

PALLIATIVE CARE SERVICES IN FAMILIES OF MALES WITH DUCHENNE MUSCULAR DYSTROPHY

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ABSTRACT: *Introduction:* Palliative care services that address physical pain and emotional, psychosocial, and spiritual needs may benefit individuals with Duchenne muscular dystrophy (DMD). *Methods:* The objective of this study was to describe the palliative care services that families of males with DMD report they receive. A questionnaire was administered to families of males with DMD born prior to January 1, 1982. Thirty-four families responded. *Results:* Most families (85%) had never heard the term palliative care. Only attendant care and skilled nursing services showed much usage, with 44% and 50% indicating receipt of these services, respectively. Receipt of other services was reported less frequently: pastoral care (27%); respite care (18%); pain management (12%); and hospice care (6%). Only 8 respondents (25%) reported having any type of directive document in place. *Conclusion:* The data suggest a need for improved awareness of palliative care and related services among families of young men with DMD.

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Duchenne muscular dystrophy (DMD) is a neuromuscular disorder that is associated with progressive muscle weakness and secondary disabilities, such as loss of adaptive skills, orthopedic abnormalities, and respiratory insufficiency. In the past, complications of DMD have resulted in death during the teen years, with some rare cases of survival into the 20s. It is now common for individuals with DMD to live longer. Improved medical interventions and intensive healthcare supports, including advances in palliative care,¹ are resulting in young men with DMD who typically live well into their 20s and longer.^{2–4} Some investigators have called for increased translational research to speed the development of effective palliative treatments.⁵

Abbreviations: AHIMSA, Acculturation, Habits, and Interests Multicultural Scale for Adolescents; BMD, Becker muscular dystrophy; CDC, Centers for Disease Control and Prevention; DMD, Duchenne muscular dystrophy; MDA, Muscular Dystrophy Association; MD STARnet, Muscular Dystrophy Surveillance Tracking and Research Network; PPMD, Parent Project Muscular Dystrophy

Key words: advance directives, Duchenne muscular dystrophy, health services model, healthcare barriers, palliative care

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Palliative care now encompasses an array of services that extends beyond the care that is usually associated with the end stages of diseases. These services may range, for example, from respiratory care to improve functioning and maintain quality of life, to case management services, and may also include counseling of families about decision-making they will face as the disease progresses and legal planning such as advance directives. As described by the American Academy of Hospice and Palliative Medicine:

“The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.”⁶

Thus, palliative care is sometimes viewed as an extension of the principles of hospice care, which focuses on end-of-life concerns, for individuals who might respond favorably to interventions, such as respiratory therapy, earlier in the disease process.⁷ However, although traditional hospice care and palliative care share a similar philosophy and many of the same concepts, the former is now viewed by some as a type of palliative care that deals exclusively with end-of-life, whereas palliative care can be employed throughout the course of a chronic, progressive disease such as DMD.⁸

The fact that individuals with DMD and many other chronic progressive disorders are living longer supports the need for palliative care services to be introduced earlier in the progression of the disease, especially to address the developing psychosocial problems encountered by both affected individuals and their families⁸ and the ethical challenges faced by clinicians⁹ and families. Some have advocated that these services need to be incorporated into the work of interdisciplinary care teams,⁸ so that the challenges that families face can be anticipated and addressed throughout the course of the disease, with advance planning undertaken to address this need in a manner that respects both individual and family wishes. However, there is still much debate among clinicians about the role of palliative care in neuromuscular diseases.^{10,11}

The literature that exists on palliative care services for young individuals with DMD suggests that families are not routinely accessing these services. Despite the potential need for these services, there is considerable variation in the utilization of palliative care in individuals with DMD.¹² Therefore, although very little published research exists, a major gap in services can be assumed to exist for these individuals, which may reflect services being nonexistent, not being offered, a lack of knowledge about these services, or all of these.

The reasons for variation in the use of palliative care services are multifaceted and likely include factors such as service availability, the age-appropriateness of services, cost of services, and a complicated mix of psychosocial forces. These include individual, family, and health-care provider perceptions and understanding of palliative care; interpretations of its benefit; and, ultimately, acceptance of these services. A recent study of physicians and nurses who provide care to seriously ill children in a tertiary care hospital examined their perceptions of existing barriers to the utilization of palliative care services for the children and their families.¹³ The four most frequently reported barriers among the 26 possible responses included: an uncertain prognosis for the child; the family's inability to acknowledge that their child has an incurable condition; language barriers; and time constraints. These four barriers alone emphasize the diverse nature of the influences that shape the decision to offer palliative care services to a family and whether or not the family chooses to access the array of services that comprise the palliative care system.

