Milestone achievement in emerging adulthood in spina bifida: a longitudinal investigation of parental expectations

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PUBLICATION DATA
Accepted for publication 12th August 2016.
Published online

ABBREVIATION
PPVT-R Peabody Picture Vocabulary Test – Revised Edition

AIM To assess changes over time in parents' expectations of adult milestone achievement (college attendance, full-time job attainment, independent living, marriage, parenthood) for young people with spina bifida, to examine how expectancies relate to actual milestone achievement, and to compare milestone achievement in emerging adults with spina bifida with that of peers with typical development.

METHOD Sixty-eight families of children with spina bifida (mean age 8y 4mo, 37 males, 31 females) and 68 families of children with typical development (mean age 8y 6mo, 37 males, 31 females) participated at Time 1. At all subsequent timepoints, parents of young people with spina bifida were asked to rate their expectations of emerging adulthood milestone achievement. At Time 7, when participants were 22 to 23 years old, milestone achievement was assessed.

RESULTS Parents of young people with spina bifida lowered their expectations over time for most milestones; parents of children with higher cognitive ability reported decreases of lower magnitude. Parent expectancies were optimistic and unrelated to actual milestone achievement. Emerging adults with spina bifida were less likely than individuals with typical development to achieve all milestones.

INTERPRETATION Optimistic parental expectations may be adaptive for children with spina bifida and their families, although it is important for families to set realistic goals. Healthcare providers serve a key role in helping families of young people with spina bifida prepare for emerging adulthood.

Spina bifida is a relatively common congenital birth defect that affects approximately three out of every 10 000 live births.[1] Individuals with spina bifida experience impaired mobility, hydrocephalus, and bowel and bladder dysfunction, as well as cognitive and social challenges that affect their day-to-day lives.[2]

Although parental expectations for child functioning likely affect children at all ages, parental expectations during childhood and adolescence may be particularly relevant for the attainment of developmental milestones in emerging adulthood (i.e. 18–25y). Life goals and expectations for chronically ill children previously centered on medical management, life expectancy, and health-related quality of life. With medical advances increasing the lifespan,[3] expectations have shifted towards the developmental milestones expected of young people with typical development. Common milestones of early adulthood include transition from secondary education to higher education or employment, independent living, and the initiation and maintenance of romantic relationships.[4]

The National Longitudinal Transition Study-2[5] indicated that young people with disabilities and their parents have positive long-term goals for the future. Parents of young people with intellectual disabilities, however, tend to endorse lower expectations for their children compared with parents of young people with typical development.[6] Regardless of expectations, children with chronic health conditions struggle to reach emerging adulthood milestones compared with peers of typical development.[7,8] Zukerman et al.[9] found that individuals with spina bifida at 18 to 19 years of age were less likely than their peers with typical development to live independently, attend college, obtain employment, and have romantic relationship experiences. Other research had demonstrated lower likelihood of adulthood milestone achievement in this population.[10] Although research on individuals with intellectual disabilities suggests that parental expectations during adolescence are related to future milestone attainment (e.g. employment),[6,11] little is known about parental expectations for adult milestone attainment in young people with spina bifida.

Parental expectations tend to fluctuate during the child's development.[12] Parents may be more likely to have higher expectations for adulthood milestones when children are younger.[13] Furthermore, parents of children with developmental delays tend to adjust their expectations over time based on their child's current functional abilities.[12,13] Trajectories of parental expectations for young people with differing physical and cognitive disabilities, such as those that occur in spina bifida, however, are relatively unknown.

To date, scholars have suggested that optimistic expectations for future functioning are positively associated with later outcomes and act as a source of motivation.[14,15] Currently, no study has shown such a relationship in young people with chronic health conditions. The objectives of this study were to: (1) examine how parental expectations of adult milestone achievement for young people with spina bifida change over time, and whether these changes differ by cognitive ability or lesion level; (2) investigate how longer-term expectations change according to actual milestone achievement in emerging adulthood for individuals with spina bifida; and (3) extend findings from Zukerman et al.[9] by comparing milestone achievement between individuals with spina bifida and individuals with typical development during the emerging adulthood phase.

