

Mapping The Journey: Family Carers' Perceptions of Issues Related to End-Stage Care of Individuals with Muscular Dystrophy or Motor Neurone Disease

SKY DAWSON and LINDA J. KRISTJANSON, School of Nursing and Public Health, Edith Cowan University, Churchlands, Western Australia, Australia

Abstract / Progress in medical technology and treatment has resulted in more people with neurodegenerative conditions surviving for longer periods of time. This increased lifespan means that these individuals have a longer period of dependency on others, with a heightened need to maintain quality of life for both the individual and the family. Our paper reports on the findings of a study involving in-depth interviews with 16 carers to determine their perceived needs during the final stage of caring for someone with muscular dystrophy (MD) or motor neurone disease. Results suggest that the palliative care model has much to offer individuals with degenerative neuromuscular conditions and their families, but it is not yet recognized as an important part of care for young people with MD. Three major themes emerged in the analysis: reactions and responses, health system crossing points, reaching forward.

Résumé / Grâce aux progrès de la technologie médicale et à l'amélioration des traitements pour les maladies neuro-dégénératives, de plus en plus de personnes atteintes de ces maladies survivent pour de plus longues périodes de temps. Cette augmentation de la durée de vie signifie que ces personnes ont une plus longue période de dépendance sur d'autres, laquelle intensifie la nécessité de maintenir une qualité de vie tant pour le malade que sa famille. Cet article rapporte les résultats d'une étude comportant des interviews auprès de 16 soignants naturels afin de déterminer quels étaient pour eux, les besoins qu'ils percevaient comme importants durant le stade final de la maladie d'une personne souffrant de dystrophie musculaire ou d'affections du neurone moteur. Les résultats de cette étude démontrent que le modèle de soins palliatifs a beaucoup plus à offrir aux individus atteints de ces maladies dégénératives, mais qu'on ne perçoit pas encore ce modèle de soins comme étant une partie importante des soins dispensés aux jeunes adultes atteints de dystrophie musculaire. Trois thèmes majeurs émergent à l'analyse des interviews face aux maladies dégénératives: les réactions et comportements des proches, les interactions avec le système de santé, et les stratégies de la famille pour faire face à la maladie.

INTRODUCTION

Progress in medical technology and treatment has led to more people with some neurodegenerative conditions surviving for longer periods of time.

This increased lifespan means that these individuals have longer periods of total dependency on others, with a heightened need to maintain quality of life for both the individual and the family. The individual with a neurodegenerative disorder eventually uses a range of technologies and health care options to ensure adequate nutrition, cardiac and respiratory functioning, bowel motility, skin integrity, and communication. The psychological and social factors of managing the end stage of life are as important as the physical care factors, particularly for the healthy recovery of family members following bereavement.

This study examined the palliative care needs of two populations—people with muscular dystrophy (MD) or motor neurone disease (MND)—and the support families require to help them in their journey. The aims of this study were to:

- Identify the particular needs of families of young men with MD towards the end of their lives.
- Identify the particular needs of families of people with MND towards the end of their lives.
- Identify issues for carers that are inadequately addressed and find possible solutions.
- Evaluate the suitability of palliative care for families of young men with MD. ~

BACKGROUND

Although many people still associate palliative care with cancer, provision of the palliative care model to individuals with a broader range of diseases is beginning to occur. There is some evidence that palliative care may be offered to those with MND (1-5), however, it has not been recognized as a usual model of care for individuals coping with MD (6). Literature related to the issues and palliative care considerations of these two disease groups were examined to help guide development of the study.

Muscular Dystrophies

The muscular dystrophies are a group of muscle diseases that have three features in common: they

are hereditary, progressive, and each causes a characteristic, selective pattern of weakness. Empirical studies have shown that intensive, supportive care can promote improved quality of life and longevity. With continuous multidisciplinary management, young men with Duchenne MD usually survive into their 20s and beyond (7).

For individuals living with MD, the usual focus is on rehabilitation. Supportive care needs may extend over a long period. The focus for the family during this time is on continuing quality of life and optimal functioning of the child. It may be particularly difficult for the family and child to adjust to the onset of the terminal phase of the illness (6). The assumption that there is no place for palliative care until all curative options have been exhausted may interfere with early discussion of palliative issues, including limitations of unduly burdensome interventions at the end of life. Families may feel that a discussion with health professionals about not resuscitating their child or a move to comfort care is equivalent to giving up. To date, use of an integrated approach to care that might include a palliative care emphasis from early illness stages is uncommon. Maddocks et al. explored the needs of individuals with MD and spinal muscular atrophy, and identified deficiencies including coordination of care, issues of medical and hospital care, support for families and siblings, and bereavement care (6).

