

Supporting Transition Education for Families of Youth with Autism Spectrum Disorder: TEAm Study

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BACKGROUND

The transition from pediatric to adult care for youth with autism spectrum disorder (ASD) is an important but complex topic. Only 20% of these individuals receive appropriate assistance with transition of care.

There is limited evidence concerning effective interventions that address the challenges faced by youth with ASD and their families in transition of care.

Transition Education in Autism (TEAm) study objectives:

- To develop a direct, focused web-based intervention that enables caregivers of youth with ASD to better navigate the transition process
- To determine if this intervention results in improvement in caregivers' knowledge base, comfort level, and satisfaction in addressing transition of health care

METHODS

- Needs assessment survey completed by local health care professionals, community leaders, and caregivers of youth with ASD
- Webinar developed based on survey results (Figure 1)
 - Topics covered: concept of transition, self-advocacy, adolescent health care issues, communicating with adult health care providers, and legal issues
- Study population: caregivers of youth diagnosed with ASD, ages 14-21 years
- Case-control study design
 - Group 1 ("cases") received the webinar
 - Group 2 ("controls") received a list of commonly used web-based resources on transition
 - Surveys at three time points: pre-intervention, immediate post-intervention, and three months post-intervention



Figure 1. Selected screenshots from the transition educational webinar with content informed by needs assessment survey results.

RESULTS

To date, eight caregivers in group 1 and seven caregivers in group 2 have completed the pre-intervention survey, viewed their respective intervention tools, and completed the immediate post-intervention survey.

There is no significant difference in demographic data, knowledge base, comfort level, and satisfaction level in addressing transition of care between the two groups at the time of pre-intervention.

Among group 1 participants, knowledge base, comfort level, and satisfaction level all increased from pre-intervention to post-intervention. Among group 2 participants, knowledge base, comfort level, and satisfaction level increased by a smaller percentage from pre-intervention to post-intervention, compared to the increases seen in group 1 (Figures 2a-2c).

