Predictors of Independence, Functional and Adaptive Skills in Adolescents and Adults with Fragile X Syndrome

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Adaptive Behavior

- * An individual's ability to demonstrate effective and appropriate interactions with his or her environment
- * Trajectory in FXS
 - * Reports of plateau or decline with increasing age
 - Unable to keep pace with typically developing peers (as opposed to actually losing skill)
 - * Childhood is critical

Aberrant Behavior

- Individuals with FXS may display problem behavior similar to individuals with autism, and often are diagnosed as such.
- * Social withdrawal is one of the most prominent aberrant behaviors associated with FXS.
 - * Seeking isolation or solitary activities, resistance or negative reaction to physical contact, and averted eye gaze

Aberrant Behavior

- * Promising new research:
 - Seemingly inevitable syndrome-specific behavior (like social withdrawal) might be amenable to intervention
 - * Example: Hall, Maynes, & Reiss, 2009
 - Shaped increased durations of eye contact in 5 out of 6 individuals with FXS using a reinforcement procedure
 - * Emphasis on early detection and intervention

Adult Life in FXS

- * Bailey et al., 2009
 - * Characteristics associated with functional skills:
 - * Overall thinking, reasoning, and learning ability
 - Adaptability
 - Ability to pay attention
 - * Total number of co-occurring conditions
- * Hartley et al., 2011
 - * Strongest correlates of independence:
 - * Level of functional skills (adaptive behavior)
 - ★ Ability to interact appropriately
 - * Autistic symptoms

Current Study

- * 59 individuals with fragile X syndrome
 - * 36 males, 23 females
- * Participants seen at two points in time:
 - * Time one: childhood/early adolescence
 - * Time two: late adolescence/young adulthood

Current Study

- * Time 1 (T1):
 - * Participants aged 6 to 15 years (mean = 11.7 for males, 11.9 for females)
 - * Adaptive skills and aberrant behavior assessed
- * Time 2 (T2):
 - * Participants aged 16 to 26 years (mean = 20.4 for males, 20.5 females)
 - Independent, adaptive, and functional academic skills assessed

Measures

- * Vineland Adaptive Behavior Scales (VABS) First and Second Editions
- * Aberrant Behavior Checklist-Community (ABC-C)
- * Independent Living Scales (ILS)
- * Kaufman Functional Academics Skills Test (KFAST)

Vineland Adaptive Behavior Scales (VABS)

- * Widely used caregiver interview
- * Measures social and personal sufficiency
- * Comprised of questions relating to competency in:
 - Communication
 - * Receptive, expressive, and written
 - ★ Daily Living Skills
 - * Personal, domestic, and community
 - * Socialization
 - Interpersonal relationships, play and leisure time, and coping skills

Aberrant Behavior Checklist-Community (ABC-C)

- * 58-item questionnaire
- * Five problem behavior factors:
 - * Irritability/Agitation/Crying
 - * Lethargy/Social Withdrawal
 - * Stereotypic Behavior
 - * Hyperactivity/Noncompliance
 - * Inappropriate Speech

Independent Living Scales (ILS)

- * 70 items across five subscales:
 - ★ memory/orientation
 - * money management
 - * managing a home and transportation
 - health and safety
 - * social adjustment
- * "What is your address?" "Why is it important to pay your bills?" "What information can you get from a bus schedule" etc.
- * Demonstrate the use of a telephone, count change, address an envelope, write out checks, etc.

Kaufman Functional Academics Skills Test (KFAST)

- * Two domains:
 - * Functional Reading
 - Interpreting rebuses, abbreviations, or words, phrases, sentences, and paragraphs that are seen frequently in commonplace situations
 - * Functional Mathematics
 - * Counting coins, using maps, telling time, etc.

