

Jennifer Steinberg, PhD, RN
Gayle M. Roux, PhD, NP-C, FAAN
Department of Nursing
University of North Dakota
Grand Forks, ND

Background

Mothers of children with ASD are vital members of the care team for their children and families overall¹. Mother's experiences include:

- Diagnosed child's challenging behaviors^{2, 3}
- Mother's psychological distress^{4, 5, 6}
- Caregiver burden⁷
- Difficulty obtaining correct diagnosis⁸
- Coping and adaptation^{9, 10}

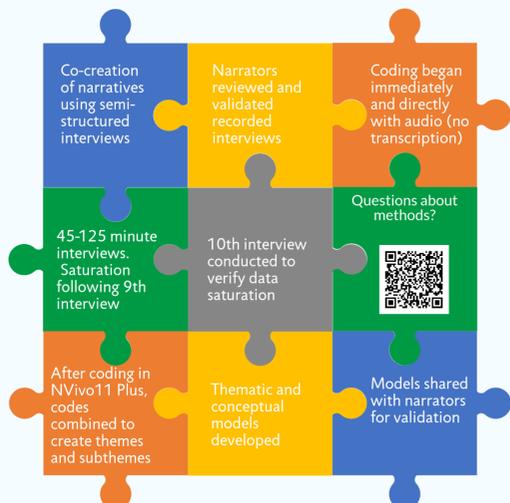
The Theory of Inner Strength¹¹ moves beyond resilience to describe the processes which occur as women move through challenging life events.

- Dimensions:
 - Engagement
 - Connectedness
 - Anguish and searching
 - Movement
- Outcome: living a new normal.



Oral History Research Methods

Oral history using a postmodern feminist philosophical framework was selected for this study. Theoretical frameworks included oral history theory and feminist standpoint theory. Narrators were recruited in Olmsted County, MN using purposive and snowball sampling.



Research Questions

What are the experiences of mothers of children with autism spectrum disorders?

How do the experiences of mothers of children with autism spectrum disorders inform the Theory of Inner Strength in Women?

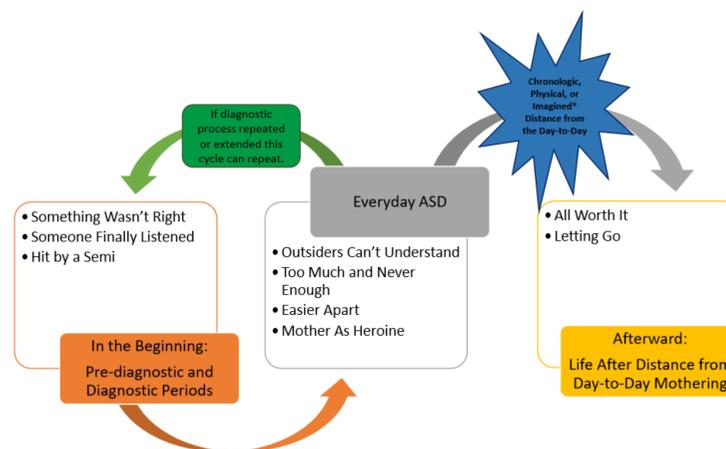


Demographics

Mother's Information					Affected Child's Information			
Mother	Age	Children	Profession	Ethnicity	Household income range	Age(s)	Diagnosis	Age at Diagnosis
M.D.	32	1	RN	Caucasian	\$100 - 150K	10	Autism	4
M.H.	38	4	nurse practitioner	Caucasian	>\$150K	16	Autism	12
M.F.	41	2	paraprofessional	Caucasian	\$60K-80K	14	PDD-NOS	3
M.W.	42	4	temporary worker	Native American	<\$40K	17	Asperger's Syndrome	6
S.N.	43	2	RN	Caucasian	\$40K - 60K	10	Autism, Down's Syndrome	6
M.B.	43	2	nurse practitioner	Caucasian	\$100K - 150K	17	Asperger's with low IQ	5
J.H.	50	5	mother	Caucasian	>\$150K	24 & 17	Autism, Autism	1.5
K.L.	59	4	librarian	Caucasian	\$100K - 150K	29	Atypical PDD	3.5
M.M.	61	3	bookkeeper	Caucasian	\$100K - 150K	15	Autism	3
N.B.	63	3	dietician	Caucasian	\$100K - 150K	36	PDD-NOS	13

Findings

Thematic Model: Experiences of Olmsted County, MN Mothers of Children with ASD



*Imagining a life without a child due to death or due to incarceration created enough distance for the women in this study to engage in activities which grow inner strength.

The pattern which emerged through analysis of the interviews collected included three distinct phases:

- *In the Beginning* (pre-diagnostic and diagnostic periods)
- *Everyday ASD* (phase during which the mother lives with her child or provides for her child's day-to-day needs)
- *Afterward* (period after some distance from the day-to-day)
 - This distance contributes to the mother's ability to generate inner strength in a way allows her to look at the phase of *Everyday ASD* in a retrospective manner.

Implications for Nursing Practice and Suggestions for Research

The findings of this study can be used to further inform practice in a variety of practice settings including:

- Psychiatric mental health clinics
- Schools and public health nursing
- Pediatrics

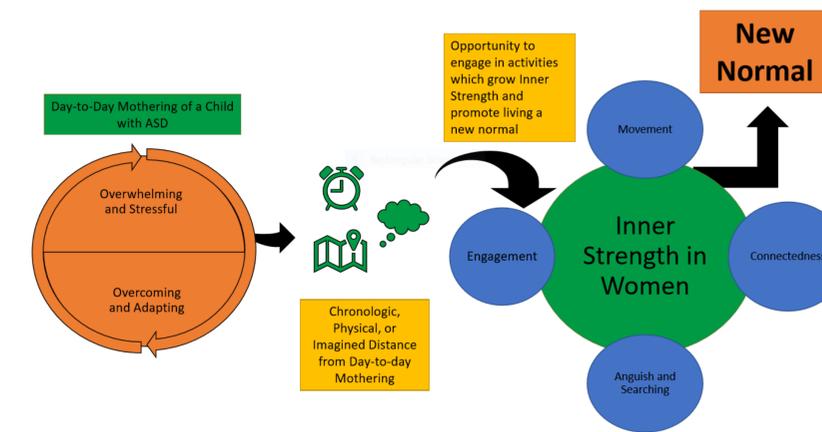
Recommendations for further research include further testing for adaptation of the Inner Strength Questionnaire¹².

Mothers of Children with Autism Spectrum Disorders: Oral Histories of Inner Strength

Discussion

Mothers of children with ASD live challenging lives as they engage in the day-to-day activities of parenting. Tailoring nursing interventions for these mothers has potential to improve psychological well-being of mothers and to improve ability to care for the family. Distance from the day-to-day activities of parenting, based on the findings of this study, is necessary for mothers to grow in their inner strength and achieve a healthy new normal.

Conceptual Model: Genesis of Inner Strength in Olmsted County, MN Mothers of Children with ASD



Scan to contact