term benefit is a value judgement all of us make and, as we age, our answers change. In terms of our practice as disability nurses in general, our ageing client base makes end of life management and these decisions an issue for more than just the clients at Summer Hill.

Staffing Issues

As the first PC plan was being put together, we began a training program for unit staff. All nurses were given the option of being transferred to another unit if they wished to not be involved. None then, or since, have taken up this ongoing option. Regular team meetings, individual debriefings and personal support, plus access to the department's free external counselling service were all in place when the plan was signed off. Since then we've had in-service training as well as team and individual debriefings when appropriate.

In 2009 the unit, with two of its nine residents on Palliative Care, took on two teenaged AIN cadets. We spent some time in their induction explaining exactly what Palliative Care was and what they would actually be doing for these two clients. In retrospect, the cadets relative ease in providing that care was due to a combination of their individual personalities and commitment plus the fact that they met these clients as frail individuals confined to bed.

Long-term staff, with in many cases over 20 years experience, had fond memories of these clients' earlier lives, found the experience much more emotionally challenging.

We soon realised that while Palliative Care is seen as a complex medical issue, the paradox is that in terms of day to day care it is nursing at its most fundamental. Pressure area care, oral care, positioning for comfort, bed baths etc are all basic nursing skills and the standard at which they were carried out was consistently high. Staff liked being able to do things to improve comfort and care.

When our first PC client became unable to leave her bed any more, even for the comfort chair, the team decided that when she was awake and alert, she would not be on her own in her room. Someone would always be with her. Unlike providing the nursing basics, in the early stages some staff found it difficult to just "be" with someone. Nurses *do*, they don't just *sit*.

This client had always enjoyed one to one interactions with staff so having someone always with her was something she appeared to greatly enjoy, right up until the end of her life. In order to offer a variety of experiences staff each found their own way to provide that one to one support. One AIN regularly read Jane Austin, doing all the characters' voices, another read *New Idea* and commented freely on the gossip there-in, another brought CDs of music she and the client both liked. The diversity of interactions provided emotional, physical, social and spiritual support.

Early in this client's care we also realised it was necessary to more formally explain what was going on to our drivers, domestics and other non-nursing staff at Summer Hill. They too were given the option of spending time with the client if they wished, and many did. The same offer was made to nurses who knew the client but were now working in other units and again, many did.

This client had no biological family leading to a blurring of roles, particularly by long-term staff who had known her for many years. Rules were relaxed around staff visiting her when not on duty. The father of another client on Palliative Care once referred to these visitors as "aunties" and the label stuck.

We were fortunate in having very strong encouragement and support from both local and regional management in carrying out Palliative Care at home for our clients. A decision such as 'always having someone with a client in their final days' does have budget implications, as does the purchase of items such as comfort chairs and specific PC mattresses etc. As our practice evolved, having someone external that we could de-brief to about the day to day issues was an essential element in managing the unit through the changes.

Non-medical goals

As a client's medical condition changed and they moved from chair to comfort chair and finally to bed only, the importance of the non-medical goals became apparent. Lifestyle goals such as community access became impossible in their previous form. We began modifying what we offered to match the new circumstances. Notions such as “mini-outings” evolved. One client, for example, attended the Easter Show for one hour. The whole experience was designed around the maximum time he could comfortably stay in his chair. We noticed that beds have wheels, so clients confined to bed, when up to it, attended on-site events in their bed. Decisions on participation were based entirely on how the client was travelling on any particular day and their involvement continued until they appeared to be tiring.

Other Issues

We monitored the impact of this increased focus on one or two clients for its impact on the other residents of the unit, both in terms of how they appeared to be reacting to it, and in terms of how much nursing time they were potentially no longer receiving. Specific one to one activities were planned for other clients for when they appeared to be reacting to a perceived lack of attention.

Our research on Palliative Care found much information and focus on pain management. While this is a major issue for patients with cancer, it is not a major problem for clients such as ours with respiratory failure. While we had Schedule 8 PRN available, it was rarely needed. What our clients experienced was a slow, gentle decline and an easy passing, if any death can be called easy. One client was on PC for 14 months, another for seven months and we currently have a client who has been on PC for 18 months. Another client, whose family chose not to put on Palliative Care, died in hospital during this time.

Family Issues

Issues that confront the family in the early years of their disabled child's life - well documented in disability literature – can all get revisited by the parents in the end of life situation. Decisions made about their young child's care thirty or forty years ago, as well as life-changing decisions concerning their own futures made back then, may be recalled by parents during the ongoing discussions around palliative care and over the client's final months.

Even more significant for the family, especially the parents, are the changes that happen once their son or daughter passes. The backpack of

responsibility, however small or large, that parents assumed would be life-long is suddenly taken off. In some cases their whole life has been structured around their son or daughter's care. Their activities, their contacts, all their long-term relationships with service providers and their actual routine day to day plans - all suddenly end or totally change once their son or daughter dies. This becomes a significant part of their grief process.

The literature on Palliative Care talks a lot about treating the whole family as the unit of care, rather than just the patient. This is especially true when the patient is a client with a disability. We dealt with each situation in a way that left open the option of the family keeping in as much contact as they felt they wanted with our service in the future.

Over the past couple of years several families have said no to further discussions about Palliative Care for their loved one. Their perspective is that every possible treatment should be accessed to prolong life and this can only be provided in hospital. It's also a fact that hospitals can and do recommend ceasing all treatment when death is inevitable. It's a difficult decision for families either way and our role is to clearly explain the options and support them in whatever choice they make. There are no right or wrong answers for families, only tough decisions.

Conclusions

In preparing this paper we looked back on what has happened over the past four years. Mack's story, our own personal experiences with Palliative Care and the department's decision to change policy all combined to challenge us to continue to care for our clients for the whole of their lives.

Some parts of our experience since then were predictable. What we didn't perhaps expect was just how much more comfort and quality basic care, as well as dignity and respect, is possible in a home environment for clients being cared for by those who know them best. Despite the sadness at times, it's been deeply rewarding for us as nurses to be there when our clients need us most.

This paper is merely an overview of what is an ongoing learning process and evolving practice. We predict there will be future papers on the practical nursing implications of the ageing of our client base, papers on the impact of client death on parents, papers on specific elements of palliative care, from ethics to feed regimes.

This conference is looking at where Disability Nursing has come from and where we are moving to in the future. Our client base has changed dramatically over the past 20 years and will continue to change, due in no

small part to better medications, better technical aids, gastrostomy feeding and so on.

Twenty years ago at Summer Hill we spent our days in starched uniforms and capes or schoolboy grey pants feeding large numbers of clients, often with teaspoons, then re-positioning them, busy all day providing basic nursing care.

Today our clients are living much longer lives with a huge focus on the quality of that life. We're now also out in the community with our companion cards enabling our clients to fully participate in the world.

It's that quality of life, of dignity, of equality, and ultimately, of respect, that as nurses we are uniquely enabled to provide for the whole of our clients' journey through life.

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