Motor Neurone Disease

MND is an uncommon degenerative disorder of motor neurones, which leads to progressive paralysis of cranial and skeletal muscles. Information and support are needed from the onset of symptoms, during the often-protracted period of uncertainty prior to diagnosis, and in response to progressive deterioration and its effect on family life. The illness is characterised by a series of losses with the accompanying issues of grief (3).

People with MND and their families are often well informed about the nature of the disease, but they may not be as well informed about the progression of the disease. Many people may be given the impression that, because they have a fatal and incurable disease, nothing can be done for them (8). Worthington suggests that effective multidisciplinary care can be provided only with recognition of MND as a multisystem disorder encompassing a broad range of psychological factors (9).

The issue of when to introduce palliative care as an appropriate model of care in MND is rarely clarified in the literature, other than to suggest that it should start at the time of diagnosis (2). Albert and colleagues designed the first prospective study of MND, examining the rate at which people with MND reach a variety of palliative care

milestones, including the need for adaptive aids, formal home care, health care directives, and technological interventions (1). These milestones may help clarify when palliative care can be introduced to people with MND and their families. The extent to which this type of transition is common practice, however, is not well documented, and anecdotal evidence suggests that involvement of palliative care providers in end-stage MND is limited and inconsistent across this population (10).

Palliative Care and the Family

Any life threatening illness may result in changes in the family life trajectory, and the developmental progression may be disrupted. Issues for families facing a life-threatening illness include hope, control, open communication, access, support, and normality (11). Grief is a journey or a process that begins before the death of a family member. Anticipatory grief will occur throughout the disease process, as losses are experienced on an ongoing basis. Families who can anticipate these losses are better prepared to cope with the end stage of the person's illness. Health professionals can assist families to accept the inevitability of the death by providing compassionate care and information (12).

The health of the family may be affected when one member has a life-threatening illness (12). Family life can be changed when there are technological devices and changes in the internal environment of the home, and a constant stream of helpers reducing privacy (6). Professional services usually focus on the medical or physical needs of the individual with the life-threatening illness, and carers receive little guidance for their role (13). Perrin and colleagues report that the burden of care may fall disproportionately on mothers. They found that depression was more common in mothers who cared for children with health problems or children who were ventilator-dependent (14). Carers of people with MND demonstrate signs of anxiety and depression, with the latter correlating to aspects of the individual's functional impairment (15).

Palliative care can be defined as the active total care offered to a person with a progressive illness and his/her family, concentrating on the quality of life and the alleviation of distressing symptoms. There is evidence that palliative care can be a valued support for families during these illnesses and bereavement (1,2,5,6,16), however, many families of individuals with these chronic and progressive conditions may not be usual recipients of palliative care services.

In summary, it was evident from this literature review that issues of disease progression, anticipatory grief, developmental milestones, and family care were relevant concerns to those coping with MND or MD. However, to date, little empirical

work had been undertaken to specifically examine the palliative care needs of individuals coping with MD or MND and their family members. Health care professionals working with both populations in Western Australia had identified a need for clarification of family carers' requirements, in the later stages of both diseases, to improve service provision. Therefore, this study was undertaken to address this gap in knowledge.

METHOD

An exploratory qualitative methodology was used to elicit detailed descriptions of family carers as they provide care during the final stage of life for people with MD and MND. Qualitative in-depth interviews were conducted to gather data on the needs of family carers who were caring for a relative with either condition, or who have cared for an ill relative in the past. Interviews were conducted with parents of young men with MD, both current and retrospective, and spouses of people with MND, both current and retrospective. Individuals living with MD and MND, and health professionals involved with MD and MND were also interviewed.

Reference Group

Use of a reference group can be helpful in enhancing trustworthiness of study findings, and ensuring that sampling strategies and emerging results are meaningful and comprehensive (17). The eight-member reference group used in this study comprised health professionals who had extensive knowledge of MND or MD, representatives from the MND and MD associations, and experienced family carers familiar with these illnesses. The reference group assisted with the issues of sampling, interview guide design, and synthesis of results.

Population and Sample Criteria

The reference group helped identify potential participants, based on their associations with the MND society and the primary care facility for individuals with MD. Reference group members identified potential participants, and obtained consent and contact details. The lead researcher then contacted potential participants to inform them of the study and to invite them to participate in an interview.

Sixteen carers were interviewed for the study, 11 family carers of individuals with Duchenne MD and five family carers of individuals with MND. Three of the participants from MD families and three from MND families were bereaved. In addition, three young men with MD participated in this study. They discussed the issues for their families, as they perceived them, as well as issues regarding hospitalization, continuous losses, and increasing dependency.