What this paper adds

- Parental expectations of adult milestones decline for young people with spina bifida.
- Decline in parental expectations is smaller for young people with higher cognitive ability.
- Parental expectations are unrelated to actual achievement of adulthood milestones.
- Young people with spina bifida are less likely to achieve milestones in early adulthood.

METHOD

Participants

Participants were part of a larger, longitudinal investigation examining family and psychosocial functioning among young people with spina bifida and a comparison group of young people with typical development.[16] Families of children with spina bifida were initially recruited from three hospitals and a statewide spina bifida association from 1993 to 1996. Study eligibility criteria included ability to speak English, residence within 120 miles of the research laboratory (to allow for home visit data collection), diagnosis of spina bifida, and age of 8 to 9 years. Out of 310 names received from the above sources, 72 families lived too far away to be contacted (more than 120 miles from the laboratory), 56 could not be contacted because of incorrect addresses and/or phone numbers, 64 declined to participate, 11 had children who did not have spina bifida, 14 had children who turned 10 years old before they could be scheduled for a family visit, 16 had parents and/or children who did not speak English, and seven were eliminated for miscellaneous reasons, giving a final total of 70 families. Families from the comparison group were recruited from schools at which participating children with spina bifida were enrolled. Seventy-two families with children with typical development agreed to participate.

Young people with spina bifida and young people with typical development were matched on 10 demographic variables (i.e. child age, maternal age, paternal age, child age, child ethnicity, child birth order, marital status, maternal income, paternal income, and Hollingshead socioeconomic status). A demographic comparison of the original samples (n=70 spina bifida, n=72 typical development) revealed sample differences on 3 of the 10 demographic matching variables (child age, socioeconomic status, and child ethnicity). Families who were most discrepant from the mean of their subsample were dropped until matching was achieved on all 10 variables. Thus, two families from the spina bifida sample and four families from the comparison sample were dropped from the analyses to facilitate group-level matching and to achieve equal sample sizes (n=68) in each group.[16] Obtaining a larger sample was not possible given spina bifida incidence, geographical, and data collection limitations. The final sample sizes allowed for detection of medium effects at α=0.05 and power of 0.80 for analyses of covariance (ANCOVA), regression, and χ^2 analyses.[17]

Data collection occurred every 2 years after the T1 data collection. The present study focused on data that were collected at Time 2 (T2; ages 10–11y), which is when assessment of parental expectations began, and Time 5 (T5; ages 16–17y), given higher likelihood of changes over a longer time period. Milestone achievement was assessed at Time 7 (T7; ages 22–23y). Table I includes descriptive information on all participants at T1.

Procedure

This study was approved by university and hospital institutional review boards. Trained research assistants collected data during a 3-hour home visit at each timepoint through T5. Parents and young people completed a series of counterbalanced questionnaires separately. At T1 only, medical chart data were collected and a brief test of verbal cognitive ability was administered. Families received monetary compensation on completion of each visit ($50 for T1; $75 at T2 and T5). At T7, data were collected from emerging adults via questionnaires sent and returned by mail. Emerging adults were then reimbursed $50 following the receipt of their completed questionnaires.

