



Workshop report

Facilitating family adjustment to a diagnosis of Duchenne muscular dystrophy: April 24–25, 2008, Miami, Florida

James Poysky^{a,*}, Kathi Kinnett^b^a School of Allied Health Sciences, Baylor College of Medicine, One Baylor Plaza, MS: BCM115, Houston, TX 77030, USA^b Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, Cincinnati, OH 45229, USA

1. Introduction

Fifteen participants representing clinicians and parents from Canada, the Netherlands, the UK, and the USA met in Miami on April 24–25, 2008 to attend a workshop that focused on facilitating family adjustment to a diagnosis of Duchenne muscular dystrophy (DMD). The workshop, sponsored by Parent Project Muscular Dystrophy (PPMD), was organized in response to parent and clinician concerns that many families do not receive adequate psychosocial support following diagnosis. DMD is a complex multi-systemic medical condition with characteristics of both chronic and terminal disease [1,2]. This can present significant challenges to a family's ability to adjust to a diagnosis of DMD, and a greater understanding of strategies that can be implemented to maximize positive outcome is necessary. Although not exhaustive, the topics covered in this workshop were judged to be of particular importance to those with DMD, and amenable to the development of specific interventions that could be implemented at the clinic level. The aims of the workshop were to (1) examine important factors that can have an impact on family adjustment and function following a diagnosis of DMD and (2) identify potential interventions and important windows of opportunity for affecting positive adjustment. It is our hope that these initial results will serve as a foundation for future exploration in this area.

2. At diagnosis

2.1. Parent experience

As representatives of parent-advocacy groups, Elizabeth Vroom (Netherlands) and Jill Castle (USA) began the workshop by presenting on the parental experience of receiving the diagnosis of DMD. Parents have reported a variety of experiences leading to the diagnosis of DMD, ranging from inadvertent identification of DMD while conducting tests for other medical conditions, to full clinical work-up at neuromuscular centers. Parents have also encountered

professionals with varying degrees of specialty in or familiarity with DMD. The expertise of the physician did not always directly correlate with how satisfied they were with their experience; professional expertise was helpful to the process, but not entirely sufficient. Additional factors had a significant impact on their overall experience [3–5].

Prior to diagnosis, parents needed to feel that their concerns were being validated. It was not unusual for parents to report that when they first brought up concerns to their pediatrician (regarding delays in development, etc.), they were told, "He'll grow out of it." or "That's just how boys are."

Receiving a diagnosis of DMD is a very difficult process for any patient and their family. The way the diagnosis was communicated had a significant impact on the parents. Too often the message was, "Nothing can be done, he is going to die. Take him home and love him, because that is all you can do." This message was perceived as particularly unhelpful by parents, and resulted in parental feelings of alienation and abandonment, essentially shutting down dialogue between families and physicians. The parent representatives believed that it was crucial for parents to hear a message of hope during the diagnostic process. It should be noted that this was not interpreted as false promises of an imminent cure, but rather was conceptualized as promoting aggressive and comprehensive medical care to maximize quality of life while potential new treatments are in development. Although this does little to soften the blow of the initial diagnosis of DMD, it is an important first step in helping parents and families adopt a broad view of life with DMD that is not focused exclusively on the negative [6].

Parents also needed to feel that they understood the diagnosis of DMD, that they had their information needs met, and that they have had the opportunity to have all of their questions answered [3]. While physician background in DMD is helpful in this regard, it is not sufficient if clinics are structured in a way that inhibits dialogue. The setting of the visit, who else is in the room (e.g., number of interns), perceptions of physician concern and empathy for the family, and ensuring that all of the parents or other important family members normally responsible for directly caring for the child are present for important discussions about the diagnosis and treatment are only a few of the variables which can impact the quality of information gleaned from any medical visit, including the time of initial diagnosis.

* Corresponding author. Tel.: +1 832 217 0065.

E-mail address: jamespoysky@gmail.com (J. Poysky).¹ On behalf of the Behavior in DMD Study Group.

