



HHS Public Access

Author manuscript

J Neuromuscul Dis. Author manuscript; available in PMC 2023 January 01.

Published in final edited form as:

J Neuromuscul Dis. 2022 ; 9(3): 447–456. doi:10.3233/JND-210709.

Role attainment in emerging adulthood: subjective evaluation by male adolescents and adults with Duchenne and Becker muscular dystrophy

Holly L Peay, PhD, MS,

Genomics, Bioinformatics, and Translational Research Center, RTI International, Research Triangle Park NC

Barbara T. Do, MSPH,

Clinical Research Network Center, RTI International, Research Triangle Park NC

Neil Khosla, MPH,

Oak Ridge Institute for Science and Education (ORISE) Fellow, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Pangaja Paramsothy, PhD, MPH,

National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Stephen W Erickson, PhD,

Genomics in Public Health & Medicine Center RTI International, Research Triangle Park NC

Molly M. Lamb, PhD,

Department of Epidemiology, Colorado School of Public Health, University of Colorado Anschutz Medical Campus, Aurora, CO

Nedra Whitehead, PhD, MS,

Genomics in Public Health & Medicine Center, RTI International, Research Triangle Park NC

Deborah J. Fox, MPH,

New York State Department of Health, Albany, NY

Shree Pandya, DPT,

School of Medicine and Dentistry, University of Rochester, Rochester, NY

Kathi Kinnett, MSN,

Parent Project Muscular Dystrophy, Hackensack, NJ

Jodi Wolff, PhD,

Santhera Pharmaceuticals, Burlington, MA, Stride Bio, Research Triangle Park, NC

James F Howard Jr, MD

Complete correspondence addresses: Holly Peay, PhD, RTI International, 3040 E Cornwallis Rd, Research Triangle Park NC 27613 USA, Phone 919-485-7734, hpeay@rti.org.

Conflict of interest statements:

Jodi Wolff was an employee of Santhera Pharmaceuticals when the work was conducted and is now an employee of Stride Bio. The remaining authors have no conflicts of interest.

Department of Neurology, University of North Carolina at Chapel Hill, Chapel Hill, NC

Muscular Dystrophy Surveillance, Tracking, and Research Network (MD *STARnet*)

Abstract

Background: Youth with Duchenne and Becker muscular dystrophy (DBMD) experience challenges in attaining adult roles, which may impact quality of life. New interventions and treatments may facilitate adult role attainment through improved function. Historical data on adult role attainment is important to assess the impact of new interventions on teens and young adults with DBMD. This study assesses medical knowledge, independence and employment, and relationships among adolescents and young adults with DBMD.

Methods: This study uses data from a 2013 Muscular Dystrophy Surveillance, Tracking, and Research Network (MD *STARnet*) survey on adult transition. Males with DBMD aged 16-30 years were included.

Results: Sixty-five of 258 eligible males participated; we report results on 60 participants with an MD *STARnet* case definition of DMD or BMD. Individuals with BMD reported higher rates than those with DMD of frequently staying home without supervision (50% BMD; 14% DMD), independently performing daily physical needs (93% BMD; 7% DMD) and being employed full or part time (33% BMD; 4% DMD). Most participants understood medication and physical therapy goals; less than half indicated being often or always responsible for scheduling DMBD-related management and refilling medications. Most had not been in a romantic relationship but reported desiring such relationships.

Conclusions: Our data reinforce the impact of DMD (and to a lesser extent, BMD) on transition to adult roles. These results provide an important historical comparator for teen and adult patients who are trying new interventions and therapies. Such data are important for assessing the quality-of-life impact of new treatments and to inform support and training programs for people with DBMD as they transition to new adult roles and responsibilities.

Keywords

Muscular dystrophies; transition to adult care; transfer from pediatric to adult care; self-care; adolescent

Introduction

The developmental period from the teenage years through the twenties is a time of profound transition to increased independence and adult role attainment [1]. Individuals with significant disabilities experience barriers to adult transition [2-7]. For those with disabilities, the lack of successful planning for this transition can result in a deterioration of health status, a loss of confidence in the adult health care system, and a limited ability to direct one's health care [8] For teens and adults with Duchenne muscular dystrophy (DMD), which is a progressive neuromuscular condition with pediatric onset, adequate treatment options and lifetime care are essential for a successful transition into adulthood [9]. As DMD progresses, teens and adults are faced with increasing weakness, loss of mobility, and

cardiac or respiratory deficiencies. Treatment options including corticosteroids and cardiac and respiratory interventions have extended the average lifespan [10].