This sample size was judged to be sufficient for the purposes of this study, since the main aim was to

allow the researcher to learn about and describe the needs of families/carers. Interviews were continued until no new information was being elicited and data was redundant. With qualitative methods, the issue is not the size of the sample, but the participants' ability to articulate the phenomena being investigated.

Data Collection

In-depth interviews were conducted at the place of choice of the participants. A semi-structured interview guide was developed, based on the literature and clinical experience with these populations. As interviews proceeded, the questions became more focused on end-of-life issues. Probes were used to clarify meaning of responses and to pursue with sensitivity topics about dying.

Interviews were audiotaped and transcribed and ranged from one to two hours in length. Using content analysis (18) and constant comparison techniques (19), the interviews were coded to yield common themes. Coding was checked by having a member of the reference group code interviews independently to ascertain the closeness of the coding by two people. Combining similar topics and developing headings that captured the participants' experience and perception resulted in a synthesis of three key themes.

Ethical Considerations

The proposal was approved by the Rocky Bay Inc. and MND Association of Western Australia Inc., and by Edith Cowan University ethics committee. Participants were guaranteed that no names would be used in any reports or discussions regarding this study, and that they would have the right to withdraw from the study at any time.

RESULTS

Three key themes emerged from the interviews:

- reactions and responses;
- health system crossing points;
- reaching forward.

The issues were similar for all carers regardless of the patient's condition.

Reactions and Responses

This theme refers to the reactions and responses of family members to the illness situation and changes in the disease trajectory. Three subthemes emerged in this analysis: grieving every day, fearing each crisis may mean the end, watching life in reverse. The descriptions included in these themes depict the anxiety, uncertainty, and ongoing loss that these family members face daily. A description of each is given below.

Grieving Every Day. Each person with MD or MND usually passes through stages, and each stage re-

sults in the need to grieve another loss. The carers of patients with either condition mentioned the inability to walk, breathe, or roll over in bed. Grieving is hard to cope with, and support is essential. All carers reported that health professionals from their main organizations offer vital support to families.

Every day it [the grief] is with you...the whole time it never leaves you. Then you go through the different stages, when they stop walking, when they're in chairs...You get used to a new stage and then you carry on, then the next one comes.

Personal losses for carers differed with MD and MND. Carers of people with MND mentioned loss of social networks, loss of husband and companion of 50 years, loss of the retirement years, loss of dreams. Carers of boys with MD mentioned loss of extended family members who cannot cope with the disease or are not interested, loss of social networks, loss of future grandchildren, loss of dreams. All participants mentioned loss of normal daily life.

Fearing Each Crisis May Mean the End. Each family experienced many crises, and needed help and support through each one. Carers strived to maintain a sense of competency and coping, but each illness crisis brought a fear that this might be a sign of approaching death.

I know it is getting to the really scary part because, I mean, they can get ill at any stage and pass away, but I think, "He'll be alright, he'll keep going."

Carers experienced uncertainty about the reversibility of each crisis episode. Crises were stressful and the stress increased if hospital admission was required. Many carers (MND or MD) reported avoiding hospitals. All carers identified the importance of a case coordinator to help them anticipate what might happen next and avoid crises.

Watching Life in Reverse. All carers described the pain of watching the deterioration of their family member. The move from rehabilitation to acceptance of increasing weakness and associated complications was difficult. One carer (MND) described her retirement as caring for a confused and incontinent husband, washing sheets and clothes continuously. A mother (MD) expressed her helplessness as she watched life in reverse. She felt positive providing intensive therapy when her son was young, prolonging his independence. As the condition changed, she felt helpless to stop the progression. The developmental stage of the family was important. The future usually involved caring for an increasingly dependent relative and facing an uncertain future, instead of moving forward in life.

Health System Crossing Points

This theme refers to the interactions that families reported when encountering the health care sys-

tem and their efforts to work with existing resources or to obtain information and support. Participants said interactions with the health care system were characterized, for the most part, by tension, varying levels of trust, uneven amounts of information giving, and a sense of struggling to achieve what was needed for the individual with the illness. Three subthemes identified within this theme were: getting lost in the system, living with limits, I want to know but who do I ask?

Getting Lost in the System. Families reported that they want access to competent and compassionate care. Access to resources becomes crucial as the disease progresses. Needed resources were often not available. This was a time when the family felt vulnerable, overstretched and less able to fight for services. Families (MND) who received palliative care found it an important aspect of care, but others had not been offered this service.

When discussing hospitalization issues, all the carers reported problems obtaining appropriate care due to lack of resources or understanding of the condition. When asked what would be helpful, one reply was:

They acknowledge that the person they are looking after is still a human being, and has the normal needs that you and I have. The fact that someone is lying in bed unable to move doesn't make them an inanimate object. And you find that people tend to talk down to them, like they are non compos mentis when, in fact, they are. Their mental capacity is to the forefront.