Two studies have addressed palliative and hospice care in individuals with advanced and end-stage muscular dystrophy.^{12,14} Each study used qualitative research methods to identify commonalities in the needs for palliative care in individuals with muscular dystrophy and their families. One

study concluded that palliative care services for children have typically not been well developed,¹² and the same is true for adolescents and young adults. A comprehensive Australian study of palliative care for individuals with advanced muscular dystrophy and spinal muscular atrophy¹⁵ indicated that palliative care so far has not been recognized as the usual care model for individuals who are coping with muscular dystrophy.¹⁴

This study represents the first attempt to quantify the utilization of palliative care services among families of individuals with DMD. The aims of this report are: (1) to describe the palliative care services that families of males with DMD currently receive at home or in health-care facilities; and (2) to evaluate the factors associated with the utilization of these services by the families.

METHODS

This study was performed in collaboration with the Muscular Dystrophy Surveillance and Research Network (MD STARnet), a network of four United States geographic regions (Arizona, Colorado, Iowa, and western New York) funded by the Centers for Disease Control and Prevention (CDC) to conduct population-based surveillance and research for DMD and Becker muscular dystrophy (BMD).¹⁶

Participants. The study population included adult caregivers of individuals with DMD born prior to January 1, 1982, or the individuals themselves in two instances. Caregivers were recruited through multiple methods, such as by announcements in Muscular Dystrophy Association (MDA) and Parent Project Muscular Dystrophy (PPMD) publications and through neuromuscular clinics that provide services to individuals at each participating site of the MD STARnet.

Questionnaire. A structured questionnaire was developed using data collected from a focus group transcript of parents of children affected with DMD in Arizona and discussions by members of the MD STARnet sites who participated in a Palliative Care Working Group. A summary of the questions is provided in Table 1. Questions included several that related to the caregiver's understanding of palliative care and documents such as advance directives or living wills. The services shown in item 6 are typical of palliative care services, regardless of whether they are provided through a formal palliative care agency or coordinated by other providers. Although palliative care services can include multiple types of coordinated services over a span of many years, the subjects in this study were more likely to be in later stages of the disease and therefore would

Table 1. Summary of questions asked of adult caregivers of individuals with Duchenne muscular dystrophy.

Questions
1. About the individual with Duchenne muscular dystrophy
Date of birth
Date of death
Cause of death
Currently living with caregiver
Age when first walked
Age at confirmation of diagnosis
2. About the caregiver and biological parents
Age and gender
Ethnic group and racial background
Grade level completed
Language use
Work or attend school
Extra care provided
Support system
Transportation needs
3. About the family
Family history
Total household income
Sources of payment of medical bills
4. Medical services
Neuromuscular specialist
Cardiologist
Pulmonologist
Orthopedic surgeon
Primary care physician
5. Therapy visits
Occupational therapy
Physical therapy
Speech therapy
6. Services received
Attendant care
Case manager services
Dietary counseling
Home meal delivery
Homemaker/household services
Hospice services
Mental health services
Pain management
Pastoral care
Respiratory care
Respite care
Skilled nursing services
Social work services
Transportation assistance
7. Use of assistive technology and medical devices
8. Palliative care
Familiarity with term
Use of palliative care or hospice care services
Legal documents in place
Living will
Advance directive
Durable power of attorney
Guardianship plan

likely have already received many of the palliative care services either at earlier ages or recently.

Data were also collected about individuals with DMD. These included the individual's age and a measure of functional ability: functional ability dysfunction. Functional ability dysfunction was

measured by asking the caregiver, "Has your son lost the ability to play video games or use a joystick?" Responses to this question were recorded as "yes" or "no."