Though much attention has focused on facilitating medical transition, other important components of quality of life (QoL) include advancing mental wellbeing, independence, and activities of daily living for teens and adults with DMD and Becker muscular dystrophy (BMD) (collectively, DBMD) [11-16]. Individuals with DBMD report self-care, social, employment, and economic challenges to adult role attainment [12-16], and a 2008-2018 chart review of teen to adult patients with DBMD found low levels of employment and living independently [17]. Though independence has been found to be impacted by progression of DMD [18], several studies suggest that QoL improves as individuals with DMD get older [19,20].

This study presents a subset of data from the Muscular Dystrophy Surveillance Tracking and Research Network (MD *STARnet*) Health Care Transitions and Other Life Experiences Survey [21-23] conducted in 2013 to explore medical transition and adult role attainment. This study contributes to the limited data known on adult role attainment in DBMD, a topic that becomes increasingly significant as individuals with DBMD are living longer [10; 24] and as new therapies become available. These data are reported to provide a comparator for current and future cohorts of teens and adults with DBMD, to facilitate assessments of the impact of new interventions and treatments. They also inform support and training programs that facilitate transition to adult roles and responsibilities among people with DBMD.

Materials and Methods

MD *STARnet* is a population-based surveillance study funded by the Centers for Disease Control and Prevention to determine, among other outcomes, the prevalence of DBMD [22]. An online survey was developed to obtain additional data on transition from childhood to adulthood. Data collection for the MD *STARnet* Health Care Transitions and Other Life Experiences Survey spanned April 2013 through October 2013 at five MD *STARnet* sites: Arizona, Colorado, Georgia, Iowa and Western New York. Participants were identified in the MD *STARnet* system, lived in the surveillance area, were affected with DBMD, were the oldest living male with DBMD in the household, and were at least 16 years old. The survey was available in English and in Spanish. Recruitment letters with a unique survey link were sent to 258 eligible males, who then received up to three reminder telephone calls and/or letters. IRB approval was obtained from each participating sites. Additional detail has been previously reported [21].

The Transition survey comprised patient-reported items related to medical transition, adult role attainment and physical function; additional information about the data collection and findings on medical transition have been reported previously [21].

Domains associated with role attainment reported here include (Tables 1, 2 and 4):

- Medical knowledge and awareness, including items on medications and therapy programs

- Independence, including staying home alone, ability to complete daily physical needs, having choice in selecting personal attendants, responsibility for own care, employment, and managing daily living expenses; and
- Social support and relationships, including experience with peer and romantic relationships, desire for romantic relationships, and satisfaction with experienced intimacy.

Survey questions reported here were adapted from the 2012 MDA transition survey [25] and a survey of adolescents and young adults living with spina bifida [26]. The instrument was developed by a working group of clinicians, researchers, and representatives from advocacy organizations. Questions were pilot tested at two neuromuscular clinics by teenage and adult males with DBMD. Participants' survey data was linked to their MD *STARnet* surveillance data, permitting the use of MD *STARnet* determination of phenotype (Duchenne, Becker, or unable to determine) [23].

Statistical analysis

Analyses were descriptive given the small sample sizes. Two analysts conducted statistical analyses independently at different sites. Participants with MD *STARnet* phenotype determinations of DMD or BMD were included. Because of the milder phenotype in BMD [27] than DMD, data are reported separately by diagnosis. Adult role attainment is expected to increase with age. And yet the progressive nature of DBMD leads to worse motor function over time, particularly the ability to use one's arms and hands [27]. We thus selected, for exploratory assessment, three adult role items to investigate for evidence of improvement with age and/or better function, as we defined by the ability to use one's arms and hands: frequency of responsibility for remembering medications, frequency of staying home alone for longer than two hours, and whether anyone else helps manage expenses associated with daily living. For each response option, we calculated the mean age and frequencies of limb function status. Limb function was assessed using an ordinal scale spanning full use of arms and hands (4), ability to lift hand to mouth (3), inability to lift hand to mouth but ability to use hands (2), inability to lift hand to mouth or use hands (1); for analysis we dichotomized items 4 and 3 to "can lift hand to mouth" and items 2 and 1 to "cannot lift hand to mouth." This function item was adapted from prior MD *STARnet* questionnaires.

Participants were given the opportunity to opt out of entire question sets or individual items on romantic relationships and sexual experiences because of the sensitive nature of the questions; as a result, smaller samples were available for the descriptive analyses on these items. Analyses were conducted using SAS 9.4 software (Cary, NC).

