

Navigating the Ship: Goal Setting and Well-Being for Caregivers of Children with Autism



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Introduction

Caregivers of children with autism experience greater stress and poorer well-being than other parents with special needs children (Gupta, 2007; Khanna et al., 2011). They face unique caregiving burdens such as managing rigid and disruptive behaviors, constant vigilance, and extensive time demands (Larson, 2010; Sawyer et al., 2010). In this national public health crisis in which more than 1.5 million individuals are diagnosed with autism spectrum disorders, more families than ever are grappling with these challenges (Centers for Disease Control and Prevention, 2011). Traditional caregiver supports, such as support groups & respite care, have been of limited usefulness (Hare, Pratt, Burton, Bromley, & Emerson, 2004). A strengths-based program may be useful to increase caregiver well-being. In the context of a broader lifestyle wellness intervention program, this study focused on how setting and pursuing personal goals influenced caregiver well-being.

Design & Methods

Participants: Five mothers 45-61 years of age of sons with autism spectrum disorders ranging from 12-18 years of age participated. These mothers were recruited from previous studies and outreach through autism networks.

Design & Procedures: In this participatory action research project, researchers & caregivers developed key elements for a lifestyle wellness intervention program during 2 focus groups. Next, participants were interviewed using motivational interviewing & an activity card sort to facilitate goal selection for their personalized program. Each participant selected 5-8 goals, identified likely barriers & facilitators for goal achievement, rated their initial goal achievement confidence, & identified next steps. These personalized programs encouraged use of “micro-interventions” (10-minutes or less), an iPad with a customized app, & personal coaching over a 6-month period. Caregivers rated their goal attainment near the conclusion of the project.

Analysis: Focus groups, personal coaching, email exchanges, and other field data were generated, transcribed, and coded using an iterative approach based on grounded theory.

Results

Goals set by caregivers reflected a desire to balance their physical health, personal interests, and family well-being outcomes. All five participants set goals related to exercise and hobbies. Four set goals related to enhanced management of basic self/family care, such as healthy eating, as well as fostering family connections through outings and play. Only two participants set goals situated outside the family arena, such as volunteering. The qualitative analysis yielded overarching themes described below.

Calm or Stormy Seas

Setting and pursuing goals was influenced by factors beyond the caregiver’s control. These factors created a context where life was relatively calm or extremely stormy. They included the caregiving demands, ease or difficulty in school for the child with autism, the presence or lack of autism support services, or financial and/or other resource constraints.



The Family Vessel

Mothers, similar to ship captains, tended to the well-being of the entire family often balancing competing needs. Family vessel and crew condition reflected both past trauma, and spousal and other family support. If seas were stormy caregiver’s goals addressed basic occupations such as sleep, healthy eating, exercise, and home management to achieve family or individual health, household order, and stress relief for the caregiver. Participating in activities to improve health were priorities for both the caregiver and the child with autism, but the child’s rigid behaviors often made introducing new routines challenging.

Desired Destinations

In calmer seas, caregiver goals focused on occupations beyond “basic needs” such as volunteering, work, hobbies, outings with friends or family, and travel. Desired “destinations” emphasized connection with family or friends, ability to focus on activities of interest to the caregiver, and doing fun new things that brought joy. Support from family or friends, and planning & tracking aids were useful in establishing new routines. By participating in the study, caregivers felt they had “permission” to focus on their own well-being.

“I think what’s working right now for us is the biggest major thing is that we have had a really good school year after 3 years of absolute hell.”

“[T]he best thing that ever happened was the autism insurance because now my insurance will pay for his therapy which he never received ever in the past.”

“I gotta lose another five to ten pounds and I also have to get my son exercising. So I’m hoping if I’m exercising then he would do it also. It hasn’t been working so far. The autistic brain doesn’t work the same.”



“You know I might read to them at that point, or make sure they had a book that they were really engaged in and that I was like cuddled up... with them... with my own book, you know so that we’re all happily reading.”

Conclusion

Caregivers felt this program gave them “permission” to focus on their own well-being. Caregiver goals for the personalized lifestyle wellness intervention program reflected desires to:

- improve personal and family health,
- pursue personal interests, &
- foster stronger family connections.

Current life demands strongly influenced which goals were given priority. In stormy seas, occupations aimed at enhancing management of the most basic family needs were pursued. In calmer seas, goals that promoted the caregiver’s individual growth, physical health and interests were possible.

Introducing new routines was difficult because of the rigid behaviors of the child with autism. Important sources of support included emotional & logistical support from family or friends, particularly spouses, & high quality autism services. Planning & tracking aids also helped some caregivers establish new routines.

Implications for Practice

Occupational therapists supporting children with autism or the caregivers need to be sensitive to the current caregiving & life context as well as the resiliency of the family. In stormy times sustaining the health or well-being of the family should be emphasized. In calmer periods, intervention goals that help the family find connection, joy, and fulfillment through leisure, volunteering, and other occupations are appropriate.

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