Recommendations to address these factors include the following:

- (1) Physicians and healthcare teams should acknowledge parental concerns and emphasize their role as experts on their child.
- (2) Physicians and health care teams should work toward general awareness of current research and clinical trials for DMD.
- (3) Physicians and health care teams should strive to project a message of hope, as well as caring, empathy, and teamwork.
- (4) Care should be given to the setting in which the diagnosis is given (as well as other medical visits).
- (5) Sufficient time should be scheduled to meet family information needs and to allow them to ask questions.
- (6) Opportunities for follow-up in person or on the phone should be scheduled. This does not necessarily need to be with the physician, but should be with someone who has sufficient medical knowledge to answer questions and provide anticipatory guidance as needed.

2.2. Physician experience

Timothy Lotze (USA) and David Schonfeld (USA) presented on the physician experience of giving a diagnosis of DMD. Patients can be referred to a neuromuscular clinic from a variety of sources including pediatricians or other physicians, hospitals and community clinics, neuromuscular organizations/foundations, paraprofessionals (e.g., physical therapists), and self-referrals. Some may have undergone previous testing and evaluation and are only seeking confirmation or specialized care, while others may be at the starting point of the diagnostic process. The degree to which the patient and family are aware of the possibility of a diagnosis of DMD is highly variable.

The diagnostic process can be a lengthy for DMD. While some tests have a quick turn-round (e.g., CPK, ALT, AST), other tests (e.g., genetic sequencing or muscle biopsy) can take several months. This can be anxiety-provoking for some families, and can be frustrating for physicians because it is beyond their control to speed the process along.

Informing a family that their child has a life-limiting condition can be one of the most stressful and difficult parts of practicing medicine. The emotional reaction of the physician can have an impact on how a diagnosis of DMD is delivered. Even when it is done in an appropriate manner, the process of delivering bad news and experiencing the distress of patients and families will result in the physician's own feelings of distress and discomfort. As a consequence, physicians may be tempted to withhold the diagnosis or use vague terms [7]. Other maladaptive coping strategies on the part of the physician that have been reported by families include rushing through the diagnostic process, providing false promises or reassurance, encouraging families to hide their emotions, "objectifying" patients or viewing them merely as an intellectual exercise, or placing their own emotional needs before the needs of the family. In rare cases physicians may avoid contact altogether and may notify the family about the diagnosis via letter or proxy phone call. Problems in this area may be perpetuated on a systemic level, resulting in medical schools and residency training programs that provide insufficient formal training in how to deliver potentially life-limiting diagnoses and other important aspects of physician-family communication [8,9]. In addition, there may be biases in some medical circles that view any physician feelings of empathy, grief, or distress for patients as potential impediments to the delivery of optimal medical treatment.

Families vary greatly in their ability to understand the meaning and implications of a diagnosis of DMD, and it can be challenging

for the physician to tailor the explanation of the diagnosis to the family's level of medical knowledge and life experiences. The shock and grief that occur immediately following the diagnosis also interfere with the family's attention to and comprehension of any subsequent discussion.

Recommendations:

- (1) Physicians should be aware of their own feelings and how these feelings are being communicated to the family and patient or may be impacting the quality of care they deliver.
- (2) Physicians should be encouraged to care for their own mental health and emotional adjustment and should be able to cope with their own distress and discomfort in ways that do not negatively affect their patients.
- (3) Physicians should consider developing a consistent framework and strategy for discussing potentially life-limiting diagnoses. Included are some general recommendations that can be adapted or tailored to meet each physician's personality or their patients' needs:
 - a. Give thought to the setting in which the diagnosis will be given, including appropriate privacy and adequate time.
 - b. Provide a brief review of information up to that point (e.g., parent concerns and observations, test results, etc.).
 - c. Give advance warning to prepare for the conclusions (e.g., "I'm afraid that these things lead us to some difficult news...").
 - d. Use the accurate name (DMD) instead of a euphemism or vague term for the diagnosis and provide a brief description of what DMD is and what it entails. For families not yet ready for more information, a description of basic expected symptoms is sufficient (i.e., "His muscles will become weaker and weaker and at some point he will need a wheelchair, etc."). Families ready for more advanced information may benefit from a broader description (i.e., "Because of his genetic mutation, he is missing a protein that helps hold his muscles together. As a result he will become weaker and weaker, etc."). When in doubt, start with a simple and brief explanation and pause for the family to process and react to the diagnosis. Be aware that some families' need for information may increase over time.
 - e. Encourage and respond to questions.
 - f. Project empathy and understanding of the family's grief and distress. Expect a variety of possible reactions, including anger directed at the physician. Allow families this time to express their emotions.
 - g. Do not provide false promises, but try to end on a positive note. This may include assurances of ongoing care and management, or noting the positive gains that have been made in research over the course of the past decade. Obviously these things may do little to assuage the immediate grief and distress the family is experiencing. However, they will remember it later and it is an important first step in helping them adjust and become proactive.
- (4) Physicians should consider including a member of the palliative care team, mental health worker, or other member of the clinical team (such as a child life specialist) to assist in delivering the diagnosis and providing emotional support.
- (5) Because families will remember little information following the diagnosis and will have questions later, opportunities for scheduled and flexible follow-up should be provided, as noted in the previous section.
- (6) Although the physician's interactions are particularly influential in this process, these recommendations are applicable to all members of the health care team.