Results

Sixty-five out of 258 eligible males with DBMD completed the survey (completion rate 25%). Though participants came from all five sites, completion rate differed by site, with a 47% completion rate in Iowa, 30% in Western New York, 26% in Arizona, 22% in Georgia, and 14% in Colorado. Survey completion rates were lower among Hispanics and non-Hispanic black eligible individuals ($p < 0.01$) but did not differ based on age or

Duchenne or Becker diagnosis [18]. Of the 65 participants, investigators characterized the diagnosis as DMD or BMD for 60 participants, which comprised the dataset reported in this analysis. Additional data about the cohort have been reported previously [18].

The majority (n=45) had a DMD diagnosis. Forty-seven (87%) identified as Caucasian. The average age of participants with DMD and BMD in this cohort was similar (22.1 and 23.2 years, respectively) and ranged from 16-30 years (Table 1). Seventeen reported full function, 13 reported ability to lift hands to mouth, 23 reported inability to lift hands to mouth but maintained use of their hands, while seven participants reported no longer having use of their hands. As expected, participants with BMD reported better upper limb function than those with DMD (mean (SD): 3.9 (0.4) vs 2.3 (0.8), respectively). Also as expected, all 30 participants who could not lift their hands to their mouths indicated being unable to perform daily physical needs such as bathing, dressing and eating independently. Of the 30 who could lift their hands, 17 indicated being able to perform all activities independently and 13 indicated not.

Medical knowledge and awareness

Of 53 participants who responded to the medication management questions, the majority knew the names of most or all their medications (86% DMD; 75% BMD) and the reason for taking them (71% DMD; 92% BMD). Fifty-nine percent of those with DMD and 83% of those with BMD reported being responsible for remembering to take medication most or all the time. Of those who reported that they participated in a therapy program, all reported knowing why they do most or all of their therapy programs, and most very often or always remember to do their therapy program without reminder (63% DMD; 80% BMD) (Table 2).

Independence

Most participants with DMD reported never or rarely being home alone longer than two hours (74%) and being unable to perform daily physical needs independently (93%). Most participants with BMD, however, frequently or occasionally stayed home alone (75%) and could independently perform daily physical needs (93%). Most respondents with DMD (70%) reported that someone helps manage their daily living expenses while most respondents with BMD (67%) indicated not having help. Only a minority were employed full or part time, while 33% of those with DMD and 20% of those with BMD reported being students.

Regarding responsibility for DBMD management, 18% of individuals with DMD and 67% of individuals with BMD indicated that they were usually or always responsible for making sure medication prescriptions were filled, and among those who had therapy appointments, 35% of respondents with DMD and 40% of respondents with BMD were responsible for scheduling those appointments. Only one individual with BMD indicated having a personal care attendant or aide, and he indicated having a choice in the selection of a personal care attendant. Among participants with DMD, 72% with an aide indicated choice in selection and 43% indicated very often or always scheduling the aide (Table 3).

Participant age, arm function, and selected medical knowledge and independence items

Table 4 shows average age and frequencies of being able to lift hand to mouth for three adult role items. For remembering to take medications, results suggest a possible trend to improvement in the role with increasing age, but also a trend toward diminishment with worse arm function. There is a possible trend toward higher frequency of staying home alone with the ability to lift hand to mouth. Help in managing daily living expenses showed very small possible trends in the expected directions with age and arm function.

Social

Most participants (76% DMD; 73% BMD) reported spending time with friends face-to-face and the large majority (93% DMD; 93% BMD) reported contacting friends through use of technology. Most participants (64% DMD; 80% BMD) indicated that none or few of their close friends were other individuals with disabilities.

Of those who responded to the associated questions, the majority with DMD and BMD agreed or strongly agreed that they desired a romantic partner (73% DMD; 89% BMD), emotional (74% DMD; 89% BMD) and physical (66% DMD; 89% BMD) intimacy, and sexual intercourse (63% DMD; 66% BMD). While some participants reported having experienced romantic physical intimacy such as hugging, touching, or holding hands (40% DMD; 75% BMD), the majority never experienced a romantic relationship (60% DMD; 50% BMD) or sexual intercourse (80% DMD; 62% BMD). Over half agreed that they have someone to talk to about romantic desires (57% DMD; 66% BMD). Fewer respondents with BMD endorsed that they had someone to talk to about sexual desires than respondents with DMD (57% DMD; 44% BMD). Overall, most respondents reported being neutral or dissatisfied with their experience with emotional and physical intimacy (Table 5).