In addition, data were collected about caregivers. These included the caregiver's age, ethnicity, a measure of acculturation, educational level, income, family size, and two measures of the burden of caring for an individual with DMD. Ethnicity, rather than race, was included in the analysis, because the sample was predominantly white, non-Hispanic, and Hispanic. Respondents' levels of education were measured by asking, "What is the highest grade level you have completed?" in 10 categories of response. For analytical purposes, the variable was dichotomized such that the grade level completed was either less than or equal to a high school diploma or greater than a high school diploma. Income was measured by asking, "In the past year, what was your total household income?" in six categories of response. For analytical purposes, the variable was dichotomized such that the reported annual income was either \leq \$30,000 or $>$ \$30,000. Family size was assessed by asking, "How many people are supported by this income, including both adults and children?"

Caregiver acculturation was measured using a modified version of the Acculturation, Habits, and Interests Multicultural Scale for Adolescents (AHIMSA) scale.¹⁷ Although the questions were developed for use among adolescents, as phrased they are applicable to adults. The AHIMSA scale measures language usage as a proxy for acculturation, because language fluency affects a person's ability to communicate both with members of the host culture and members of the culture of origin. Although language usage is not the only important component of acculturation, studies have indicated that language usage explains a significant portion of the variation in many acculturation measures.¹⁸ The assessment consists of five questions, each concerning language use. Each of the five questions was scored from 1 to 5. The questions asked the caregivers in what language they generally speak, read, speak at home, think, and speak with their friends. We employed a 5-point Likert scale, ranging from 1 (English only) to 5 (another language only). Responses were averaged, with averaged scores ranging from 1 to 5, and lower scores indicating higher levels of acculturation.

In order to analyze ages of caregivers and children, it was necessary to compute the following variables: age at time of interview for living individuals; age at time of death for deceased individuals; caregiver's age at time of interview for caregivers of living individuals; and caregiver's age at time of individual's death for caregivers of deceased

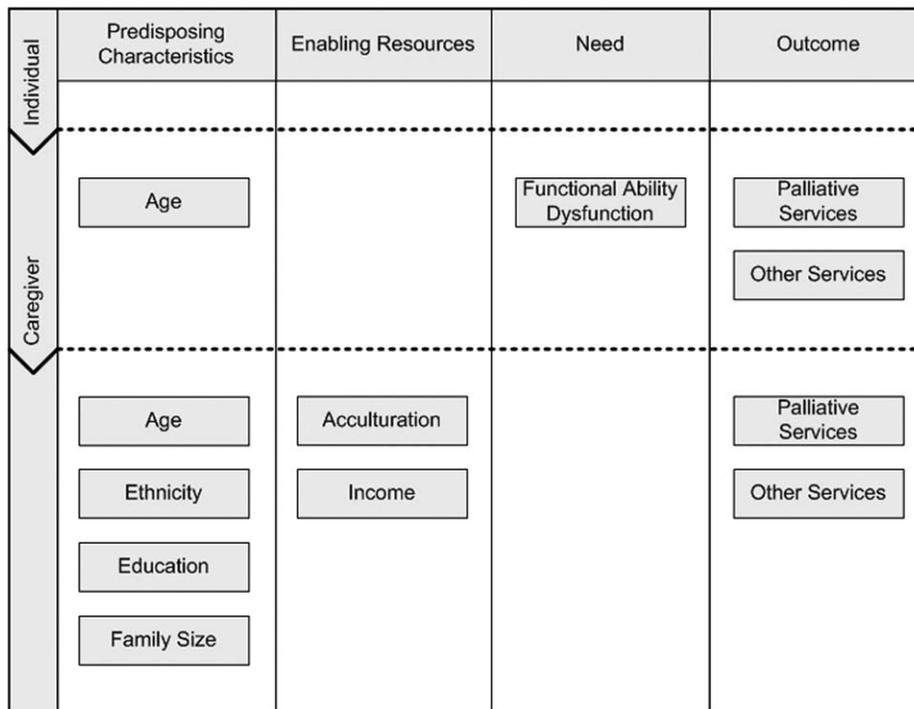


FIGURE 1. Theoretical model for use of palliative care services.

individuals. In this way, we were able to compare the ages for caregivers of living and deceased individuals as well as the ages of the living and deceased individuals themselves.

The questionnaire was administered through telephone interviews conducted in both English and Spanish during October 2005 and July 2006. Most interviews (31 of 34, 91%) were conducted by a trained staff member at the Arizona MD STAR-net site. Three interviews were conducted in Spanish by a second trained staff member. Each interviewer was experienced in interviewing techniques. Participants received a \$20 check for their participation in the study upon completion of the telephone interview. The study had the approval of the human subjects' review committee of the University of Arizona.

