

clearing the airway of mucus except when there is focal atelectasis and mucus plugging the airways (Kravitz, 2009).

Survival in individuals with DMD may be prolonged several years with the use of noninvasive ventilation and MAC as alternatives to tracheotomy and airway suctioning (Bach and Martinez, 2011; Simonds, 2006). The American Thoracic Society has published extensive guidelines for respiratory monitoring and care of children and adults with DMD (Finder, Birnkrant, Carl, et al, 2004).

The American Academy of Pediatrics Section on Cardiology and Cardiac Surgery (2005) recommends an extensive cardiac evaluation of the child diagnosed with either DMD or Becker MD. Patients with neuromuscular conditions may not have the typical signs and symptoms of cardiac dysfunction. Therefore, symptoms such as weight loss, nausea and vomiting, cough, increased fatigue on performance of ADLs, and orthopnea should be carefully evaluated to detect early signs of cardiomyopathy.

Genetic counseling is recommended for parents, sisters, and maternal aunts and their daughters. Long-term care, end-of-life care, and palliative care options are issues that the health care team must discuss with the child and family affected by MD (Finder, 2009). Professional counseling is necessary in some cases to allow frank discussion of these issues, and referrals should be made as appropriate.

## **Nursing Care Management**

The care and management of a child with MD involve the combined efforts of a multidisciplinary health care team. Nurses can help clarify the roles of these health care professionals to family and colleagues. The major emphasis of nursing care is to help the child and family cope with a chronic, progressive, incapacitating disease; to help design a program that will afford maximal independence and reduce the predictable and preventable disabilities associated with the disorder; and to help the child and family deal constructively with the limitations the disease imposes on their daily lives. Because of advances in technology, children with MD may live into early adulthood; therefore, the goals of care should also involve decisions regarding quality of life, achievement of independence, and transition to adulthood.