Discussion

These historical data on attainment of adult roles by teenagers and adults with DBMD reinforces the impact of DBMD on important adult roles such as employment, staying home alone, and being able to independently complete activities associated with daily needs. While most participants indicated responsibility in understanding and remembering several important components of DBMD management, the majority did not take the active roles of scheduling and ensuring prescriptions are filled. As expected, our results suggest that at least some aspects of adult role achievement are being hampered by impairments in physical function that accompany DBMD. These data contribute to the limited literature that reflects the broad impact of DBMD functional impairments on self care, employment, and independence (11-20).

Regarding social outlets and interactions, participants reported high rates of both face-to-face interactions and contacting friends using online technologies. These data are rather optimistic about overall social engagement. Additional research would aid the exploration of barriers and facilitators to peer relationships for those with DBMD as peer relationships are increasingly conducted virtually. While romantic experience was reported as lacking, the desire for such experience among participants was not. Participants felt neutral about

their experience with emotional intimacy overall, were dissatisfied or neutral about their experience with physical intimacy, and only about half had someone to talk to about their romantic and sexual desires. Interpretation of these findings are limited by the small sample size and potential response bias, since a number of participants did not respond to this question set. These data suggest, however, that romantic and sexual relationships and emotional intimacy are an area of need, and that facilitators of such relationships are important as new interventions improve function and lifespan. Two studies on individuals with DMD living in Europe reinforce the importance of sexuality and relationships (16, 28), and studies of adolescents and adults with other types of physical disabilities report a similar disconnect between desired and actual romantic and sexual relationships (29, 30); this is an important area for future research.

Though limited by a low response rate and few participants with BMD, these results provide insight into attainment of a range of adult roles and serve as a historical comparator for additional studies in current and future cohorts. Improved medical management and/or changes to family and societal expectations for adult role attainment are expected to impact transition to adulthood, as are new opportunities for employment and independent living. This study was not able to account for potential cognitive impacts of DBMD. In addition, this study focused on adult roles that have been identified in prior research. An important area of future research is to explore what adult roles are perceived by individuals with DBMD to be most appealing and important. Future studies may then assess the impact of cognitive, motor, pulmonary, and cardiac function on patients' willingness and ability to take on those prioritized adult roles, and to further evaluate the relationships among function, adult role attainment, and quality of life. In addition, future studies may explore role management of different complexity, at different stages of progression; e.g., assessing individual care tasks such as remembering to take one medication versus being responsible for one's entire DBMD care and management, in adolescence and through adulthood. Such data could inform support and training programs for teens and young adults with DBMD as they transition to new adult roles and responsibilities, especially as new therapeutic and management approaches extend lifespan and enhance function of those with DBMD. Our data may highlight the need for facilitators to engagement in intimate and sexual relationships, such as access to experts and non-expert peers to support teens and adults with DBMD.

Acknowledgements:

This publication was supported by the Cooperative Agreement numbers DD000187, DD000189, DD000190, DD000191, DD000833, DD001116, DD001123, DD001126 funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Diseases Control and Prevention or the Department of Health and Human Services.

Data Access:

Due to privacy concerns (detailed personal information was obtained from a small number of individuals living in a defined surveillance area), data from MD *STARnet* Health Care Transitions and Other Life Experiences Survey is not publicly available. Data from this analysis is kept at the Centers for Disease Control and Prevention.