Theoretical Model. A modified version of the health services model guided the analyses reported herein.¹⁹ This modification has been used to examine patterns and correlates of service utilization among mothers of adult children with a developmental disability.²⁰ These models each illustrate how predisposing characteristics, enabling resources, and needs can be used to predict service outcomes, as described in what follows. The model we used was further modified to incorporate variables for which we had collected data and served as the basis for the analysis of palliative care service utilization patterns among families of young men with DMD (Fig. 1).

As shown in Figure 1, the predisposing component of the model includes the individual's age and the caregiver's age, ethnicity, level of education, and family size. Predisposing characteristics are those characteristics of the individual and family that could influence whether the individual and his family utilize services. For example, the individual's age might determine if certain services are even needed. Enabling resources are characteristics that facilitate or impede service access and include income and acculturation. The perception of service needs includes the caregiver's perception of the individual's functional ability (in a small number of interviews, the individual or another relative was interviewed). Each of these components represents a factor that can be associated with an individual's or a family's utilization of specific services. Outcome, which in the model was use of palliative care-related services, was measured as receipt of the 14 specific services shown in Figure 2 and includes services such as respiratory care, case manager services, and skilled nursing services. The overall research question for the analyses is: What are the patterns of predisposing characteristics, enabling resources, and need factors that predict which families report the utilization of palliative care services?

Statistical Analysis. All statistical analyses were done using statistical software (SPSS, version 15; SPSS, Inc., Chicago, Illinois). We used binary logistic regression to analyze service utilization data. Services were placed in one of two categories:

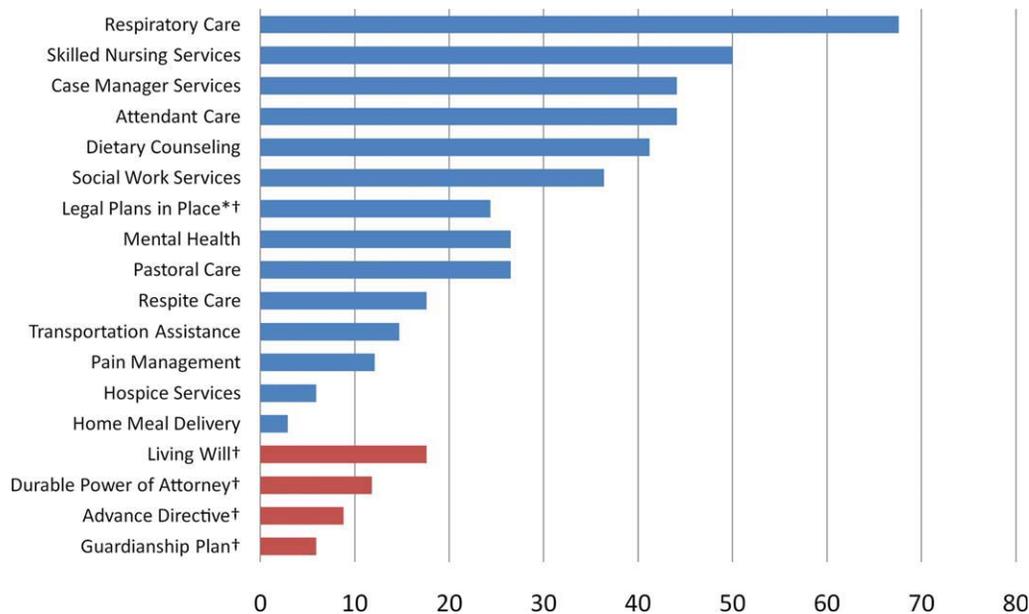


FIGURE 2. Frequency of use of palliative care services reported in survey ($N = 34$). *The 8 respondents who answered 'yes' to this question could select more than one legal plan in place. †The legal plans in place that were reported. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

service received and service not received. Prior to conducting the regression analyses, we examined the relationships between service outcomes and the predictive variables using univariate statistical methods (chi-square analysis and *t*-tests). Fisher exact tests were done when appropriate.