3. Facilitating ongoing coping/adjustment

3.1. Patients

Cognitive deficits, developmental delays, and emotional/neuropsychiatric disorders can accompany the diagnosis of DMD and can have an impact on patient adjustment and coping [10–13]. These factors have been previously examined in the literature, and will not be comprehensively addressed here. In general, early identification and intervention for these problems is encouraged.

Maria Britto (USA) and David Schonfeld (USA) presented on additional factors often overlooked that can have a significant impact on patient coping and adjustment. There is a risk that patients, in particular young children, will be viewed as passive participants in the communication related to their medical care [14]. However, some children highly value being included in the communication process, and view this as an important factor in their care [15]. Health care teams should keep in mind that patients who are not included in an age-appropriate manner in the communication process do not receive information about their diagnosis, are not involved in decision-making, and will have limited opportunity to express their preferences and goals. This can result in feelings of frustration and loss of control, and can interfere with opportunities for the patient to implement or develop positive coping strategies.

It is not unusual for parents to want to prevent their child from learning about their diagnosis. This may stem from (1) a desire to protect the child from fear, hopelessness, or emotional distress, (2) feelings of inadequacy in knowing how or how much to explain, or (3) a desire to avoid their own feelings of distress that will occur as a result of the discussion. While this has most commonly been seen in the newly diagnosed and younger children, it has been an issue for some boys into their mid- to late-adolescent years. Unfortunately, the effort to maintain this secrecy becomes a burden and source of stress for the patients and their parents/caregivers. It sends the message that illness is not to be discussed and/or the child needs to protect his parents, and results in misunderstanding and faulty conclusions about what is happening on the part of the child. Older children and adolescents inevitably access faulty, incomplete, or unfiltered information via the internet, thereby increasing their anxiety and distress. Physicians may either directly or indirectly reinforce parent beliefs in this area, or may be caught in an ethical dilemma of trying to determine when a patient has the right to be involved in the communication process – even if it is against parent wishes. In general, fears associated with informing children about their diagnosis may be unjustified for the vast majority of cases. Children, especially young children who do not yet have significant symptoms, generally respond in a neutral or positive manner to discussions about their disease, and do not experience distress above and beyond that which would be associated with the disease anyway (e.g., frustration that they cannot run as fast, etc.). A small minority of children may demonstrate regressive behavior, but it can be difficult to determine how much of this is a response to being informed about their diagnosis, or a behavioral reaction to significant parental/family distress.

Physicians need to be aware that as children grow their ability and desire to participate in their own care will change. If parents have been the sole focus of communication, it can be difficult to make the shift to include the patient. Research indicates that most adolescents with chronic illness prefer to have physicians communicate directly to and primarily with them [16]. Although they may not want to be the primary decision maker, they want to play a central role in the communication process. Physicians often overlook adolescent concerns about privacy, and may not realize the importance of explaining why they are asking certain questions. Physicians may also minimize the impact of distressing or painful

aspects of treatment, and erroneously conclude that because the patient is an adolescent he will not be distressed by blood draws or other painful procedures. It should also be noted that adolescents with chronic illness have concerns about normal adolescent development, in addition to questions about their disease.