References

1. Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*. 2000;55(5):469–80. [PubMed: 10842426]
2. van Mechelen MC, Verhoef M, van Asbeck FW, Post MWM. Work participation among young adults with spina bifida in the Netherlands. *Dev Med Child Neurol*. 2008;50:772–7. [PubMed: 18699861]
3. Lindsay S. Discrimination and other barriers to employment for teens and young adults with disabilities. *Disabil Rehabil*. 2010;33:1340–50. [PubMed: 21067349]
4. Verhoef JAC, Miedema HS, Meeteren JV, Stam HJ, Roebroek ME. A new intervention to improve work participation of young adults with physical disabilities: a feasibility study. *Developmental Medicine & Child Neurology*. 2013;55:722–8. [PubMed: 23621846]
5. Scott HM, Havercamp SM. Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellect Dev Disabil*. 2014;52(6):409–18. [PubMed: 25409129]
6. Joly E. Access to services for young adults with medical complexity. *Nurs Ethics*. 2017;24(3):329–36. [PubMed: 26385901]
7. Lynch ME, Kable JA, Coles CD. Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults. *Neurotoxicol Teratol*. 2015;51:52–60. [PubMed: 26247662]
8. MacKintosh EW, Chen ML, Benditt JO. Lifetime care of Duchenne muscular dystrophy. *Sleep Medicine Clinics*. 2020; 15(4): 485–495. [PubMed: 33131659]
9. Kumar SH, Athimoolam K, Suraj M, Shoba Das Christu Das M, Muralidharan A, Jeyam D, Ashokan J, Karthikeyan P, Krishna R, Khanna-Gupta A, Bremadesam Raman L. Comprehensive genetic analysis of 961 unrelated Duchenne Muscular Dystrophy patients: Focus on diagnosis, prevention and therapeutic possibilities. *PLOS ONE*. 2021;15. e0232654. doi 10.1371/journal.pone.0232654.
10. Birnkrant DJ, Bushby K, Bann CM, Apkon SD, Blackwell A, Colvin MK, Cripe L, Herron AR, Kennedy A, Kinnett K, Naprawa J, Noritz G, Poysky J, Street N, Trout CJ, Weber DR, Ward LM; DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurol*. 2018 May;17(5):445–455. doi: 10.1016/S1474-4422(18)30026-7. Epub 2018 Feb 2. [PubMed: 29398641]
11. Jacques MF, Stockley R, Onambele-Pearson GL, Reeves ND, Stebbings GK, Dawson EA, Groves L, Morse CI. Quality of life in adults with muscular dystrophy. *Health Qual Life Outcomes*. 2019, 17 (1): 121. doi. 10.1186/s12955-019-1177-y. [PubMed: 31307472]
12. Rahbek J, Werge B, Madsen A, Marquardt J, Steffensen BF, Jeppesen J. Adult life with Duchenne muscular dystrophy: observations among an emerging and unforeseen patient population. *Pediatr Rehabil*. 2005;8(1):17–28. [PubMed: 15799132]
13. Gibson BE, Young NL, Upshur REG, McKeever P. Men on the margin: a Bourdieusian examination of living into adulthood with muscular dystrophy. *Soc Sci Med*. 2007;65(3):505–517. [PubMed: 17482331]
14. Abbott D, Carpenter J, Bushby K. Transition to adulthood for young men with Duchenne muscular dystrophy: research from the UK. *Neuromuscul Disord*. 2012;22(5):445–6. [PubMed: 22425491]
15. Schrans DGM, Abbott D, Peay HL, Pangalila RF, Vroom E, Goemans N, Vles JSH, Aldenkamp AP, Hendriksen JGM. Expert meeting participants on transition and adulthood in Duchenne muscular dystrophy. *Neuromuscul Disord*. 2013;23(3):283–6. [PubMed: 22989602]
16. Rahbeck J, Steffensen BF, Bushby K, de Groot IJM. 206th ENMC International Workshop: Care for a novel group of patients - adults with Duchenne muscular dystrophy Naarden, The Netherlands, 23–25 May 2014. *Neuromuscul Disord*. 2015;25:727–38. [PubMed: 26099652]
17. Donaldson A, Guntrum D, Ciafaloni E, Statland J. Achieving Life Milestones in Duchenne/Becker Muscular Dystrophy: A Retrospective Analysis. *Neurol Clin Pract*. 2021;11(4):311–317. doi:10.1212/CPJ.0000000000000970 [PubMed: 34484931]