RESULTS

Respondents. Of the 48 families who consented to participate in the study, 34 (71%) completed the interview. The total number of individuals recruited is unknown, because letters were sent out from local physicians in Arizona, Colorado, Iowa, and New York, and study announcements were posted on listservs, websites, and publications, including those of the MDA and PPMD. Of the 14 who did not complete the interview, 1 family consented but then decided not to participate, and 13 could not be contacted again by telephone to complete the interview. The majority of the families resided in Arizona (22 of 34, 65%). The others were distributed among New York (10, 29%), Iowa (1, 3%), and Kansas (1, 3%).

Thirty (88%) of the respondents were biological parents, one was a step-parent, one was a relative of the individual with DMD, and 2 (6%) were the individual himself. Sixty-seven percent of the responding biological parents were married or living together.

The individual's age as converted for analysis ranged from 12 to 34 years, and the caregiver's age ranged from 27 to 64 years. Family sizes ranged from 1 to 5 individuals.

The vast majority of the respondents were females (28, 82%). Twenty-five (73%) of the

respondents were white, non-Hispanic, and 9 were Hispanic (27%). Twenty-five respondents (73%) regularly spoke English only, whereas 7 (21%) regularly spoke English and another language. Two respondents (6%) reported that they regularly spoke a language other than English.

Regarding level of education, 53% of the respondents had achieved more than a high school diploma. Fifty-three percent (17 of 32) of respondents reported a total household income of \leq \$30,000.

In most families (22, 65%), the individual with DMD was living. For those 12 individuals who were deceased at the time of the interview, the average age at death was 21.8 years, with a standard deviation of 5.4 years. The median age of death was 22.5 years.

Services Received and Resources Reported. Only 5 (15%) of the respondents were familiar with the term "palliative care." Figure 2 presents information about the extent to which each palliative care service was received. Respiratory care was received by a majority of the young men with DMD. Skilled nursing services were received by half of the males. Attendant care and case manager services were received by somewhat less than half of the individuals, whereas services such as respite care, transportation assistance, pain management, and hospice services were received by $<20\%$.

Less than 25% of respondents (8 of 34) reported having any type of directive document in place. Figure 2 displays the frequency with which each of four directive documents were reported to be in place. Such documents as the living will, advance

Table 2. Service providers and other resources reported by families (N = 34).

Service	Indicated as resource	
	n	%
Neuromuscular doctor	12	35.3
Family doctor	9	26.5
Other healthcare provider*	5	14.7
Neuromuscular nurse	2	5.9
Physical therapist	1	2.9
MDA representative	1	2.9
Call-line	0	0
Friend or family	0	0
Other†	4	11.8

MDA, Muscular Dystrophy Association.

*Includes: doctor (1), pulmonologist (2), or unknown (2).

†Includes: case manager, computer, library journalist, or library literature.

directives, and durable medical care power of attorney are considered important in disease management of individuals with a terminal illness. Only 2 (6%) of the families had guardianship papers in place for the care of their son with DMD in the event of incapacitation or death of the parent.

Table 2 shows the responses to the survey question that asked: "If you have a health concern or question about your son's muscular dystrophy, whom are you most likely to ask for help?" The healthcare providers (neuromuscular doctor and neuromuscular nurse) in the neuromuscular specialty clinics accounted for most (41%) of the responses, with family doctor (26.5%) as the next most frequently indicated resource.

Factors Associated with Services Received. The preliminary univariate analyses produced mixed results. Receipt of services had no relationship to the caregiver's education level, ethnic group, or income level, nor was it related to the functional ability (functional ability dysfunction) of the individual with DMD.

The results of univariate analyses of the remaining predisposing characteristics, enabling resources, and needs are presented in Table 3. Individuals with DMD who had received respiratory care, dietary counseling, case manager services, attendant care, and skilled nursing services, and those who had a legal plan in place were older than those who had never received these services. Caregivers of those individuals who had received attendant care or who had a legal plan in place for their child were older than those who had never received these services. Those caregivers who had received case manager and pain management services for their son had lower acculturation scores, meaning that they were more acculturated than those who had never received these services. More acculturated in the context of the acculturation scale that we used probably relates mostly to greater fluency in the dominant language of the healthcare system, which in each of the sites of the study would be English.