Carers found medical reviews stressful:

They are an absolute waste of time, but you have to do it to keep in the system. We go there and we tell them, they don't tell us anything.

Living with Limits. Carers were constantly struggling to obtain the services they need. They reported applying for funding for a service, eventually being successful, then the situation would change and more services would be required. The carers reported frustration gaining access to respite care and believed more funding is necessary to support families. One spouse of a person living with MND said:

The main difficulty is that you are restricted by the amount of help that you can get. You are limited to a number of hours.

I Want to Know but Who do I Ask? Carers wanted information about these diseases in the early stages, after diagnosis, preferring written materials. They wanted information about resources and services and how to acquire them. General practitioners could be helpful providing information, if they were actively involved with the families and confident about the disease process.

People with MND found the Internet vital for getting current information and making contact with other people with the condition, for finding out the latest treatments, and for maintaining contact with family and friends. The wife of one man said:

He got depressed a few times, but he was fighting it. He had access to the Internet and he liaised with people all over the world. It was his lifeline.

Carers stressed that they needed information about future progression of the disease at an appropriate time along the illness trajectory. They reported that health professionals wait until the family asks for information about the end, and sometimes this was perceived as being too late. Some felt that explicit information given prematurely might affect a family's ability to cope, while others wanted to be informed. All families had some idea of what to expect at the end, gaining this information from other carers. Open discussion with the family doctor was reportedly helpful.

Carers found it hard to know what to say to children and grandchildren about dying. One mother spoke of her difficulty when siblings asked if their brother was going to die. She said, "There are books on everything but how to adjust to a terminally ill child."

Several carers (MND and MD) were concerned about the future and how to reintegrate into life after their role as carer ended. They wanted information on how to rebuild their lives. All the carers clearly stated that their lives were on hold and their days totally occupied with the role of carer.

Reaching Forward

This theme included the various ways in which carers managed day-to-day situations, the philosophical stance that they took coping with the illness, and strategies they used to solve problems. Most of these had been learned through trial and error, often following periods of frustration and confusion. The descriptions of experiences offer useful direction for supportive recommendations. Five subthemes were apparent within this theme: holding onto the big picture, learning from other carers, needing to plan for the future, just getting on with it, don't forget the children.

Holding on to the Big Picture. Families attempted to maintain normal life for as long as possible. Carers sometimes struggled to see the big picture, because they were constantly trying to cope with daily issues. Difficult decisions to be made included decisions about ventilation or spinal fusion. They wanted to feel they could make informed choices. Quality of life was important.

Every family has different needs. It's being able to make your choice, being respected for it, and not

being looked upon as doing something wrong because you decide to not go with the usual flow.

When a crisis hit the family and they rushed to hospital, they tried to stay calm and to get the staff to understand that the carers did know what was required.

You are already stressed out and you have to try and keep your patience so you don't start yelling at somebody, "He can't breathe without a respirator." They [the nursing staff] don't listen because they think that these silly distraught over-the-top mothers, what would you know!

All carers (MD) reported hoping for a miracle cure, but this became difficult as years passed. They also spoke of the continuous confrontation with the future with the deaths of other young men, and watching their sons attend the funerals. Some parents counselled their sons that it was not obligatory to go to every funeral. One parent said, "Since the time my son went there at the age of 12...till he died, there was 20 he saw go through there and die."

Learning from Other Carers. Support groups are considered invaluable, providing social support and direct assistance with problems. Men experienced a sense of isolation and benefited from interacting with other male carers. All carers indicated a sense of isolation and loss of contact with family and friends.

Carers initially avoided attending support groups because they were shocked to see others with advanced MND or MD. Yet all the carers who did attend support groups felt that the benefits outweighed the drawbacks. Several (MD) mothers attended a mother's camp and found the group support invaluable. One mother commented:

So that's where I did a lot of my crying, at the camp with the other mothers....You would go every six months and let it all out, then you would carry on for the next six months.

Needing Help to Plan the Future. Planning for the future is a delicate balance of living for the present and facing the inevitable. The carers identified a need to anticipate and plan ahead. A trusted care coordinator was identified as important. Planning empowered the family, and allowed them to give optimal care and avoid crises. It can be a lonely journey. Carers wanted to discuss the future with their doctors. In discussing the plans for the end of life issues, one couple said:

Nobody else wants to deal with it. That would be a good idea, to let people know what you can do, and what you have to do, and what takes place.

One carer expressed her fears and reported that she had sought counselling to face the future.

I've actually found that I've started seeing a psychologist so that when (S) dies, I've got someone that knows us and I feel that I can open up to if I need to talk. I imagine that it's going to be a horrible experience. I just know how upsetting it's going to be so for me. I like to plan ahead and make sure there is somebody out there for me.

