



# Occupational Needs and Lifestyle Redesign Goals for Parents of Children with ASD: A Qualitative Study

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## Introduction

Parents of children with autism spectrum disorder (ASD) often experience high stress and mental health challenges that interfere with their ability to engage in meaningful, health-promoting occupations.<sup>1,2</sup>



**5Minutes4Myself** is a user-friendly, occupation-based wellness program and mobile app designed for caregivers of children with ASD.<sup>3</sup>

**Purpose:** this study seeks to 1) identify occupations that parents of children with ASD need for their wellness, and 2) explore parents' strategies to pursue personalized goals for engagement in wellness-promoting occupations.

## Research Design & Methods

**Design:** qualitative, case-based approach used with thematic coding as a secondary analysis of data.

**Participants:** 15 parents of a child with ASD between the ages of 8-18 years old. The audio for one participant's initial interview was lost; we used the coach's notes to determine their goals. Parents were an average of 48 years old and were primarily female (92.9%) and white (100%).

**Data Collection:** semi-structured, one-on-one lifestyle consultation interviews to elicit participants' wellness goals and plans to achieve these goals. Monthly check-ins following the initial interviews took place over four months. Coaches used an activity card sort and motivational interviewing techniques to elicit wellness goals and plans. Some examples of interview questions were:

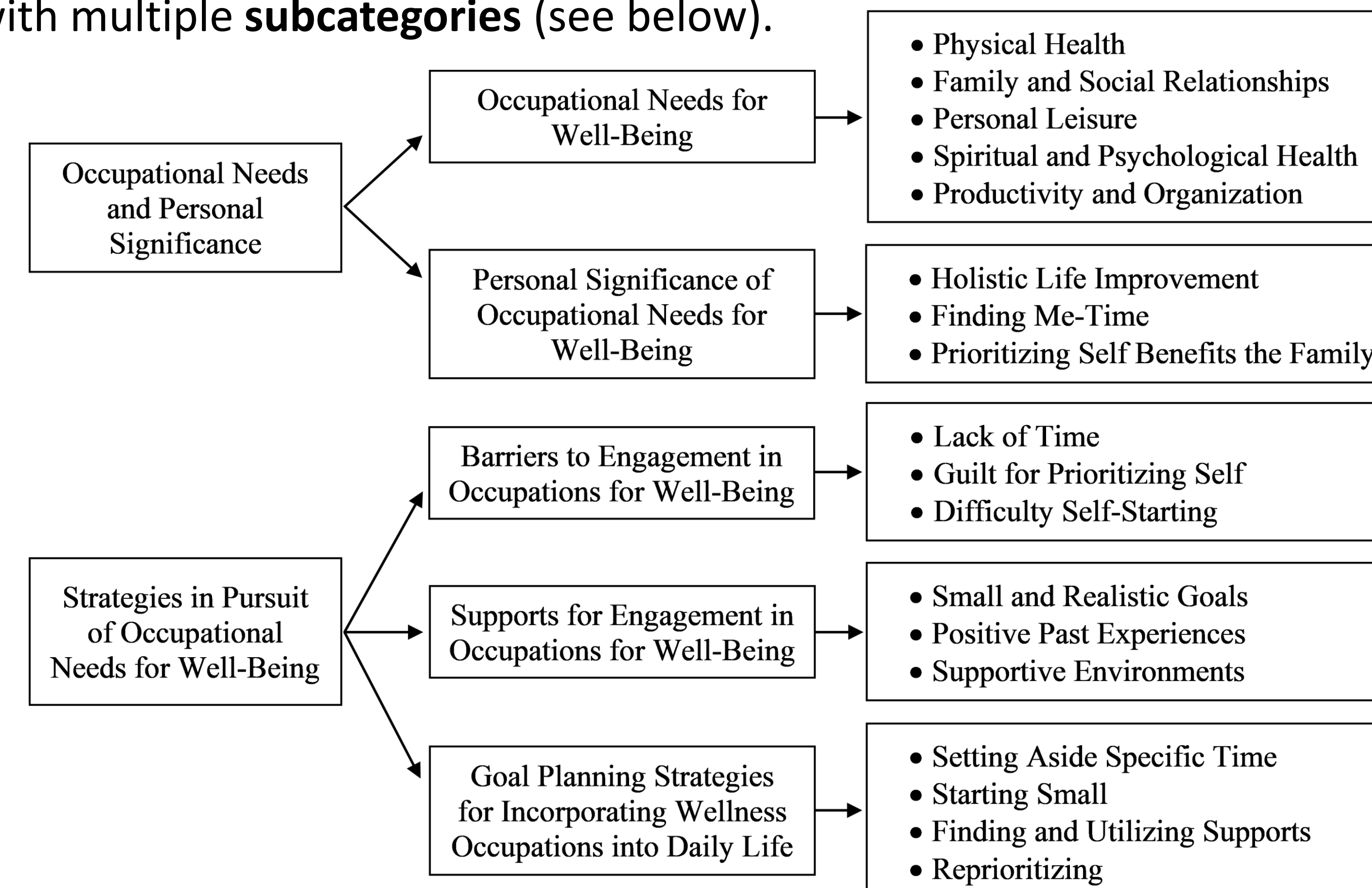
*"Why is this goal important?  
How do you think this would  
change your life?  
What are you already doing  
to achieve this goal?"*