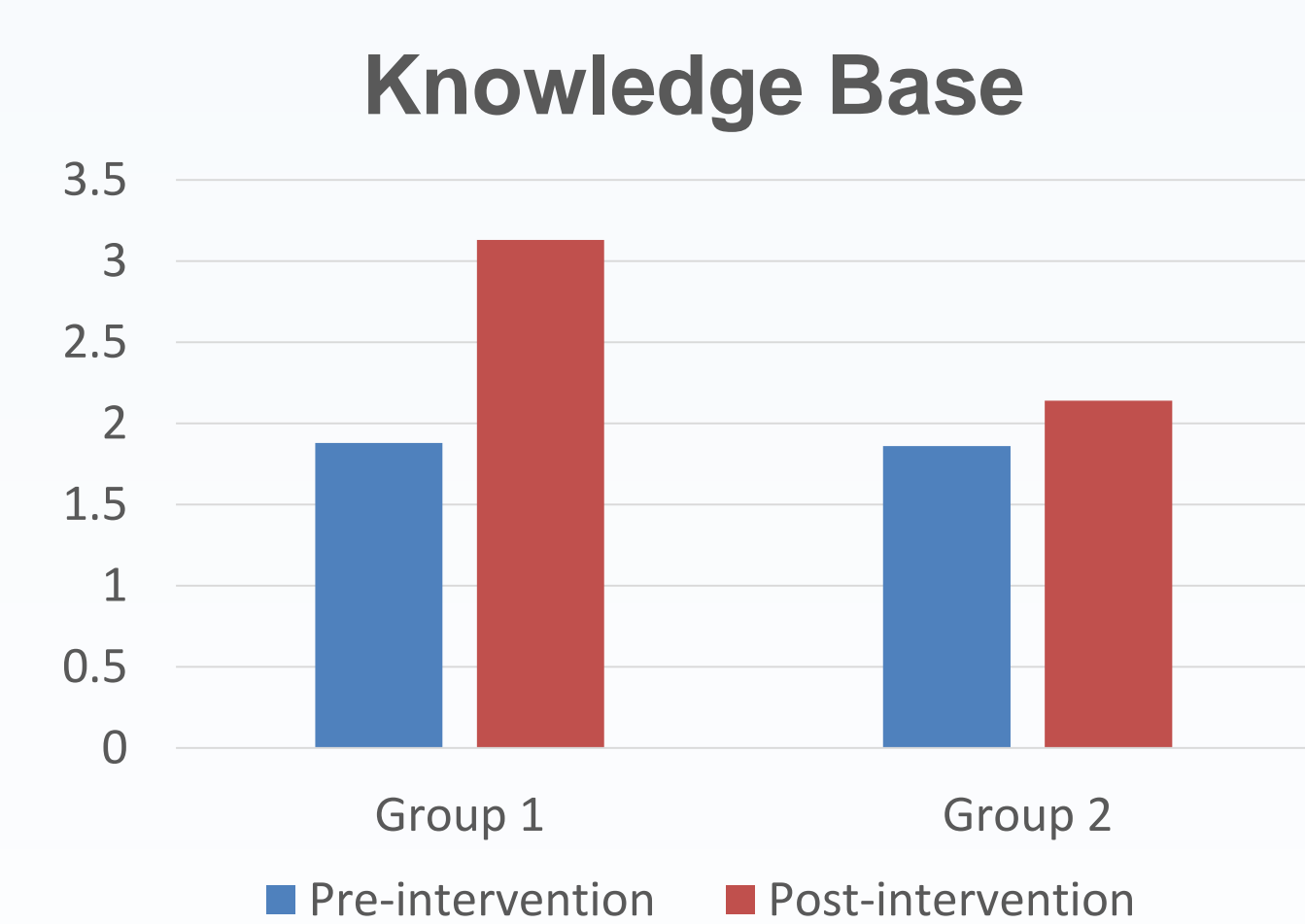


Figure 2a. Knowledge of transition of care issues measured by number of correctly answered multiple choice questions. Group 1's knowledge base increased by an average of 66.5% and group 2's knowledge base increased by an average of 15.1%.

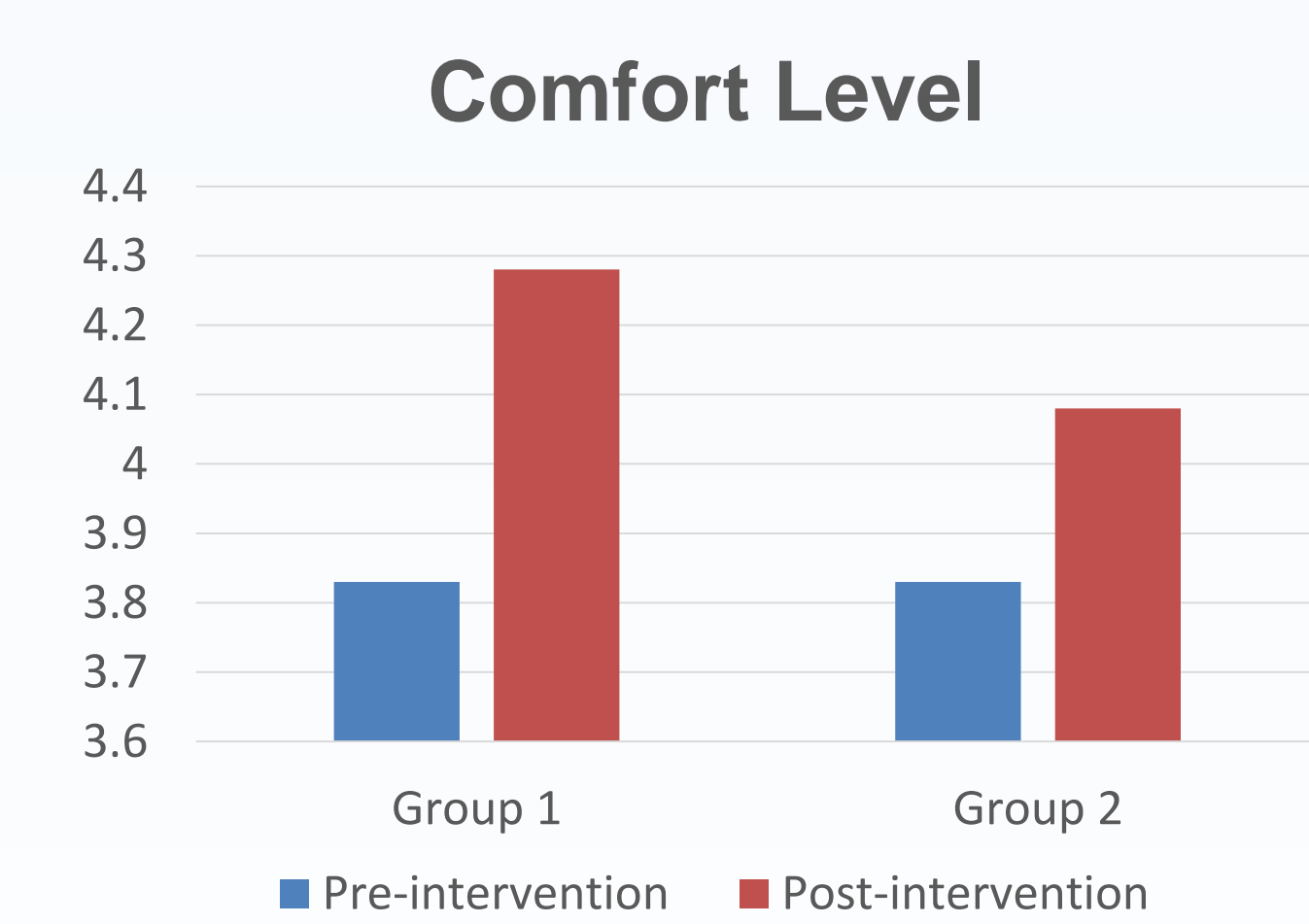


Figure 2b. Comfort level with transition of care issues measured by answers to various statements on a 5-point Likert scale. Group 1's comfort level increased by an average of 11.7% and group 2's comfort level increased by an average of 6.5%.