Carers of young men with MD shared their willingness to discuss the future, explaining that they did not want their sons to fear death or prolong life unnecessarily. One mother said, "I said to him, as long as you want to prolong it, this is for yourself. If you are tired of being tired, or sick of being sick, then you should stop." They were able to plan the future, talk about dying and the funerals, and felt this was a positive process. As one family member said, "We talk about it because I don't want him to be frightened of death."

Carers (MND) shared their difficulties planning the future with their spouses and their children, not wanting to give up hope or acknowledge the inevitability of death. They then found themselves unprepared. No carers reported being ready for the final stage, even though they had been aware it was going to happen.

Just Getting On With It. Carers initially believed that the diagnosis would not affect their lives. Families preferred to focus on living a normal life. Some families had paid caregivers who stayed overnight. One explained the difficulty of maintaining a normal life: "I was having a total of 39 people through my house per week."

The carers managed physical requirements of care, but often had difficulty coping with feelings, emotions, and grief.

You are like on a hurdy-gurdy, and there is no one that can really help you with it. The nursing home and hospice have been really helpful. When I am upset, they have sat and talked, like I am talking to you now, giving not so much information but support. Someone that will put their arm around you and say, "Come on." It helps.

One person expressed despair:

It was only in July when I guess I sort of started screaming and shouting and putting up my hand for help, and stuff like that. I got a bit extra. Sometimes it was just so frustrating. I used to say to hell with it, I'll just try and work on my own and just juggle things.

People with MND were willing to attend palliative homecare, day hospice, or respite hospice care when they realized that their carer was not able to continue caring without relief. Most young men with MD moved into residential care or community living as a transition into adulthood, and they chose to remain there. They preferred not to be a burden on their parents when they required more care.

Don't Forget the Children. Carers (MND and MD) felt in need of support for the children and grandchildren. They wanted to know how to discuss the future, death, and dying, to help the children make sense of what was happening and to support them in their grief. No specific support for children of a parent or grandparent with MND was identified, and counselling was expensive. Camps for siblings (MD) were helpful.

Carers who discussed their needs retrospectively were all positive about the funeral and/or memorial services. Memories of the services were vividly recounted. The memorial service provided families and staff with a healing ritual of remembrance, a source of closure after the death, and recognition of the relationships established between families and staff.

The Health Professionals

The health professionals were in agreement with the themes that emerged from the data. Those working with the MD organization reported the staff had difficulty discussing issues of dying and death. They found the funerals and memorial services helpful. They identified the transition from children's services to adult services as a time when it was crucial for carers to have access to support, information, and planning. There was interest in palliative care as part of total care adult services. The health professional with the MND association reported that families had difficulty gaining access to palliative care, though it was needed by many. Respite was essential to support the carers and was often not available. All health professionals were concerned at the lack of understanding of these two conditions in acute care facilities.

DISCUSSION

Seven findings emerged in this study:

1. Families need access to skilled experts for coordinated action and regular review of their needs in the later stages of the disease progression.
2. Gaps in supportive care services were evident. Regular respite is vital to support the carers and funding must be responsive to the needs of families. Planning for the future is not consistent, particularly in families of individuals with MD.
3. The need for appropriately paced information is critical. Inclusion of the family in case management and a family approach to care that includes children are vital.
4. Carers (MND) acknowledged the value of palliative care to help cushion the impact of progressive stages of this disease. Carers of individuals with MD expressed a need for maintaining quality of life, symptom control, and planning for the future that includes issues of dying, but did not relate this to palliative care.

5. Health care professionals need to incorporate palliative care in the care plan, to assist families in decision making and in avoiding crises.
6. Staff training in acute hospital settings is needed to improve knowledge of MND and MD.

Carers believed that gaps exist in services, particularly as regards planning for the future. They identified the importance of a care coordinator to guide the family in their journey, develop a relationship of trust, coordinate the activities of other team members, communicate with service providers, and initiate effective and timely responses to changing needs.

There was a need for information and support, as well as for access to experts from a variety of agencies. The number of agencies and the complexity of communication placed a burden on the family. Families needed to know how to secure resources in cases of emergency and as it becomes more crucial with progression of the disease.

Progressing symptoms and intensified management made normal life increasingly difficult. Carers often undertook complex and time-consuming caregiving tasks at home. They reported having little time to spend with the family, and nights during which they were disturbed regularly. Timing of hospital admissions was often unpredictable. Hospitalization could be stressful and families perceived that care by hospital staff was less than adequate. This was often a time of crisis, when carers were afraid that their relative might die. They reported a lack of trust with hospital staff, which supports Maddocks' findings (12).