Procedure

- * Statistical Analysis
 - * Raw scores used to circumvent floor effects
 - * Age did not account for a significant amount of the variance in scores on the ILS and KFAST (R²<.2)
 - * Simple regression (correlation) analyses conducted
 - * Examined the relationship between T1 variables and T2 variables

Results

- * Females obtained significantly higher scores than males on all outcomes across all domains
- * Higher levels of adaptive skills in childhood predicted of higher levels of independent living skills and functional academic skills in late adolescence/adulthood
- * Higher levels of social withdrawal in childhood predicted lower levels of adaptive skills in late adolescence/adulthood

Raw scores on the Independent Living Scales Assessment (ILS)

	Sex					
Subscale (*max)	Male N=36		Female N=23		•	
	Mean	SD	Mean	SD	t	р
Memory and Orientation (16)	8.75	4.345	14	1.689	5.523	<.001
Managing Money (34)	5.94	4.763	19.04	10.052	6.745	<.001
Managing a Home and Transportation (30)	11.06	4.951	22.52	6.875	7.445	<.001
Health and Safety (40)	14.44	6.975	28.74	7.3	7.54	<.001
Social Adjustment (20)	13.42	3.138	16.39	3.34	3.463	0.001
Factor						
Problem Solving (66)	22.39	10.808	46.13	14.121	7.294	<.001
Performance/Information (42)	11.33	6.306	28.13	9.042	8.411	<.001
Raw Total Score (140)	53.61	20.19	100.7	26.102	7.786	<.001

^{*}maximum points possible per subtest

Raw scores on the Kaufman Functional Academic Skills Test (KFAST)

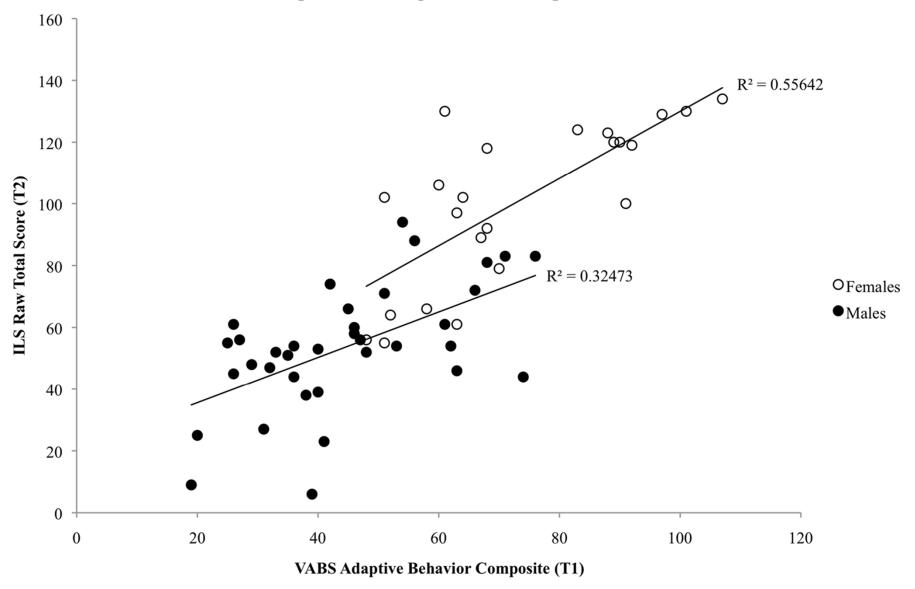
Subscale (*max)		S	•			
	Male	Male N=36		Female N=23		
	Mean	SD	Mean	SD	t	p
Reading (29)	5.83	4.954	15.39	6.148	6.575	<.001
Arithmetic (25)	1.91	1.687	8.83	6.8	5.893	<.001
Raw Total Score (54)	7.69	6.224	24.22	12.548	6.731	<.001