18. Crescimanno G, Greco F, D'Alia R, Messina L, Marrone O. Quality of life in long term ventilated adult patients with Duchenne muscular dystrophy. *Neuromuscul Disord*. 2019 Aug;29(8):569–575. doi: 10.1016/j.nmd.2019.06.599. Epub 2019 Jun 29. [PubMed: 31395305]
19. Uzark K, King E, Cripe L, Spicer R, Sage J, Kinnett K, et al. Health-related quality of life in children and adolescents with Duchenne muscular dystrophy. *Pediatrics*. 2012;130(6):e1559–e1e66. [Google Scholar] [PubMed: 23129083]
20. Hendriksen JG, Poysky JT, Schrans DG, Schouten EG, Aldenkamp AP, Vles JS. Psychosocial adjustment in males with Duchenne muscular dystrophy: psychometric properties and clinical utility of a parent-report questionnaire. *J Pediatr Psychol*. 2008;34(1):69–78. [Google Scholar] [PubMed: 18650207]
21. Paramsothy P, Herron AR, Lamb MM, Kinnett K, Wolff J, Yang ML, Oleszek J, Pandya S, Kennedy A, Cooney D, Fox D, Sheehan D. Health Care Transition Experiences of Males with Childhood-onset Duchenne and Becker Muscular Dystrophy: Findings from the Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) Health Care Transitions and Other Life Experiences Survey. *PLoS Curr*. 2018;10. pii: ecurrents.md.7de8a1c6798d7a48d38ea09bd624e1cd. doi: 10.1371/currents.md.7de8a1c6798d7a48d38ea09bd624e1cd.
22. Miller LA, Romitti PA, Cunniff C, Druschel C, Mathews KD, Meaney FJ, et al. The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet): surveillance methodology. *Birth Defects Res A Clin Mol Teratol*. 2006;76(11):793–7. [PubMed: 17036307]
23. Mathews KD, Cunniff C, Kantamneni JR, et al. Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet): case definition in surveillance for childhood-onset Duchenne/Becker muscular dystrophy. *J Child Neurol*. 2010;25(9):1098–1102. [PubMed: 20817884]
24. Passamano L, Taglia A, Palladino A, Viggiano E, D'Ambrosio P, Scutifero M, Rosaria Cecio M, Torre V, DE Luca F, Picillo E, Paciello O, Piluso G, Nigro G, Politano L. Improvement of survival in Duchenne Muscular Dystrophy: retrospective analysis of 835 patients. *Acta Myol*. 2012;31(2):121–5. [PubMed: 23097603]
25. Muscular Dystrophy Association [homepage on the internet]. Cited 2021 April 5. Available at www.MDA.org
26. Soe MM, Swanson ME, Bolen JC, Thibadeau JK, Johnson N. Health risk behaviors among young adults with spina bifida. *Dev Med Child Neurol*. 2012;54(11):1057–64. [PubMed: 22937873]
27. Andrews JG, Wahl RA. Duchenne and Becker muscular dystrophy in adolescents: current perspectives. *Adolesc Health Med Ther* 2018;15;9:53–63. doi: 10.2147/AHMT.S125739. [PubMed: 29588625]
28. Almendro-Martínez I, Llorente-Parrado C, Cadarso-Mora A, Nuño-Estévez M, Dumitrescu A, Arroyo-Riaño O. Perspectivas de pacientes con distrofia muscular de Duchenne: grupo focal para mejorar la calidad asistencial [Perspectives of patients with Duchenne muscular dystrophy: A focal group to improve healthcare quality]. *J Healthc Qual Res*. 2020;35(5):273–279. doi:10.1016/j.jhqr.2020.06.009 [PubMed: 33011147]
29. Wiegerink DJ, Roebroek ME, Donkervoort M, Stam HJ, Cohen-Kettenis PT. Social and sexual relationships of adolescents and young adults with cerebral palsy: a review. *Clin Rehabil*. 2006;20(12):1023–1031. doi:10.1177/0269215506071275 [PubMed: 17148513]
30. Kattari SK, Turner G. Examining More Inclusive Approaches to Social Work, Physical Disability, and Sexuality. *J Soc Work Disabil Rehabil*. 2017;16(1):38–53. doi:10.1080/1536710X.2017.1260517 [PubMed: 28187696]

Table 1.

Adult role attainment demographics for 60 male participants

Characteristics, n (%)	Total (N=60)
Race/Ethnicity	
Black or African American	*
Caucasian	47 (87)
Hispanic or Latino/Latina	*
Multiple	*
Missing	6
State	
Arizona	13 (22)
Colorado	8 (13)
Georgia	13 (22)
Iowa	15 (25)
New York	11 (18)
Age, years	
16-18	14 (23)
19-21	15 (25)
22-24	15 (25)
25-30	16 (27)

* denotes cell size of 5 or fewer.

Table 2. Medical knowledge and awareness among males older than 16 years who are affected with Duchenne or Becker Muscular Dystrophy, MD STARnet Survey 2013

Medical Knowledge/ Awareness Survey Questions	Responses	Duchenne MD (N=45) n (%) ^f	Becker MD (N=15) n (%) ^f
Do you know the name of each medication you take?	I know the names of none or some of my medication.	6 (15)	3 (25)
	I know the names of most of my medication.	13 (32)	0 (0)
	I know the names of all my medication. <i>Missing</i>	22 (54) 4	9 (75) 3
Do you know why you take or need each medication?	I do not know why I take all my medication.	12 (29)	1 (8)
	I know why I take all my medication. <i>Missing</i>	29 (71) 4	11 (92) 3
	I am not responsible for remembering when to take any of my medication.	4 (10)	2 (17)
How often are you responsible for remembering to take your medication?	I am responsible for remembering to take my medication some of the time.	13 (32)	0 (0)
	I am responsible for remembering to take my medication most of the time.	8 (20)	0 (0)
	I am responsible for remembering to take my medication all the time. <i>Missing</i>	16 (39) 4	10 (83) 3
	I know why I do most of my therapy programs.	4 (22)	2 (40)
Do you know why you do each therapy?	I know why I do all my therapy programs. <i>Missing</i>	14 (78) 27	3 (60) 10
	Never or Occasionally	6 (38)	1 (20)
	Very Often Always <i>Missing</i>	4 (25) 6 (38) 29	4 (80) 0 (0) 10

^f Percentages are based on non-missing responses.