Some carers expressed lack of clear direction from health professionals towards the end of life. At this time, problem identification needs to be reframed to emphasize issues relating to the caregiving process (20). The abilities of the carers and their willingness to provide care influence the outcomes of health services more than the relatives' physical and functional status (20).

Diseases associated with palliative care services are usually identified as terminal conditions with progressive, relatively short-term trajectories. Carers (MND) confirmed the importance of palliative care, but access to this service was often limited. Individuals with MD know they have a life-limiting condition, but an acceptance of palliative care may be in conflict with their hopes. Sachs suggests that, for families to accept palliative care, they need to let go of their dream for a cure (21). This study found some families were hoping for a cure, yet acknowledged giving up hope as the years passed. Individuals with MD and their families are not keen to be labelled as coping with a terminal condition or to live their lives with this in mind (6). They perceived palliative care to be terminal care.

CONCLUSION

This study suggests a need for health professionals and others who provide care to cushion or ease the journey of these families. To begin with, active rehabilitative care is essential. Palliative care measures may cushion the physical and emotional deterioration that occur later. Palliative care approaches such as symptom management, quality of life, counselling, and family care plans are useful for those with MND. Carers of relatives with MD also identified the importance of quality of life, symptom management, information, and future planning as being particularly useful in helping anticipate needs and prevent crises.

Date received, March 26, 2002; date accepted, June 10, 2002.

REFERENCES

1. Albert SM, Murphy PL, Del Bene ML, Rowland LP. Prospective study of palliative care in ALS: choice, timing, outcomes. *J Neurol Sci* 1999; 169: 108-113.
2. Borazio GD, Voltz R. Palliative care in amyotrophic lateral sclerosis. *Neurology* 1997; 244(suppl.4): S11-S17.
3. Barby TFM, Leigh PN. Palliative care in MND. *Int J Palliat Nurs* 1995; 1(4): 183-188.
4. O'Brien T, Kelly M, Saunders C. MND: a hospice perspective. *BMJ* 1992; 304: 471-473.
5. Parker D, Forster W. The Palliative Care of Motor Neurone Disease. Report to the South Australian Health Commission. Palliative Care Unit. Adelaide: The Flinders University of South Australia, 1998.
6. Maddocks I, Stem L, Parker D. The Palliative Care of Advanced MD and Spinal Muscular Atrophy. Adelaide: The Flinders University of South Australia, 1998.
7. Kakulas BA. Problems and solutions in the rehabilitation of patients with progressive MD. *Scand J Rehabil Med Suppl* 1999; 39: 23-37.
8. Norris FN. MND: treating the untreated. *BMJ* 1992; 304: 459-460.
9. Worthington A. Psychological aspects of motor neurone disease: a review. *Clin Rehabil* 1996; 10(3): 185-194.
10. Oliver D, Webb S. The involvement of specialist palliative care in the care of people with motor neurone disease. *Palliat Med* 2000; 14: 427-428.
11. Leonard KM, Enzle SS, McTavish J, Cumming CE, Cumming DC. Prolonged cancer death: a family affair. *Cancer Nurs* 1995; 18(3): 222-227.
12. Whittam EH. Terminal care of the dying child: psychosocial implications of care. *Cancer Suppl* 1993; 71(10): 3450-3462.
13. Denham SA. Part 2: Family health during and after death of a family member. *J Family Nurs* 1999; 5(2): 160-183.
14. Perrin J, Shayne M, Bloom S. Home and Community Care for Chronically Ill Children. New York: Oxford University Press, 1993.
15. Goldstein LH, Adamson M, Jeffrey L, Down K, Barby T, Wilson C, Leigh PN. The psychological impact of MND on patients and carers. *J Neurol Sci* 1998; 160(suppl.1): S114-S121.
16. Oliver D, Borasio GD, Walsh D (eds). *Palliative Care in Amyotrophic Lateral Sclerosis*. Oxford: Oxford Press, 2000.
17. Patton MQ. *Practical Evaluation*. Newbury Park: Sage Publications, 1982.
18. Field P, Morse JM. *Nursing Research: the application of qualitative methods*. London: Croon Helm, 1985.
19. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: strategies for qualitative research*. New York: Aldine, 1967.
20. Bye RA. When clients are dying: occupational therapists' perspectives. *Occup Ther J Res* 1998; 18(1): 3-24.
21. Sachs S. *When a Child Dies—caring for children with life-limiting-threatening conditions*. Victoria: Victorian Government Department of Human Services, 1995.