Recommendations:

- (1) Families should be encouraged to discuss DMD with their affected child in an age-appropriate manner, beginning around the time of diagnosis. Discussion about topics as they relate to the child's daily experience living with DMD will make the most sense for the child (e.g., "DMD makes your muscles different and makes it hard to run as fast as other kids."), rather than abstract explanations. Clinic staff should make themselves available to help parents determine what and how much to say to their child.
- (2) Health personnel should include the patient in discussions about their health and care during clinic visits.
- (3) Adolescent and adult patients should have an opportunity to speak with the physician and medical staff without their parents present. Physicians should not be afraid to initiate discussions regarding sexuality or other adolescent-related topics that may be of concern.
- (4) Health personnel should explain why they are asking certain questions, as patients may not otherwise understand their purpose and may be concerned about privacy.
- (5) Adolescent and young adult patients should be strongly encouraged to begin to take responsibility for their own health care decisions, and independence in this area should be promoted.

3.2. Parents

3.2.1. Grief process

The diagnostic process of DMD will at some point result in a severe emotional crisis for the vast majority of families. Acute grief reactions occur, and may last from several months to a year or longer. The experience typically includes overwhelming emotions of shock, denial or suspicion, despair, anger, sadness/depression, anxiety, and guilt. Traditional grief theories have been well documented elsewhere and will not be reviewed here. However, the long-term chronic and eventual life-limiting nature of DMD indicates that traditional grief models may not accurately capture the experience of parents and families of children with DMD. George Eakes (USA) presented on the theory of chronic sorrow, which may better describe the grief process that occurs in DMD [17].

Traditional grief models advocate that a normal or healthy resolution to the grief process is "acceptance" of the loss. The chronic sorrow model proposes that it is normal and healthy for people to periodically re-experience the same grief-related feelings that occurred when initially confronted with the loss (e.g., at diagnosis). These episodes are triggered by circumstances or settings that emphasize the disparity that was created as a result of the loss between the individual's current reality and that which was desired or expected. Thus, although the grief feelings associated with these episodes may be less intense at times, the chronic sorrow model holds that grief can be cyclical in nature, and allows for periods of happiness and satisfaction to be interspersed with episodes of re-grief. Professionals and parents need to be aware that chronic sorrow is a normal reaction to loss, and should not be considered pathological. Parents may not anticipate that they will have episodes of re-grief and may be unprepared for them. Particular times of difficulty appear to be associated with transitional milestones (e.g., loss of ambulation, adolescence, later stages of the disease), and providing them with support and guidance is necessary [18].

Some parents have a hard time modifying rigidly held expectations for how life should have been. As a result, some become “stuck” in the grief or re-grief cycle and experience significant life impairment. Chronic sorrow can also be related to anticipatory grieving, wherein family members experience graduated feelings of loss while the child is still alive. Family members may experience this at different rates, resulting in conflict. Premature acceptance of death may in some cases result in emotional abandonment of the patient, or may cause parents to feel guilty when they wish for an end to the ordeal.

3.2.2. Parent emotional health

Veronica Hinton (USA) presented research examining stress in parents of boys with DMD. Approximately 60% of parents surveyed reported experiencing frequent worry about their child’s physical health, while approximately 45% reported experiencing frequent worry about their child’s emotional health [unpublished data]. However, additional research suggests that the overall severity of stress experienced by caregivers (in this case mothers) is significantly related to non-medical factors. Dr. Hinton’s results indicated that one of the most robust predictors of maternal stress was the presence of behavior problems in the child with DMD [2]. In particular, difficulty with social interactions and social skills appears to be particularly stress-inducing. One of the reasons for this could be that while mothers can anticipate and accept the physical limitations and challenges that come with the diagnosis of DMD, behavior issues are unexpected, carry more social stigma, and/or are less likely to be addressed or acknowledged by the child’s medical team.

Joseph Dooley (Canada) and Kathi Kinnett (USA) also presented research examining the mental health of parents of children with DMD. They reported a higher probability of depression in these parents, with about 1/3 being at risk for a major depressive disorder [19]. Parents of children with DMD also reported lower self-esteem and perceptions of less control over their life than parents of children without DMD [20]. These problems appear to be particularly prevalent in parents of older children and single parents.