Measures

Demographic information

At T1, parents completed a demographic questionnaire to report on age, sex, and race/ethnicity of the young people. Parents also reported on their education and employment, which were used to compute the Hollingshead index of socioeconomic status, with higher scores indicating higher socioeconomic status.[18]

Illness information

At T1, for families of young people with spina bifida, information on health-related variables was collected via

Table I: Descriptive information at T1: comparisons across samples

Demographic characteristic	Spina bifida, *M* (SD) or *n* (%)	Typical development, *M* (SD) or *n* (%)	Statistical test
T1 *n*	68	68	
Mothers	68	68	
Fathers	55	52	
T1 child age	8y 4mo (6mo)	8y 6mo (6mo)	$t(134)=-1.8$
T2 *n*	67	66	χ^2 (1)=0.3
Mothers	66 (99%)	–	–
Fathers	49 (73%)	–	–
T2 child age	10y 5mo (7mo)	10y 7mo (7mo)	$t(130)=-1.6$
T5 *n*	52	61	χ^2 (1)=3.4
Mothers	51 (98%)	–	–
Fathers	33 (63%)	–	–
T5 child age	16y 7mo (7mo)	16y 8mo (8mo)	$t(107)=-1.3$
T7 *n*	56	61	χ^2 (1)=1.0
T7 child age	22y 8mo (1y)	22y 10mo (1y 2mo)	$t(109)=-0.4$
Child sex: male	37 (54%)	37 (54%)	χ^2 (1)=0.0
Child ethnicity			
Caucasian	56 (82%)	62 (91%)	χ^2 (1)=2.3
Other	12 (18%)	6 (9%)	
Family SES	43.1 (10.6)	46.5 (10.9)	$t(131)=-1.8$
PPVT-R	92.5 (18.5)	109 (15.1)	$t(133)=5.7$[a]
Spina bifida type		n/a	n/a
Myelomeningocele	56 (82%)		
Lipomeningocele	12 (18%)		
Lesion level		n/a	n/a
Thoracic	8 (12%)		
Lumbar	37 (54%)		
Sacral	20 (29%)		
Unknown/missing	3 (4%)		
Ambulation assistance		n/a	n/a
Wheelchair	12 (17%)		
Braces	27 (40%)		
No assistance	29 (43%)		
Shunt present	48 (71%)	n/a	n/a

[a]$p< 0.001$. Significance testing should be interpreted with caution because of limited power. SES, socioeconomic status measured by Hollingshead Four Factor Index (higher values indicate higher SES, range is 8–66); PPVT-R, Peabody Picture Vocabulary Test – Revised Edition.

mother (or father if mother was unavailable) report (i.e. method of ambulation, shunt status) or medical chart review (i.e. type of spina bifida, lesion level, number of shunt surgeries).

Cognitive ability

The Peabody Picture Vocabulary Test – Revised Edition (PPVT-R)[19] was used at T1 to assess receptive verbal cognitive ability.

Parental expectations

At T2 and T5, parents' expectations for their children's future functioning were assessed using a measure designed for this study. Parents rated the extent to which they believed their children would be capable of attaining a specific adulthood milestone using a 4-point Likert scale ranging from (1) very unlikely to (4) very likely. Specific milestones included college attendance, attainment of a full-time job, ability to live independently, marriage, and parenthood.

Emerging adult milestones

At T7, emerging adults answered questions about milestone attainment. The five items used for the present study correspond directly with those of the parental expectations questionnaire described previously. Individuals who reported current college attendance were not included in analyses of full-time job attainment.

Statistical analysis

Statistical analyses were conducted using SPSS Version 22 (IBM SPSS Statistics; IBM Corporation, Armonk, NY, USA). Participants with missing data (e.g. three with unknown lesion levels, one with missing PPVT-R score) were excluded listwise in multivariate analyses. For all analyses, statistical significance was determined by *p*-values below 0.05. Bivariate Pearson correlations were conducted between PPVT-R scores and indicators of changes in parent expectation over time. To examine changes in parental expectations for each emerging adulthood milestone over time, repeated measures ANCOVAs were run, with the two-level within-subjects variable of time (parent expectations at T2 and T5) and two continuous independent variables: cognitive ability and lesion level. The main effect of time indicated change in parental expectations from T2 to T5 while adjusting for cognitive ability and lesion level. Significant interactions between time and the continuous independent variables were probed post-hoc using linear regression analyses; examination of regression coefficients allowed for more information about the relationship between the covariates and the within-subjects effects. Specifically, difference scores were computed by subtracting parental expectations at T2 from those at T5 and then entered as the dependent variable in the regression model. Cognitive ability and lesion level were then entered using forward entry, a stepwise procedure where the variable with the highest R^2 is entered first followed by the next variable that has the highest change in R^2 after the first variable is entered.