19:1/2003

Journal of Palliative Care

SPRING 2003

Published quarterly by the Centre for Bioethics, Clinical Research Institute of Montreal. Subscriptions and inquiries: Centre for Bioethics, Clinical Research Institute of Montreal, 110 Pine Avenue W., Montreal, Quebec, Canada H2W 1R7. Tel: (514) 987-5617, extension 222, Fax: (514) 987-5695, E-mail: stamous@ircm.qc.ca Website: http://www.ircm.qc.ca/bioethique/english/publications/journal_of_palliative_care.html

Abstracted and/or indexed in: Cumulative Index to Nursing & Allied Health Literature, Canadian Periodical Index, Psychological Abstracts, Psyc INFO—Psyc ALERT databases, Index Medicus, Medline, Terminal Care Index, Current Contents/Social & Behavioral Sciences, Research Alert and Social SciSearch, Database of the British Library, INFORCYT, Referativnyi Zhurnal. Also available on microfilm through Micromedia Limited, Toronto, Ontario, Canada and University Microfilms, Ann Arbor, Michigan, USA. Editorial and subscription details on inside front cover.

© Copyright 2003 by the Centre for Bioethics, Clinical Research Institute of Montreal. Printed by Imprimerie Gagné Ltée, Louiseville, Quebec, Canada. Computer-assisted typesetting: Suzanne St-Amour. All rights reserved. ISSN-0-825-8597 Legal Deposit First Quarter Bibliothèque nationale du Québec

Editorial / On the Eve of a New Suffering...

DAVID J. ROY

3

Guest Editorials

Research at the Interface of Palliative Care and Geriatrics GREG A. SACHS

5

The Quandary of Cultural Diversity

ANTONELLA SURBONE

7

Articles

Pressure Ulcer Prevention and Treatment in Hospices: a Qualitative Analysis

ANDREW EISENBERGER and JOMARIE ZELEZNIK

9

The Impact on Families of a Children's Hospice Program

BETTY DAVIES, JOHN B. COLLINS, ROSE STEELE, INGRID PIPKE, and KAREN COOK

15

Examining the Perspectives of Family Members Involved in the Delivery of Palliative Care at Home

KELLI I. STAJDUHAR

27

Mapping The Journey: Family Carers' Perceptions of Issues Related to End-Stage Care of Individuals with Muscular Dystrophy or Motor Neurone Disease

SKY DAWSON and LINDA J. KRISTJANSON

36

The Cultural Differences in Perceived Value of Disclosure and Cognition: Spain and Canada

ROBIN L. FAINSINGER, JUAN M. NÚÑEZ-OLARTE, and DONNA M. DEMOISSAC

43

Hospice Use by Older Women Dying with Breast Cancer between 1991 and 1996

NUHA A. LACKAN, JEAN L. FREEMAN, and JAMES S. GOODWIN

49

No part of the *Journal* may be reproduced, stored in a retrieval system or transmitted, in any form or by any means, without the prior written permission of the publisher or, in case of photocopying or other reprographic copying, a licence from CANCOPY (Canadian Copyright Licensing Agency), 1 Yonge Street, Suite 1900, Toronto, Ontario, Canada M5E 1E5, Tel.: (416) 868-1620.

The publication of this issue of the *Journal of Palliative Care* is made possible in part by support received from an anonymous donor. The *Journal* also recognizes the support received from the former Palliative Care Foundation, Toronto. We acknowledge the financial support of the Government of Canada, through the Publications Assistance Program (PAP), toward our mailing costs.

EDITORIAL BOARD

Editorial inquiries for the *Journal of Palliative Care* may be sent to the Editor-in-Chief,
Journal of Palliative Care, Centre for Bioethics, Clinical Research Institute of Montreal, 110 Pine Avenue West, Montreal, QC, Canada H2W 1R7

EDITOR-IN-CHIEF

David J. Roy, BA (MATH), STB, STL,
 PH L, DR. THEOL
 Director, Centre for Bioethics
 Clinical Research Institute of Montreal
 Montreal, Quebec

ASSOCIATE EDITOR

Balfour Mount, CM, MD, FRCS(C)
 Eric M. Flanders Professor of
 Palliative Medicine
 McGill University
 Montreal, Quebec

ASSOCIATE EDITOR

Neil MacDonald, MD, CM, FRCP, FACP
 Director
 Nutrition and Rehabilitation Program
 Department of Oncology
 Professor, Oncology, McGill University
 Montreal, Quebec

ASSOCIATE EDITOR

Eduardo Bruera, MD
 Director and Chair, Department of Palliative
 Care and Rehabilitation Medicine
 University of Texas
 MD Anderson Cancer Center
 Houston, Texas, USA

ASSISTANT EDITOR

Electa Baril
 Centre for Bioethics
 Clinical Research Institute
 of Montreal
 Montreal, Quebec

BOOK REVIEW EDITOR

Position to be filled

VIDEO REVIEW EDITOR

Linda Crelinsten, RN, MS
 Assistant Director
 Program Development
 Palliative Care McGill
 Montreal, Quebec