A common theme emerged throughout these research studies: parents reported that DMD can cause significant disruption in the life of the primary caregiver. As a result, parents can find it increasingly difficult to meet their own needs and maintain their quality of life, and social isolation can be problematic. These things can have a negative impact on their emotional adjustment, and can result in increased levels of stress and depression.

Recommendations:

- (1) Neuromuscular clinics should include on their staff a mental health worker (e.g., social worker, psychologist, or nurse with appropriate training) or other appropriate professional who can:
 - a. Inquire into and monitor parents’ emotional adjustment during clinic visits and at other times, if necessary.
 - b. Validate the grief process and educate parents on the appropriateness and normality of experiencing grief and re-grief. Also important is helping parents understand that their spouse may experience and/or express grief in a different manner.
 - c. Provide parents with an opportunity to discuss their feelings and grief related to the disease at each visit. Parents may feel more comfortable discussing these things without their children present, so clinic staff should have a routine strategy in place to accommodate this for brief periods. In some cases separate visits or phone calls may need to be scheduled.
- (2) Supportive counseling should be presented as an option, providing tools and positive coping skills to assist in coping

with grief. Parents who are demonstrating major depression or other psychopathology should be referred for psychotherapy or psychiatric consultation.

- (3) Parents should be encouraged to seek support from other parents, either formally through established programs or informally through responsible web sites. Receiving encouragement and positive feedback from others who are facing similar challenges allows parents to feel less isolated and more supported in their experience. Close ties between clinic staff/physicians and DMD parent-advocacy groups helps to integrate newly diagnosed families into the DMD community.
- (4) Communicating with the caregivers of slightly older boys may provide parents with anticipatory guidance. While some parents will find this helpful, it may prove to be too stressful for others.
- (5) In traditional families, parents should be encouraged to spend time alone and with each other, caring both for themselves and their relationship. Time spent alone and spent strengthening relationships is also particularly important for single parents, who are at high risk for isolation and burn-out given the entire burden of care for which they are responsible. Clinic staff are highly encouraged to help parents find possible options for respite care (sometimes offered by palliative care teams or other community resources), so that parents can have a much needed break. Without assistance, parents may feel too overwhelmed to initiate these services on their own.

3.3. Sibling adjustment

Joan Fleitas (USA) and Jill Castle (USA) presented on the impact that DMD can have on well siblings. In general, siblings of children with a chronic illness are at increased risk for psychosocial problems [21], and several factors may contribute to this. Parents may have a tendency to exclude the well siblings from discussions about the child with DMD in an effort to protect them. As a result, siblings may have incorrect information and faulty assumptions about DMD. Similarly, siblings may feel as if they receive inadequate attention from parents who are excessively focused on caring for the child with DMD. In some cases the opposite may occur, and the sibling becomes the primary social and emotional outlet for the parent. Healthy siblings may also be given additional responsibilities or burdens, such as household chores, and in some cases may be responsible for certain aspects of their affected sibling’s care. It is common for siblings to experience feelings of anger, sadness, guilt, embarrassment, and jealousy. Although these feelings are a normal response to the situation, they are seldom acknowledged or discussed among families. However, the presenters also pointed out that having a sibling with DMD can also provide unique opportunities for personal growth. Fostering a supportive family environment and providing siblings with targeted information, skills, and emotional support [22] can promote the development of increased independence, altruism, maturity, and appreciation of individual differences.

Recommendations:

- (1) Clinic staff should make a conscious effort to encourage parents to discuss DMD with siblings using accurate, age appropriate language. Similar to the recommendation regarding patient adjustment above, clinic staff should make themselves available to parents needing help and guidance in this process.
- (2) Parents should be encouraged/reminded to spend dedicated individual time with healthy siblings, such as going on a

“date” or doing a fun activity. This gives siblings time alone with parents, and provides opportunities for bonding and communication.

- (3) Sibling support groups, such as *Sibshop* [23] may be helpful in allowing siblings to express their feelings in a safe, non-judgmental environment with other siblings in similar circumstances.
- (4) Each child should be seen as having a role within the family unit, no one being excluded or seen as “special” for any reason.

