

# Psychological Well-Being, Persistence, and Cognitive Function in Middle-Aged and Older Adults with Neurofibromatosis Type 1

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## BACKGROUND

- Neurofibromatosis type 1 (NF1) is a genetic disorder affecting approximately 1 in 3,000 individuals globally...
- NF1 associated with increased risk for cognitive impairments (Gutmann et al., 2017)
  - Middle-aged and older adults (MOA) identified with NF1 are found at increased risk for dementia (de Souza Costa et al., 2014)
  - Prior research in the general population suggests psychological factors (e.g., purpose in life) are protective against cognitive decline (Sutin et al., 2018)
    - However, limited research has investigated MOA with NF1
    - Thus, the influence of these factors in the NF1 population remains undetermined

∴ We examined whether psychological factors (psychological well-being and persistence) are related to cognitive function in MOA with NF1, hypothesizing that higher well-being and persistence would relate to more favorable cognition.

## MEASURES

### Objective cognitive:

- Measured using the modified Telephone Interview for Cognitive Status (TICSm)
  - Subtests include:**
    - Working memory [0-1] (backwards word count)
    - Episodic memory [0-20] (immediate-delayed recall)
    - Processing speed [0-5] (serial 7 subtraction)

### Subjective cognitive (SC):

(1 =poor, 5=excellent)

- Memory Rating: self-rated “memory”
- Processing Speed: self-rated “ability to think quickly”

### Psychological Well-being (42-item Ryff Scale; Ryff, 1989):

(1 = Strongly disagree, 5 = strongly agree)

#### 6 subscales:

- Autonomy** (e.g., I have confidence in my own opinions, even if they are different from the way most other people think)
- Environmental Mastery** (e.g., In general, I feel I am in charge of the situation in which I live)
- Personal Growth** (e.g., For me, life has been a continuous process of learning, changing, and growth)
- Positive Relations With Others** (e.g., People would describe me as a giving person, willing to share my time with others)
- Purpose In Life** (e.g., I have a sense of direction and purpose in my life)
- Self-Acceptance** (e.g., I like most parts of my personality)

### Persistence (8-item GRIT-S; Duckworth & Quinn, 2009):

(1 = Not like me at all, 5 = Very much like me)

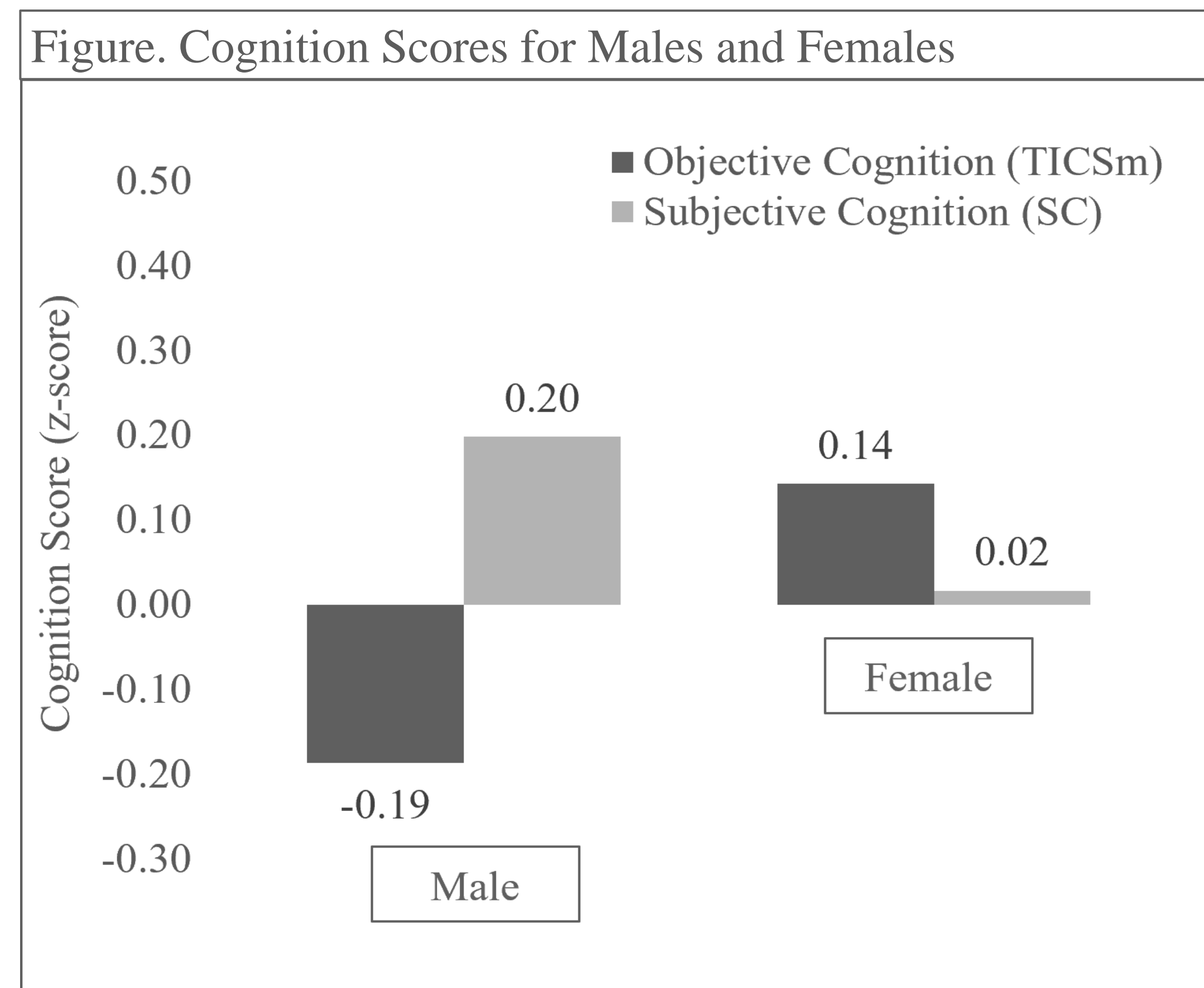
- Measures perseverance and passion for long-term goals (e.g., I finish whatever I begin)