MANAGING EDITOR

Suzanne St-Amour
 Centre for Bioethics
 Clinical Research Institute
 of Montreal
 Montreal, Quebec

SUBSCRIPTION MANAGER

Carole Marcotte
 Centre for Bioethics
 Clinical Research Institute
 of Montreal
 Montreal, Quebec

COPY EDITOR

Kathleen Hugessen, BSC, DMV
 Montreal, Quebec

EDITORS

David Barnard, PH D
 Director of Palliative Care Education,
 Center for Bioethics and Health Law,
 University of Pittsburgh,
 Pittsburgh, Pennsylvania

J. Andrew Billings, MD
 Palliative Care Service,
 Massachusetts General Hospital,
 Harvard Medical School,
 Boston, Massachusetts

Chen Miao-Lan, MD
 Vice-President,
 Chinese Academy of Medical Sciences,
 Beijing, China

Charles Corr, PH D
 School of Humanities,
 Southern Illinois University,
 Edwardsville, Illinois

Ina Cummings, MD
 Montreal, Quebec

Lesley F. Degner, RN, MA
 Associate Professor, School of Nursing,
 University of Manitoba,
 Winnipeg, Manitoba

Bernard M. Dickens, PH D, LLD
 Faculty of Law,
 University of Toronto,
 Toronto, Ontario

G. Michael Downing, MD
 Programme Co-ordinator,
 Hospice Victoria, Royal Jubilee Hospital,
 Victoria, British Columbia

Stephen J. Fleming, PH D, C PSYCH
 Professor of Psychology,
 York University,
 Toronto, Ontario

Irene Higginson, BMedSci, BMBS, MFPHM, PHD
 Professor and Head,
 Department of Palliative Care and Policy,
 Guy's, King's and St Thomas' School of
 Medicine

King's College London,
 London, England

Stein Husebø, MD
 Bergen University Hospital,
 Norway

Tetsuo Kashiwagi, MD
 Vice-President, Director of Hospice,
 Yodogawa Christian Hospital,
 Osaka, Japan

Larry S. Librach, MD
 Director, Palliative Care Service,
 Mount Sinai Hospital,
 Toronto, Ontario

Ruth McCorkle, PH D, RN
 University of Pennsylvania,
 School of Nursing,
 Philadelphia, Pennsylvania

Danai Papadatou, PH D
 Psychologist,
 School of Nursing,
 University of Athens,
 Athens, Greece

Dorothy Pringle, BSC N, MS, PH D
 Dean,
 Faculty of Nursing,
 University of Toronto,
 Toronto, Ontario

Charles-Henri Rapin, MD
 Centre de soins continus,
 Institutions Universitaires de Gériatrie,
 Geneva, Switzerland

Harvey Schipper, BA Sc, MD, FRCPC
 Toronto, Ontario, Canada

Hans-Jorg Senn, MD
 Department of Medicine C (Oncology),
 Kantonsspital,
 St. Gallen, Switzerland

Paul A. Sloan, MD
 Associate Professor,
 Department of Anesthesiology, and Oncology,
 College of Medicine,
 University of Kentucky,
 Lexington, Kentucky

Jan Stjernswärd
 Department of Community Medicine,
 Malmö, Sweden,
 Global Cancer Concern,
 London, England

Paul R. Torrens, MD, MPH
 Professor of Health Services,
 School of Public Health,
 University of California,
 Los Angeles, California

Frits S.A.M. van Dam, PH D
 Het Nederlands Kanker Instituut,
 Antoni van Leeuwenhoek Huis,
 Amsterdam, The Netherlands

Vittorio Ventafridda
 Director, Division of Pain,
 World Health Organization
 Collaborating Centre for Cancer
 Pain Relief,
 Milan, Italy

SUBSCRIPTIONS

The *Journal of Palliative Care* is a quarterly publication. The subscription year is January 1–December 31. Subscriptions to the *Journal of Palliative Care* are available as follows:
 Individuals: \$80 (Canada), \$90 (Foreign and USA); Institutions: \$120 (Canada), \$130 (Foreign and USA);
 Canadian subscribers please add 7% GST and Quebec subscribers an additional 7.5% PST. Please make cheque or money order payable to: Clinical Research Institute of Montreal.
 Send orders to: Clinical Research Institute of Montreal, Centre for Bioethics, 110 Pine Avenue W., Montreal, QC, Canada H2W 1R7
 It is also possible to subscribe from our website at http://www.ircm.qc.ca/bioethique/english/publications/journal_of_palliative_care.html
 PAP Registration No. 07768. Date of Issue: March 2003. E-mail: marcotte@ircm.qc.ca