4. Existing clinic models

Louise Hastings (UK), Christina Trout (USA), and Marie Rizzo (USA) presented examples of clinic models that have been developed with an emphasis on facilitating family adjustment. One of the factors that emerged was that these clinics have implemented procedures that are designed to quickly form a consistent and supportive relationship with families going through the diagnostic and treatment process.

One of the primary strategies is to have a designated care coordinator for each family. This person is responsible for being the main point of contact for families, coordinating care between disciplines or services, answering questions, and providing information, anticipatory guidance, and support as needed. Note that this is not merely someone who schedules appointment, greets patients, and fills out referral forms. The care coordinator is typically a nurse or another professional with a sufficient level of medical knowledge/training to meet family information needs about DMD. In some cases the role of the care coordinator begins prior to diagnosis, and involves preparing families for their first visit. This is accomplished by contacting referral sources and gathering relevant information, educating families prior to their visit about what to expect and what/why procedures will be performed, answering initial questions, and providing reliable sources for additional information as appropriate. Care coordinators are present with the clinical when the diagnosis is given to offer support, as well as afterward to answer any questions and continue emotional support when plans for long-term care and follow-up are being developed. The involvement of this person at each stage in the process can help maintain continuity of care and can serve as a source of consistency and stability for the family in crisis.

All the clinic models presented had made a commitment to providing families with a message of hope and optimism, such as a discussion of emerging research and treatment options, or tangible markers such as potential enrollment in clinical trials or a tour of the clinic’s basic science lab. Also reported were support structures addressing the mental health, educational, and financial needs of families. An emphasis was also placed on including adolescent patients in their own health care decisions in order to promote independence into adulthood. Close ties between medical/clinic personnel and community DMD groups serve to facilitate the incorporation of new families into a supportive network.

Recommendations:

- (1) Neuromuscular clinics should have one or more staff members as dedicated care coordinators for the families they serve.
- (2) Positive, patient-centered care should be part of the explicitly stated mission of the clinic.
- (3) Clinics should systematically and routinely collect information about patient/family satisfaction with their care, in order to identify emerging needs and to correct any problems that arise.
- (4) DMD advocacy groups and clinic staff should make strong efforts to develop good working relationships and avenues of communication with each other.

5. Summary and conclusions

Receiving a diagnosis of Duchenne muscular dystrophy is a difficult process for any family. Multiple factors can contribute to how well a family adjusts to this new reality. While some of these are beyond the control of health professionals, there are strategies that can be implemented in the clinic that can facilitate the process and guide families toward a positive outcome of coping in spite of the diagnosis. Certain strategies may be particularly important at specific times of crisis, such as at diagnosis or during transitional phases, while others may be ongoing to meet recurrent or emerging needs. In our opinion, the factors and recommendations discussed in this article are just as important as the actual medical care that is delivered in the clinic. Neuromuscular clinics that give thought to these issues in advance and strive to have plans and structures in place for their patients will have the biggest impact on overall adjustment.

Appendix A. List of workshop participants

Joan Fleitas, The City University of New York, USA.
 Georgene Eakes, East Carolina University (Emeritus), USA.
 Joseph Dooley, Dalhousie University, Canada.
 David Schonfeld, Cincinnati Children’s Hospital Medical Center, USA.
 Louise Hastings, Newcastle University, UK.
 Veronica J. Hinton, Columbia University, USA.
 Maria Britto, Cincinnati Children’s Hospital Medical Center, USA.
 Elizabeth Vroom, United Parent Projects Muscular Dystrophy, Netherlands.
 Marie Ritzo, Children’s National Medical Center, USA.
 Christina Trout, University of Iowa Children’s Hospital, USA.
 James Poysky, Baylor College of Medicine, USA.
 Kathi Kinnett, Cincinnati Children’s Hospital Medical Center, USA.
 Jill Castle, Parent Project Muscular Dystrophy, USA.
 Giovanna Spinella, Parent Project Muscular Dystrophy, USA.
 Tim Lotze, Texas Children’s Hospital, USA.

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