Independence domains among males older than 16 years who are affected with Duchenne or Becker Muscular Dystrophy, MD. *STARnet* Survey 2013.

Table 3.

Survey Questions	Responses	Duchenne MD (N=45) n (%) ^f	Becker MD (N=15) n (%) ^f
How often do you stay home alone for longer than two hours at one time without assistance?	Never	24 (57)	1 (8)
	Rarely (1 time per week)	7 (17)	2 (17)
	Occasionally (2-3 times per week)	5 (12)	3 (25)
	Frequently (4+ per week)	6 (14)	6 (50)
	<i>Missing</i>	3	3
Which of the following statements describe your completing daily physical needs, such as dressing, bathing, and eating?	Can independently perform all activities		
	No	42 (93)	1 (7)
	Yes	3 (7)	14 (93)
[Among those with attendant/aid] Did you have a choice in selecting your personal care attendant or aide?	No	7 (28)	0 (0)
	Yes	18 (72)	1 (100)
	<i>Missing/NA</i>	20	14
[Among those with attendant/aid] How often are you responsible for scheduling your personal care attendant or aide?	Never or Occasionally	13 (57)	0 (0)
	Very Often or Always	10 (43)	0 (0)
	<i>Missing/NA</i>	22	15
How often are you responsible for making sure your medication is filled at the pharmacy?	Never	26 (67)	2 (17)
	Sometimes	6 (15)	2 (17)
	Usually	3 (8)	2 (17)
	Always	4 (10)	6 (50)
	<i>Missing</i>	6	3
[Among those who have therapy appointments] How often do you schedule your therapy appointments?	Never or Occasionally	11 (65)	3 (60)
	Often or Always	6 (35)	2 (40)
	<i>Missing/NA</i>	28	10
Are you currently employed?	Student	13 (29)	3 (20)
	Employed full-time	0 (0)	2 (13)
	Employed part-time	2 (4)	3 (20)
	Would like to be employed but have been unsuccessful at finding a job	9 (20)	4 (27)

Survey Questions	Responses	Duchenne MD (N=45) n (%) ^f	Becker MD (N=15) n (%) ^f
	Not employed and am not currently looking for a job	13 (29)	2 (13)
	Work in a “supervised” work setting	1 (2)	1 (7)
	None of the above	5 (11)	0 (0)
	Does not apply	2 (4)	0 (0)
Does anyone help you manage your daily living expenses?	No	12 (30)	8 (67)
	Yes	28 (70)	4 (33)
	<i>Missing</i>	5	3

^f Percentages are based on non-missing responses.

Table 4.

Exploration of age and arm function ratings based on responses to selected adult roles among males older than 16 years who are affected with Duchenne or Becker Muscular Dystrophy, MD *STARnet* Survey 2013

Medical Knowledge/ Awareness Survey Questions	Responses	Duchenne & Becker MD			
		N (%)	Age (SD)	Cannot lift hand to mouth ² (N=30)	Can lift hand to mouth ² (N=30)
How often are you responsible for remembering to take your medication?	I am not responsible for remembering when to take any of my medication.	6 (11)	21.7 (4.1)	3 (11)	3 (12)
	I am responsible for remembering to take my medication some of the time.	13 (25)	22.0 (4.9)	8 (30)	5 (19)
	I am responsible for remembering to take my medication most of the time.	8 (15)	22.8 (4.6)	6 (22)	2 (8)
	I am responsible for remembering to take my medication all the time. <i>Missing</i>	26 (49) 7	23.3 (3.8) 7	10 (37) 3	16 (62) 4
How often do you stay home alone for longer than two hours at one time without assistance?	Never	25 (46)	23.5 (4.6)	20 (74)	5 (19)
	Rarely (1 time per week)	9 (17)	21.2 (3.0)	3 (11)	6 (22)
	Occasionally (2-3 times per week)	8 (15)	21.9 (4.4)	3 (11)	5 (19)
	Frequently (4+ per week) <i>Missing</i>	12 (22) 6	21.6 (3.6) 6	1 (4) 3	11 (41) 3
Does anyone help you manage your daily living expenses?	No	20 (38)	23.3 (3.6)	10 (34)	10 (43)
	Yes	32 (62)	22.8 (4.3)	19 (66)	13 (57)
	<i>Missing</i>	8	8	1	7

²Limb function status is dichotomized based on an ordinal scale. Items: "full use of arms and hands" and "can lift hand to mouth" are coded as can lift hand to mouth. Items: "cannot lift hand to mouth but can use hands" and "cannot lift hand to mouth and cannot use hands" are coded as cannot lift hand to mouth.