^{*}maximum points possible per subtest

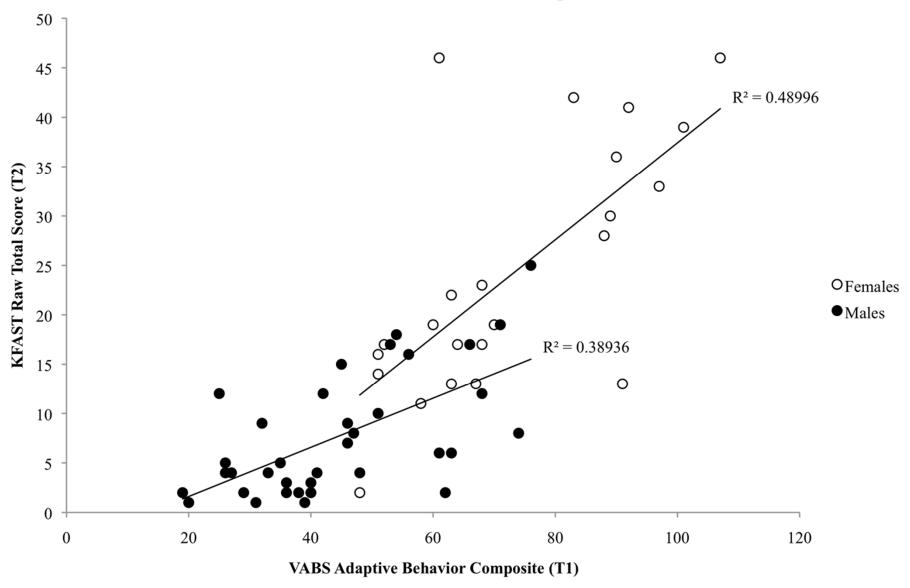
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Independent Living Skills and Adaptive Skills



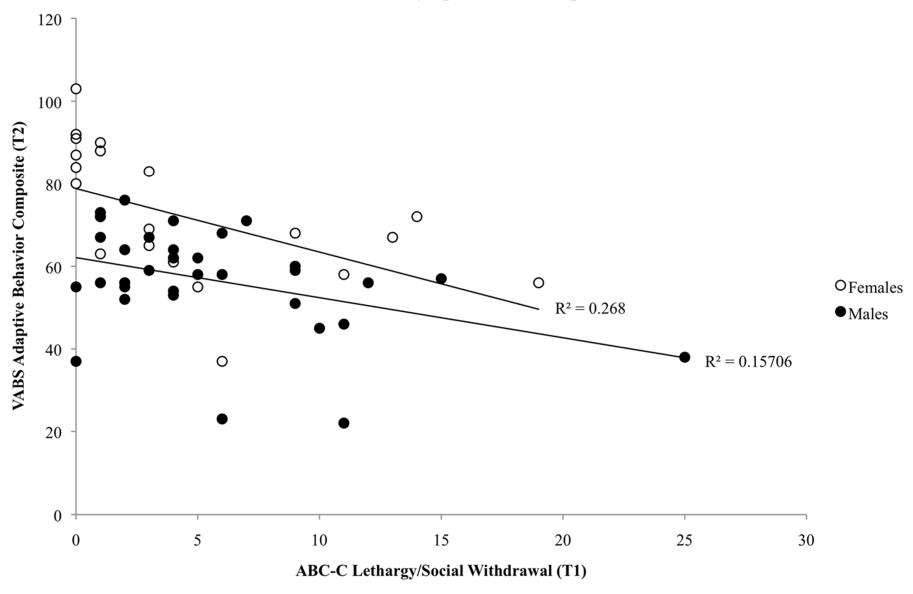
Functional Academic Skills and Adaptive Skills



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Social Withdrawal Symptoms and Adaptive Skills



Discussion

- * First direct assessment of independence in FXS
- * Suggest that relatively strong adaptive skills and little social withdrawal behavior during childhood and early adolescence have better outcomes in adult life
- * Limitations & future research:
 - * Employ more direct measures
 - * More directly assess relationship via treatment evaluations

Thank you!

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