**Data Analysis:** open coding of all initial interviews until no new themes emerged. All themes emerged from direct quotes and were agreed upon by at least two members of the research team.

## Findings

The **two overarching themes** that emerged were: 1) Occupational needs and personal significance; and 2) Strategies in pursuit of occupational needs for well-being. From these emerged 2-3 **broad thematic categories** with multiple **subcategories** (see below).



Parents' **occupational needs for well-being** focused primarily on their own holistic health needs. All but one participant created a mindfulness or meditation goal as part of the *5Minutes4Myself* program. The following were the most frequently chosen wellness goals by three or more participants: eating healthy; exercise and fitness; sleep hygiene; reflection; socialize with friends; and engage with children.

### Personal Significance

#### Holistic Life Improvement

*"I just feel like I walk out [of church] and feel really good and feel more whole as a person. Like... a more well-rounded person."*

#### Finding Me-Time

*"I just think that I don't ever do something for myself, and I think once in a while I should."*

#### Prioritizing Self to Benefit Family

*"...because if I don't start making myself a priority, I won't be there to help."*

### Barriers

#### Lack of Time

*"I just haven't been doing quiet time personally because busy life just kind of takes over, and I don't stop to do it."*

#### Guilt for Prioritizing Self

*"Just, it's hard to not have a guilty feeling. Like I'm not accomplishing anything. It's just fun time."*

#### Difficulty Self-Starting

*"I'm very aware of what the problem is (laughs). And I know how to fix it. I just haven't fixed it yet."*

### Supports

#### Small and Realistic Goals

*"...[reading and knitting] are things that I can do a little bit of as I move through the day... so they're easy to fit sort of fit into the schedule."*

#### Positive Past Experiences

*"I'm more confident in that one because I know that we've been able to do it in the past."*

#### Supportive Environments

*"I have a supervisor who is just like, 'Nope, we'll get this done. Don't worry, we'll do it together.'"*

### Goal Planning Strategies

#### Setting Aside a Specific Time

*"I think I'd have to set aside time everyday... to have it become a habit."*

#### Starting Small

*"I've got to do this the itsy bitsy... baby step routine... or I'm not gonna get it done."*

#### Finding and Utilizing Supports

*"I think I need the accountability to create the habit."*

#### Reprioritizing

*"...trying to prioritize what are the real needs and what's realistic to accomplish."*

## Conclusions

- Having time to focus on their own needs was restorative to a population who spends much of their time focusing on the needs of others.
- While personal wellness was the primary aim, parents found many of these goals important because of how they benefit their child or family.
- Parents far more frequently discussed barriers than supports for achieving their goals for wellbeing.
- Small and realistic goals were especially important for this population that often experiences high care demands and a chronic lack of time.
- Self-directed goal creation was essential for ensuring that parents' wellness goals fit into their unique, busy, and often overwhelming daily lives.

## Implications for Practice

- Identifying wellness-promoting occupations and supports for parents is essential for developing a feasible, practical, and individually-tailored wellness program that meets their unique needs.
- Future wellness programs can utilize these findings to guide program development by incorporating small and realistic goals, social accountability, etc.
- Has the potential to enhance future research with occupational therapy and other related fields that aim to promote wellness with this population.

## References

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