Hierarchical logistic regression was used to examine both the relationship between parental expectations at T2 and milestone achievement at T7, as well as the change in parental expectations from T2 to T5 and milestone achievement at T7. Cognitive ability and lesion level were included as independent variables. Finally, χ^2 analyses were used to determine differences in milestone achievement at T7 between the spina bifida and typical development groups.

RESULTS

Participants

At T1, participants included 68 families with a child with spina bifida (mean age 8y 4mo) and 68 families with a child with typical development (mean age 8y 6mo). At T2, 67 spina bifida (99% of original sample) and 66 typical

development (97% of original sample) families participated; at T5, 52 spina bifida (76%) and 61 typical development (90%) families participated; at T7, 56 spina bifida (84%) and 61 typical development (90%) emerging adults participated. Families of young people with spina bifida had higher attrition rates from T1 to T5, χ^2 (1)=4.24, p=0.04, but this difference was no longer statistically significant at T7, χ^2 (1)=2.31, p=0.13. At T7, there were no significant differences in age, sex, socioeconomic status, lesion level, shunt status, or PPVT-R scores between individuals with spina bifida who participated and those who did not. Likewise, there were no significant differences on age, sex, socioeconomic status, and PPVT-R scores in the typical development sample for those who participated at T7 and those who did not.

Parental expectations for young people with spina bifida: descriptive data

Mother and father expectations for milestones that were correlated at or above 0.40 were averaged to form an overall parent report for the given variable; this occurred for all of the adulthood milestone outcomes. For families in which only one parent participated (n=17 at T2, n=20 at T5), the individual parent's report was used.

Overall, mean parent expectations at T2 were relatively high for each of the five milestones; four of the five milestones yielded mean parental expectations between 3.33 and 3.68 (i.e. likely) in the context of a 4-point Likert scale (i.e. very likely). The lowest expectations reported were for children's likelihood of becoming parents (mean 2.9, SD 0.8).

Changes in parental expectations for young people with spina bifida

Parental expectations significantly decreased from T2 to T5 for their child's likelihood of living independently, F(1, 45)=10.74, p=0.002; attending college, F(1, 45)=6.62, p=0.013; obtaining a full-time job, F(1, 45)=7.89, p=0.007; and getting married, F(1, 45)=6.32, p=0.016. Decreases in expectations for parenthood did not reach statistical significance. Table SI (online supplementary information) provides additional statistics.

Frequency analyses were conducted to quantify changes in parent expectations over time (Table SI). The greatest changes occurred for parental expectations of college attendance and parenthood; in other words, fewer parents reported no change in expectations over time for these variables. Although a large proportion of parents remained stable in their expectations of adult milestone achievement, a higher percentage of decreases in expectations was observed relative to increases in expectations for living independently (29% vs 8%), obtaining a full-time job (25% vs 19%), getting married (33% vs 23%), and having a child (35% vs 31%). To explore the potential association between cognitive ability and parental expectancies over time, post-hoc bivariate Pearson correlations were conducted with PPVT-R scores and variables indicating change in expectancies from T2 to T5. For all five milestones, significant positive correlations indicated that higher baseline PPVT-R scores were associated with smaller decreases in expectations.

The interaction between time and cognitive ability was significant for each of the five adulthood milestones (Table SI), suggesting that parental expectations differed as a function of the child's cognitive ability. For each milestone, positive beta values indicated that parents of children with higher cognitive abilities reported decreases of lower magnitude in expectations over time. Changes in parental expectations did not differ as a function of lesion level for any of the five adulthood milestones. Significant main effects of lesion level, however, were present for parents' expectations for independent living, F(1, 45)=6.94, p=0.012, and marriage, F(1, 45)=5.82, p=0.02. Parents of young people with lower lesions had higher expectations for milestone achievement.