Binary logistic regressions were conducted to determine which independent variables (predisposing characteristics, enabling characteristics) were predictors of receipt of palliative and other

Table 3. Mean differences for age and scores between groups by receipt of service.* †

Service received	Individual's age (n = 34)	Caregiver age (n = 32)	Acculturation (n = 34)
Respiratory care			
Yes	26.9 (4.5)	NS	NS
No	23.2 (5.2) [P = 0.04]		
Dietary counseling			
Yes	27.9 (3.6)	NS	NS
No	24.2 (5.3) [P = 0.03]		
Case manager services			
Yes	28.4 (3.1)	NS	1.0 (0.1)
No	23.6 (5.2) [P = 0.003]		2.0 (1.4) [P = 0.008]
Pain management			
Yes	NS	NS	1.0 (0.0)
No			1.6 (1.2) [P = 0.01]
Attendant care			
Yes	28.5 (2.8)	53.5 (8.8)	NS
No	23.5 (5.2) [P = 0.002]	47.2 (7.5) [P = 0.04]	
Nursing services			
Yes	27.6 (4.0)	NS	NS
No	23.8 (5.2) [P = 0.02]		
Legal plans‡			
Yes	29.1 (3.2)	56.5 (4.9)	NS
No	24.8 (5.3) [P = 0.04]	48.3 (9.1) [P = 0.047]	

*P-values indicated for significant group differences by t-test (NS = not significant).

†Means and standard deviations (in parentheses) shown as age in years for individual age and caregiver age, and as scores for acculturation.

‡Legal plans indicates plans in place for one or more of living will, advance directives, durable power of attorney, or guardianship plan (legal).

services. The variables concerning need were not included in the regression analyses due to small sample size ($n = 22$). The only variable that showed predictive power was age of the individual with DMD, and only for receipt of case manager services and attendant care. For receipt of case manager services, the model accounted for 54% of the total variance. The odds ratio for age of the individual in this model was 1.7 ($P = 0.01$). For receipt of attendant care, the model accounted for 35% of the total variance. The odds ratio for age of the individual in this model was 1.4 ($P = 0.02$).

Relationships among Factors. We also examined relationships among the factors in the model. The caregiver age and age of the individual with DMD were positively correlated (0.71; $P < 0.0005$). Among those individuals who were living at the time of the interview, there was no difference in the mean age of those who had lost the ability to play video games or use a joystick (mean age 28.3 years) versus those who maintained this ability (mean age 27.5 years). At least for this measure of functionality, age made no difference in whether the ability had been lost or maintained.

DISCUSSION

Use of Palliative Care Services. In this study, fewer than 1 in 5 respondents were familiar with the term “palliative care.” This finding supports the conclusion of a recent study that palliative care has not achieved recognition as an important component of care for young individuals with DMD.¹⁴ Further support for this conclusion comes from the finding that rates of use of services that typically would be considered part of the palliative care model (shown in Fig. 2) were low, as the highest reported percentage reached only 50%. In a previous investigation from South Australia, only 2 of the 13 participants (15%) had been referred to any palliative care service.¹²

The data presented in this study describe patterns of services received as reported by caregivers of young men with DMD or the young men themselves. Even at the descriptive level, it is clear that there is variation in the utilization of services, some of which might have been more critical than others to the care of individuals in this sample as assessed by both providers and families. Some services, such as respiratory care, were received by the majority of young men with DMD, whereas others, such as hospice, were received by only a minority. Notably, the use of pain management services was only 12% in this study. This result is of interest, as a recent study has reported that almost 40% of young adults with DMD have pain on a daily basis.²¹ It suggests that pain in this group was being managed by healthcare providers other than those

associated with pain clinics or other formal pain management services, or perhaps that it was not being assessed or managed in many individuals.

Less than a third of respondents reported that they had legal plans in place, such as living wills and advance directives. The low response suggests that these types of documents and the issues involved might not have been introduced as topics of discussion in healthcare settings or among family support groups. Data from one of the qualitative studies of palliative care among families of individuals with muscular dystrophy suggested a level of discomfort by both professionals and families in dealing with the issues regarding advance directives.¹² In the same study only 1 of 13 participants had completed an advance directive. More recently, a study of parents of individuals with DMD demonstrated that they were not familiar with or experienced in communicating about advanced care planning.²²

One aspect deserving of greater attention in future studies is service availability. For example, service availability may be influenced by the ability to pay for additional services. Although this questionnaire asked how the individual’s medical bills were currently paid, it did not ask how the deceased individual’s bills had been paid, nor did it ask about palliative care services per se. Therefore, we have an incomplete understanding of what services were available or available and affordable to the caregivers and the individuals receiving care. Furthermore, it is not clear to what extent palliative care services are reimbursable or available under the various state-funded Medicaid programs or different private insurance plans. Formal palliative care services may also have varying availability in different communities and regions in the USA.

