Psychosocial burden in parents of individuals with Sanfilippo syndromes enrolled in a parent support program: preliminary findings

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BACKGROUND

- Parents of individuals with Sanfilippo syndromes and other progressive neurological rare diseases experience significant psychosocial burdens throughout their children's lifetime and beyond.
- Aiming to meet community support needs, Cure Sanfilippo Foundation launched the Aurora Program, a structured parent support program facilitated by a licensed mental health counselor, in October 2025.
- Each parent cohort meets biweekly for 6 months, with separate cohorts for parents of living or deceased children.
- This study aims to assess factors impacting access to mental health support, prevalence of symptoms of depression (PHQ-9), anxiety (GAD-7), loneliness (3-Item Loneliness Scale) as well as parental stress in the context of the child's disease symptoms (APSI). We will also assess the parent perceptions of the support group experience through the Therapeutic Factors 23-Item instrument.

METHODS

- Aurora Program participants were invited to take part in IRB-approved research via a REDCap survey link. Interested parents were presented with Informed consent materials online and consent was obtained electronically. Immediately following consent, the following data was collected before starting the group support program.
    - Demographic data;
    - Autism Parenting Stress Index (APSI)- (only presented to parents of living children);
    - Patient Health Questionnaire (PHQ-9);
    - Generalized Anxiety Disorder 7-Item (GAD-7);
    - 3-Item Loneliness Scale.
- Upon completion of the 6-month intervention program the following data will be collected.
    - Baseline measures as above
    - Therapeutic Factors 23-Item instrument

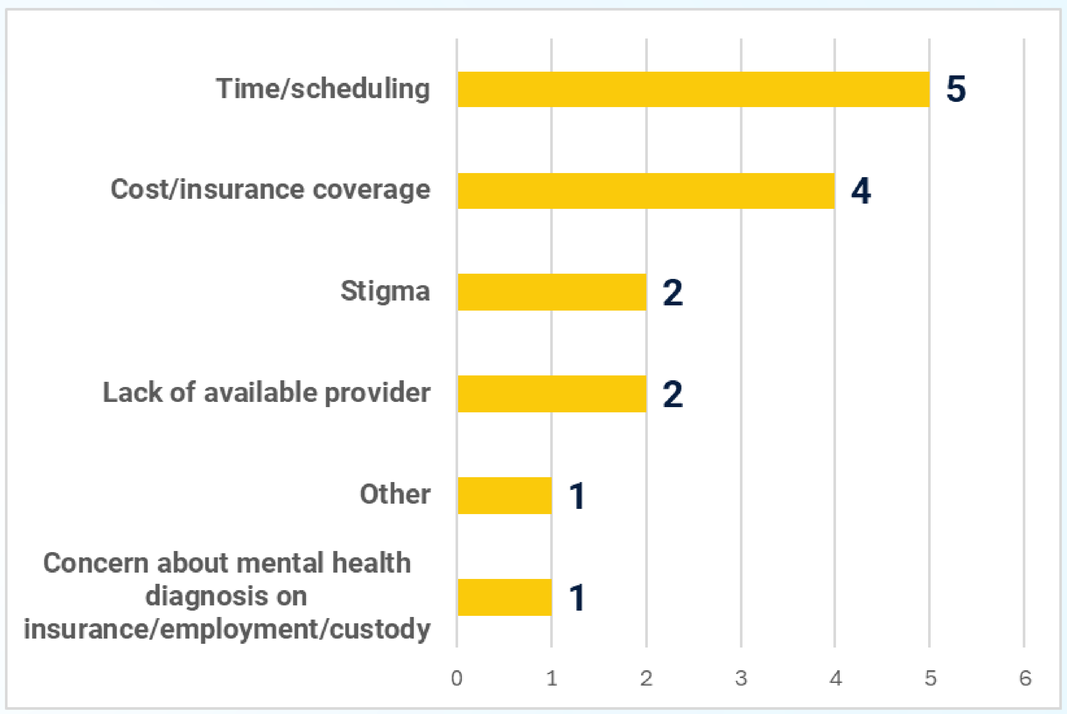
RESULTS

- Eight parents enrolled in the Aurora Program completed pre-intervention questionnaires.
    - All female, mean age 45.1.
    - One participant had multiple affected children.
    - Two participants had a child(ren) in a clinical trial.
    - Seven participants had children presently living.
- Top barriers to accessing mental health counseling or psychiatric services were 'time/scheduling' and 'cost/insurance'. (Fig 2.)
- Mean baseline assessment scores are shown in Fig 1.

Figure 1: Mean assessment scores at baseline

PHQ-9	GAD-7	LONELINESS SCALE	APSI
8.63	9.13	4.44	17.86
Mild Depression	Mild Anxiety	Not Lonely	

Figure 2: Reported barriers to mental health access



DISCUSSION

Preliminary findings indicate the presence of clinically relevant symptoms of mild depression and anxiety, as well as parental stress related to children's social, behavioral and physical symptoms of Sanfilippo syndrome.

These early findings may be subject to selection bias, as opting in to the research component may have favored parents with lower mental health burden. Thus, results may underestimate parental mental health burden across the broader Sanfilippo parent community.

Future pre and post intervention data analyses will further inform regarding parental mental health burden of Sanfilippo syndromes and potential benefit of a mental health counselor-led parent support program in this rare disease population.

Enrollment remains open for new cohorts of Aurora Program participants and this research study.

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