Parental expectations predicting milestone achievement for young people with spina bifida

Hierarchical logistic regressions for each milestone were conducted with lesion level and cognitive ability entered in the first block and parent expectations entered in the second block.[20,21] In terms of classification accuracy, C-statistics indicated adequate predictive accuracy for living independently (C=0.76), college attendance (C=0.88), marriage (C=0.74), and having a full-time job (C=0.81). Regression analyses were not possible for predicting the likelihood of parenthood, because none of the emerging adults reported having children at T7. When controlling for cognitive ability and lesion level, parental expectations at T2 (when children were 10–11y) for adulthood milestones did not significantly predict their children's actual achievement of the respective milestones at T7 (at 22–23y). Cognitive ability was significantly associated with the increased likelihood that emerging adults with spina bifida would live independently and attend college (Table SII, online supplementary information).

Similarly, the change in parent expectations from T2 to T5 did not significantly predict the likelihood of adult milestone achievement for any of the four milestones (excluding parenthood) when controlling for cognitive ability and lesion level.

Adulthood milestone outcomes

For each of the five adulthood milestones (i.e. independent living, college attendance, full-time job, marriage, and parenthood) assessed at T7, emerging adults in the spina bifida group were significantly less likely to have achieved the milestone compared with the emerging adults with typical development (Table SIII, online supporting information).

DISCUSSION

The purpose of this investigation was to examine changes over time in parental expectations of emerging adulthood milestones in a sample of young people with spina bifida and their families, as well as associations between parental

expectations and actual milestone achievement. Further, the present study compared emerging adults with and without spina bifida on achievement of independent living, college attendance, full-time job attainment, marriage, and parenthood.

Parents of young people with spina bifida tended to reduce their expectations for milestone achievement of their children over time from pre-adolescence (i.e. 10–11y) to late adolescence (i.e. 16–17y). Parents lowered their expectations that their child would live independently, attend college, obtain a full-time job, and get married, complementing previous studies suggesting that parental expectations decrease as children mature.[13] Given evidence that general health tends to decline during adolescence and emerging adulthood in this population,[10] parents may adjust their expectations as their child experiences increasing health difficulties, including shunt infections, pressure ulcers, and orthopedic complications. Further, adolescents with spina bifida tend to struggle with tasks such as decision-making, independence skills, and social adjustment,[22,23] which may negatively affect their parents' expectations for achievement of later developmental milestones.

Similar to previous research,[6] changes in parental expectations were significantly influenced by the child's cognitive ability. Across all emerging adulthood milestones, parents of children with higher cognitive ability tended to report decreases of lower magnitude in their expectations over time. Regarding young people with greater cognitive deficits, expectations may decrease as parents observed their child to encounter greater social and academic struggles and require significant supports, which has also been observed in previous work.[13]

Contrary to expected associations, neither parental expectations assessed at baseline (i.e. T2) nor changes in expectations assessed over time were related to actual milestone achievement in emerging adulthood. These findings contradict previous research that supported the longitudinal association between parental expectations of skill development and academic achievement in samples of young people with developmental disabilities.[6,11] Further, in the current study, parental expectations were relatively high across time; in line with previous research,[5] many parents indicated that their child would 'likely' achieve emerging adulthood milestones. Thus, there appears to be a disconnect between what parents in the current study expected for their children and what their children actually achieved.

At the emerging adulthood stage, individuals with spina bifida were less likely to achieve all five milestones compared with their peers with typical development. When considered with results from Zukerman et al.,[9] differences in milestone achievement persist into emerging adulthood (when individuals are approximately 22 or 23y old). It is plausible that parental expectations may have contributed to these disparities,[6] although there are likely other contributing variables (differences in cognitive ability, social skills, etc.) that influence milestone achievement differences. Additional research is needed to determine whether emerging adults with spina bifida eventually 'catch up' to individuals with typical development in achieving milestones of adulthood.