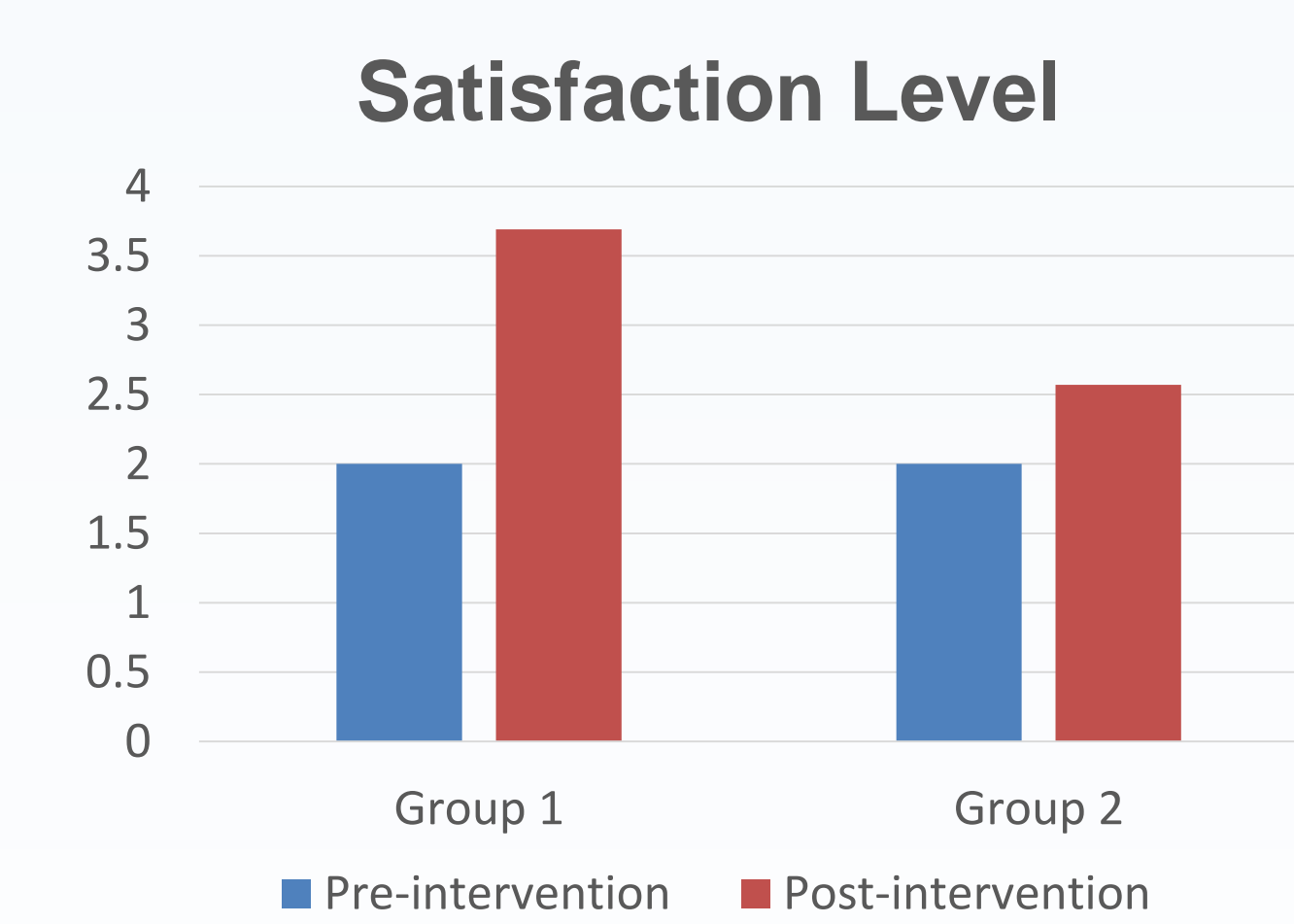


Figure 2c. Satisfaction level with addressing transition of care measured by answers to various statements on a 5-point Likert scale. Group 1's satisfaction level increased by an average of 84.5% and group 2's satisfaction level increased by an average of 28.5%.

CONCLUSIONS

Transitional care is a complex issue that requires a multidisciplinary approach. The TEAm study has aimed to bring together a diverse group of individuals to help address the varied aspects of the health care transition process, so that their fellow stakeholders – caregivers of youth with autism – can fully benefit from a web-based educational tool.

Although our study is in its infancy and ongoing, preliminary data show that there is an increase in knowledge base, comfort level, and satisfaction in addressing transition of care among those participants who viewed the webinar. There was less measurable change in these same measures among participants in the control group.

These preliminary data suggest that families of youth with ASD may benefit from a direct, focused educational tool.

FUTURE DIRECTIONS

We will continue to recruit caregivers for the study, obtain data at three months post-intervention, and perform data analysis.

The TEAm webinar is being used locally, on a small scale and currently in the context of a research study. If it proves to be an effective tool for families of youth with ASD, it may be beneficial to adapt the content for a wider audience, thereby affecting positive change on a larger scale.

ACKNOWLEDGMENTS

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