Factors Associated with Use of Palliative Care Services. The fact that the analysis of various socioeconomic indicators (education, ethnicity, income) did not yield any significant associations with palliative care services suggests that there may simply be a lack of knowledge about palliative care services throughout our sample population. This lack of awareness is evident in that only 15% of the respondents were familiar with the term “palliative care.” The low response could also have been in part due to lack of knowledge by providers, who consequently might not have discussed palliative care services with or offered them to the families in this study.

The data from South Australia suggest that there is reluctance by patients and families to use palliative care services for reasons other than lack of knowledge.¹² People tend to associate the places where palliative care services are provided,

especially hospice care, with end-of-life care. For individuals who have lived with progressive disorders such as DMD it is difficult to accept services that they associate with the end of life. Families also reported factors such as the suddenness with which their affected family member had deteriorated and the image represented by these services, especially hospice, as contributors to their not using palliative care.¹² It may be that attitudes about palliative care and lack of knowledge of these services by both families and providers tended to override the contribution of socioeconomic factors in the families we studied.

Across all of the services we examined, there is clear evidence that service utilization is greatly affected by the predisposing variable “individual’s age” (age of the individual with DMD), irrespective of other factors we studied. Our study showed age to be the only significant predictor of whether the families are receiving palliative care services. This suggests that families may be delaying receipt of these services due to some of the same factors reported in previous studies.¹²

Limitations of the Study. One limitation of our study is the small size of the sample, resulting in less power for statistical analyses. Furthermore, because our sample was voluntary and nonrandom, the generalizability of the findings is limited by the characteristics of the participants. An additional study limitation is that we did not assess need directly. Although we asked the caregivers to assess their son’s level of function and other questions related to needs, we did not ask them directly if they in fact believed they needed specific services. Furthermore, need was not assessed in the caregivers of deceased individuals because we did not believe it was appropriate to ask certain questions about their deceased son, such as the young man’s level of function at the time of death. However, there may have been a way of asking the caregivers if they felt that certain palliative care services were needed during that time period.

Another limitation involved some factors that were not included in the model we used. We did not account for availability of palliative care services in the model as an enabling resource. In addition, we did not assess whether palliative care services had been offered to families by their care providers. Moreover, we did not examine rural versus urban settings or other community characteristics, such as whether the treating centers for young men in the study had formal palliative care services.

Our study is complicated by the fact that we analyzed data from caregivers of individuals who are still living, along with caregivers of individuals who are deceased. There may be some recall bias

depending on how long it has been since the individual’s death. In addition, there are data either missing from the interviews of the caregivers of deceased individuals or not relevant timewise. For example, we gathered the caregiver’s current education level and current income. These factors could very well have been different while the individual with DMD was living. The same concept applies to the caregiver’s acculturation score that was calculated based on present responses. In addition, the question about what legal plans were in place for the deceased individual was not asked.

Last, we did not use other terms in the questionnaire to describe palliative care. Had we done this, the response rate for this question might have been higher. However, we asked the questions about utilization of services prior to asking the respondent if they were familiar with the term “palliative care.” The low response on awareness of palliative care suggests that families did not associate the services that are considered to be part of the palliative care system with the term “palliative care” itself.

In conclusion, our study sheds new light on patterns of service utilization among families of young men with DMD. The data support the following conclusions:

- Knowledge about palliative care is low among families of young men with DMD.
- Most families are not using services that are commonly associated with palliative care.
- Few families have directive documents in place for the individual with DMD.

Respiratory care, case manager services, respite care, and the other services typically included in the palliative care model are important for improving the caregiver and the individual’s quality of life. Further research into issues concerning access to and use of palliative care services will need to consider multiple factors, such as those characteristics specific to the individual, the caregiver, the medical provider, and the medical system itself. Research should also consider the level of comfort providers have with palliative care, which in turn could influence service availability and determine what services are actually being offered to families. Our findings suggest there may be a need for improved awareness of and access to palliative care and related services among families of young men with DMD.

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