Our results suggest that parents of young people with spina bifida may be somewhat optimistic in their expectations for their children's development as emerging adults. Indeed, it may be quite adaptive when parents generally expect positive outcomes for their children.[24] Optimistic expectations may cultivate resilience and prompt parents and their children to make continued efforts to achieve their goals.[12,14] Parents serve as models of optimistic thinking for their children, increasing the likelihood that their children will be optimistic about their own futures.[14] In turn, optimistic young people are more likely to experience greater psychological health and better adjustment to various life events (e.g. college, pregnancy, and surgery).[14,24]

While it may be natural and adaptive for parents to maintain high expectations for their children's adult milestone achievements, it is likely important for parents of young people with chronic health conditions to be realistic about developmental outcomes. Young people with spina bifida and their families must set a number of goals requiring significant time, effort, and skill development (e.g. self-management, social skills, self-advocacy) to support eventual milestone achievement. Healthcare providers are encouraged to assess parental expectations for their children's milestone achievements.[25] Along with parents and educators, providers can help young people with spina bifida to develop skills and plans for support and services (e.g. vocational rehabilitation, home health care) that may be needed to meet as many adult milestones as are possible.

The present study was not without limitations. First, our sample was limited to English-speaking individuals. Inclusion of more Latino families would be important in future research, given higher rates of spina bifida among Latino young people.[26] Second, missing data across time may have resulted in biased findings as well as a loss in precision and power.[27] Third, comparisons in parental expectations between the spina bifida and typical development samples could not be accomplished because parents of young people with typical development were not asked about their expectations for milestone achievement. Fourth, although the PPVT-R is an effective proxy for cognitive ability, a more comprehensive measure of intellectual ability, such as a Full-scale IQ from an intelligence test, would have been preferred. Fifth, variability across participants on items assessing parent expectations was somewhat low, with a greater number of responses at the high end of the scale. The ability to detect changes over time may have been reduced because of ceiling effects on the expectation items. Sixth, milestones were dichotomized (i.e. individuals either met or did not achieve the milestone). It is likely that there may be a continuum for meeting milestones (e.g. a young adult with a part-time job or volunteer position).

CONCLUSION

Parents of young people with spina bifida tended to have optimistic expectations for their child's achievement of emerging adulthood milestones, although expectations generally decreased over time. The decline in expectations was particularly significant for parents of young people with lower cognitive ability. Neither parental expectations assessed during childhood nor the change in expectations through adolescence predicted actual milestone achievement for emerging adults with spina bifida. Further, emerging adults with spina bifida were less likely than their peers with typical development to achieve all five milestones. Healthcare providers serve an important role in helping families of young people with spina bifida, particularly those with cognitive deficits, to set goals for the future, increase their social and independent living skills, and to make connections with community resources and programs.

ACKNOWLEDGMENTS

Completion of this manuscript was supported in part by research grants from The National Institute of Child Health and Human Development (RO1 HD048629) and the March of Dimes Birth Defects Foundation (12-FY04–0047). Funding was utilized to support study design, data collection, data analysis, and manuscript preparation. The authors thank the undergraduate and graduate research assistants for collecting, coding, and entering data related to this project. We are also very appreciative of the parents, children, and teachers who have consented to participate in this research. The authors have stated that they had no interests which might be perceived as posing a conflict or bias.

SUPPORTING INFORMATION

The following additional material may be found online:

Table SI: Repeated measures ANCOVA and frequencies: Changes in parental expectations of adulthood milestones from Time 2 to Time 5.

Table SII: Peabody Picture Vocabulary Test – Revised Edition (PPVT-R) predicting adult milestone achievement as analyzed by logistic regression.

Table SIII: Achievement of emerging adulthood milestones at T7.

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