## PARTICIPANTS

### Current Sample Size:

- 165 individuals (27.6% Males; 72.4% Females)
- Aged 40-81 years (M=53.89;  $\sigma$  = 10.55)
- Standard Cut-offs for Objective Cognition:**
  - 0% dementia (TICSm < 7)
  - 9.8% cognitive impairment without dementia (TICSm = 7-11)
  - 89.2% within a normal cognitive function range (TICSm >11)

## RESULTS



- Objective cognition (TICSm): M=15.58,  $\sigma$ =3.18, Min=8, Max=25
- Subjective cognition: M=3.46,  $\sigma$ =0.9, Min=1, Max=5
- Cognition scores (z-scores) for males and females are shown above (see Figure)
  - Males scored below average for objective cognition but above average for subjective, whereas females were at/above average for both measures of cognition

Table. Descriptives and Bivariate Correlations: Psychological Factors							
		Objective Cognition (TICSm)	Subjective Cognition	Mean	SD	Min	Max
Psychological Well-being	Autonomy	0.15	0.35**	3.49	0.73	1.57	5.00
	Environmental Mastery	0.11	0.46**	3.56	0.87	1.14	5.00
	Personal Growth	0.19*	0.49**	3.88	0.71	1.71	5.00
	Positive Relations with Others	0.21**	0.39**	3.90	0.82	2.00	5.00
	Purpose in Life	0.21**	0.51**	3.77	0.78	1.71	5.00
	Self-Acceptance	0.19*	0.45**	3.26	0.94	1.00	5.00
Persistence		0.05	0.45**	3.46	0.64	1.43	5.00

\*p < 0.05, \*\* p<0.01

## RESULTS CONTINUED

- Higher psychological well-being is related to better subjective cognition (see Table)
  - However, only personal growth, positive relations with others, purpose in life, and self-acceptance are associated with greater objective cognition
- Similarly, higher persistence was only significantly associated with subjective cognition and not objective cognition

## DISCUSSION

- Different patterns across subjective and objective cognition scores indicate divergence between self-reported perceptions of cognitive abilities and actual performance measured through testing
- Purpose in life most strongly correlated with subjective cognition, as well as objective cognition
  - Individuals that have a greater ‘purpose’ may feel more cognitively stable, regardless if their test scores do not support the same statement
- Self-acceptance was significantly related to both objective and, especially, subjective cognition
  - Individuals who accept themselves more may have higher cognitive confidence even if their scores do not reflect the same results
- Persistence was not related to objective cognition but was associated with subjective cognition
  - Those who are persistent may subjectively believe they are cognitively capable due to their determination, but have no correlation to their objective cognition testing
- Interestingly, correlations for subjective cognition were stronger than for objective cognition
  - All psychological factors are self-reported, and subjective cognition is self-reported; reporter bias may account for some of these associations
- Our findings are supportive of past research in the general population that shows purpose in life is important for later cognition (Sutin et al., 2018)
  - Interventions might focus on cultivating purpose in life in adults with NF1

### Strengths & Limitations:

- Strength: Examination of cognition. both objectively and subjectively
- Limitations:
  - Reliance on self-report measures, as they may be inaccurate
    - Subjective cognition is essential, but self-reported bias may impact interpretation and may not be completely internally valid (reliable)
  - Objective cognitive ability may not be completely externally valid (generalizable) due to its inability to capture real-world functionality

### Future Research:

- Future studies could examine change in psychological well-being and cognitive function over time to understand long-term effects
  - It is important to assess both subjective and objective cognition to better understand their impact on real-world functioning
  - Standardized cognitive tests might not fully reflect real-world cognitive ability, thus future studies should explore other valid measures to improve reliability

## REFERENCES



## DEVELOPMENT, ENVIRONMENT, AND RESILIENCE (DEaR) Lab

The DEaR lab investigates how biological and environmental factors influence individual health and development in underrepresented groups, such as families with genetic disorders. We hope to identify mechanisms that can promote resilience in these underrepresented groups. Our ultimate goal is to inform the development of evidence-based intervention programs personalized to these groups to promote their mental health and to advocate patient-centered care.