Table 5.

Social support and relationships among males older than 16 years who are affected with Duchenne or Becker Muscular Dystrophy, MD *STARnet* Survey 2013

Survey Questions	Responses	Duchenne MD (N=45)	Becker MD (N=15)
How do you usually contact your friends? (Choose all that apply.) <i>Face-to-face (in own home or outside home)</i> <i>Technology-mediated (e.g., phone, texting, social media)</i>	No	10 (24)	4 (27)
	Yes	32 (76)	11 (73)
	<i>Missing</i>	3	---
	No	3 (7)	1 (7)
	Yes	39 (93)	14 (93)
	<i>Missing</i>	3	---
How many of your close friends are other young people with disabilities?	None or Little	29 (64)	12 (80)
	Some or A Lot	16 (36)	3 (20)
I desire: -A romantic partner	Strongly disagree	3 (10)	0 (0)
	Disagree	2 (7)	1 (11)
	Neither agree nor disagree	3 (10)	0 (0)
	Agree	10 (33)	2 (22)
	Strongly agree	12 (40)	6 (67)
	<i>Missing</i>	15	6
-Emotional intimacy	Strongly disagree	2 (7)	0 (0)
	Disagree	3 (11)	1 (11)
	Neither agree nor disagree	2 (7)	0 (0)
	Agree	10 (37)	2 (22)
	Strongly agree	10 (37)	6 (67)
	<i>Missing</i>	18	6
-Romantic physical intimacy (e.g. hugging, touching, holding hands)	Strongly disagree	4 (14)	0 (0)
	Disagree	2 (7)	1 (11)
	Neither agree nor disagree	4 (14)	0 (0)
	Agree	6 (21)	2 (22)
	Strongly agree	13 (45)	6 (67)
	<i>Missing</i>	16	6
-Sexual intercourse	Strongly disagree	4 (15)	0 (0)
	Disagree	4 (15)	1 (11)
	Neither agree nor disagree	2 (7)	2 (22)
	Agree	7 (26)	2 (22)
	Strongly agree	10 (37)	4 (44)
	<i>Missing</i>	18	6
I have someone I can talk to about my romantic desires	Strongly disagree	2 (7)	1 (11)
	Disagree	7 (25)	1 (11)
	Neither agree nor disagree	3 (11)	1 (11)

Survey Questions	Responses	Duchenne MD (N=45)	Becker MD (N=15)
	Agree	10 (36)	2 (22)
	Strongly agree	6 (21)	4 (44)
	<i>Missing</i>	17	6
I have someone I can talk to about my sexual desires	Strongly disagree	2 (7)	2 (22)
	Disagree	8 (29)	1 (11)
	Neither agree nor disagree	2 (7)	2 (22)
	Agree	9 (32)	0 (0)
	Strongly agree	7 (25)	4 (44)
	<i>Missing</i>	17	6
I have experienced:			
-A romantic relationship	No	12 (60)	4 (50)
	Yes	8 (40)	4 (50)
	<i>Missing</i>	25	7
-Romantic physical intimacy	No	12 (60)	2 (25)
	Yes	8 (40)	6 (75)
	<i>Missing</i>	25	7
-Sexual intercourse	No	16 (80)	5 (62)
	Yes	4 (20)	3 (38)
	<i>Missing</i>	25	7
-Watched sexually explicit movies	No	2 (10)	5 (62)
	Yes	18 (90)	3 (38)
	<i>Missing</i>	25	7
-Looked at sexually explicit magazines or websites	No	2 (10)	2 (25)
	Yes	18 (90)	6 (75)
	<i>Missing</i>	25	7
Satisfied with:			
My experience with emotional intimacy	Very dissatisfied	1 (3)	0 (0)
	Dissatisfied	9 (30)	4 (31)
	Neutral	12 (40)	4 (31)
	Satisfied	8 (27)	2 (15)
	Very satisfied	0 (0)	3 (23)
	<i>Missing</i>	15	2
My experience with physical intimacy	Very dissatisfied	3 (10)	0 (0)
	Dissatisfied	11 (37)	5 (38)
	Neutral	12 (40)	4 (31)
	Satisfied	4 (13)	1 (8)
	Very satisfied	0 (0)	3 (23)
	<i>Missing</i>	15	2