

Driving Change: Examining the Impact of the Transition Care Model on Patient-Reported Outcomes for Adolescents with Congenital Heart Disease

– TELEMACO Study –



Angileri S.¹⁻³, Ciofi D.³, Favilli S.², Spaziani G.², Caruso R.^{4,5}, Magon A.⁴, Flocco S.⁴, De Maria M.⁶

1 Department of biomedicine and prevention University of Tor Vergata, Rome

2 Meyer Children's Hospital- IRCCS, Pediatric and Transition Cardiology, Florence, Italy;

3 Meyer Children's Hospital- IRCCS, Department of Health care Professions, Florence, Italy;

4 Health Professions Research and Development Unit, IRCCS Policlinico San Donato, San Donato;

5 Department of Biomedical Sciences for Health, University of Milan, Milan, Italy;

6 Department of Life health Sciences and health Professions, Link Campus University, Rome, Italy;

WHAT ARE THE DATA IN WORDSWIDE ?

Congenital Heart Diseases (CHD) Overview:

- Prevalence: 9.1 per 1000 live births¹;
- CHDs lead to substantial morbidity, mortality, and healthcare costs;



Global Impact:

- 1.3 million children worldwide are living with CHD²
- 90% of CHD patients survive into adulthood.

Challenges of Transition:

- Psychological Issues
- Educational Needs

- 1) Chen C-W, Su W-J, Chiang Y-T, Shu Y-M, Moons P. Healthcare needs of adolescents with congenital heart disease transitioning into adulthood: a Delphi survey of patients, parents, and healthcare providers. Eur J Cardiovasc Nurs. 2017 Feb 7;16(2):125–35.
- 2) van der Linde D, Konings EEM, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJM, et al. Birth Prevalence of Congenital Heart Disease Worldwide. J Am Coll Cardiol. 2011 Nov 15;58(21):2241–7.

Background

Importance of Health Education for CHD Patients: Targeted interventions like transitional-care (TC)

“Previous evidence suggested that TC models predict better patient-reported outcome, but, there is a lack of empirical evidence”

What is the Transition-Care (T.C.) ?

The T.C. consists in multidisciplinary standardized interventions to educate and support adolescents with CHD, representing a key element in the adequate delivery of care to these individuals during their transition from childhood to adulthood³⁻⁴

- 3) Flocco SF, Dellafiore F, Caruso R, Giamberti A, Micheletti A, Negura DG, et al. Improving health perception through a transition care model for adolescents with congenital heart disease. J Cardiovasc Med. 2019 Jan 22;[in press]:1.
- 4) Flocco SF, Caruso R, Dellafiore F, Pittella F, Giamberti A, Micheletti A, et al. [The effect of the transition care model on health perception among adolescents with congenital heart disease: a quasi-experimental study]. G Ital Cardiol. 2018;19(6):386–93.

What is the state of art knowledge on the topic: Transitional-Care?

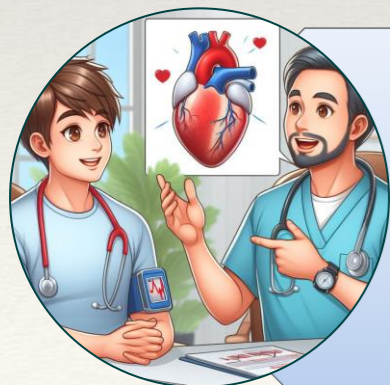


Population of adolescents and adults nearing transition



Consists of two main types of programs:

- group-based standardized
- personalized tailored to individual patient requests and needs



Expert teams in the field. In some cases, a transitional care coordinator is also present

AIMs

STUDY TELEMACO

healthcare
needs
expressed

The Primary Aim is to assess the effectiveness of health programs, such as transitional-care, on the perception of healthcare needs expressed by young adults with CHD.

The Secondary Aim is to highlight the healthcare needs expressed during follow-up

- To assess the effectiveness of transitional-care, on the perception of healthcare needs expressed by young adults with CHD
- To highlight the healthcare needs expressed during follow-up

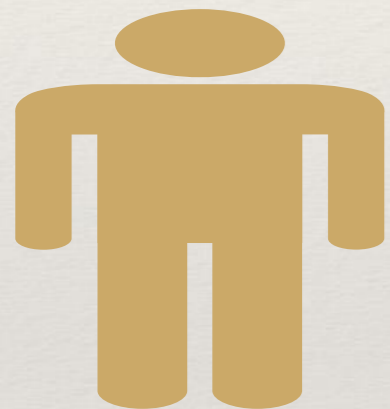


METHODS



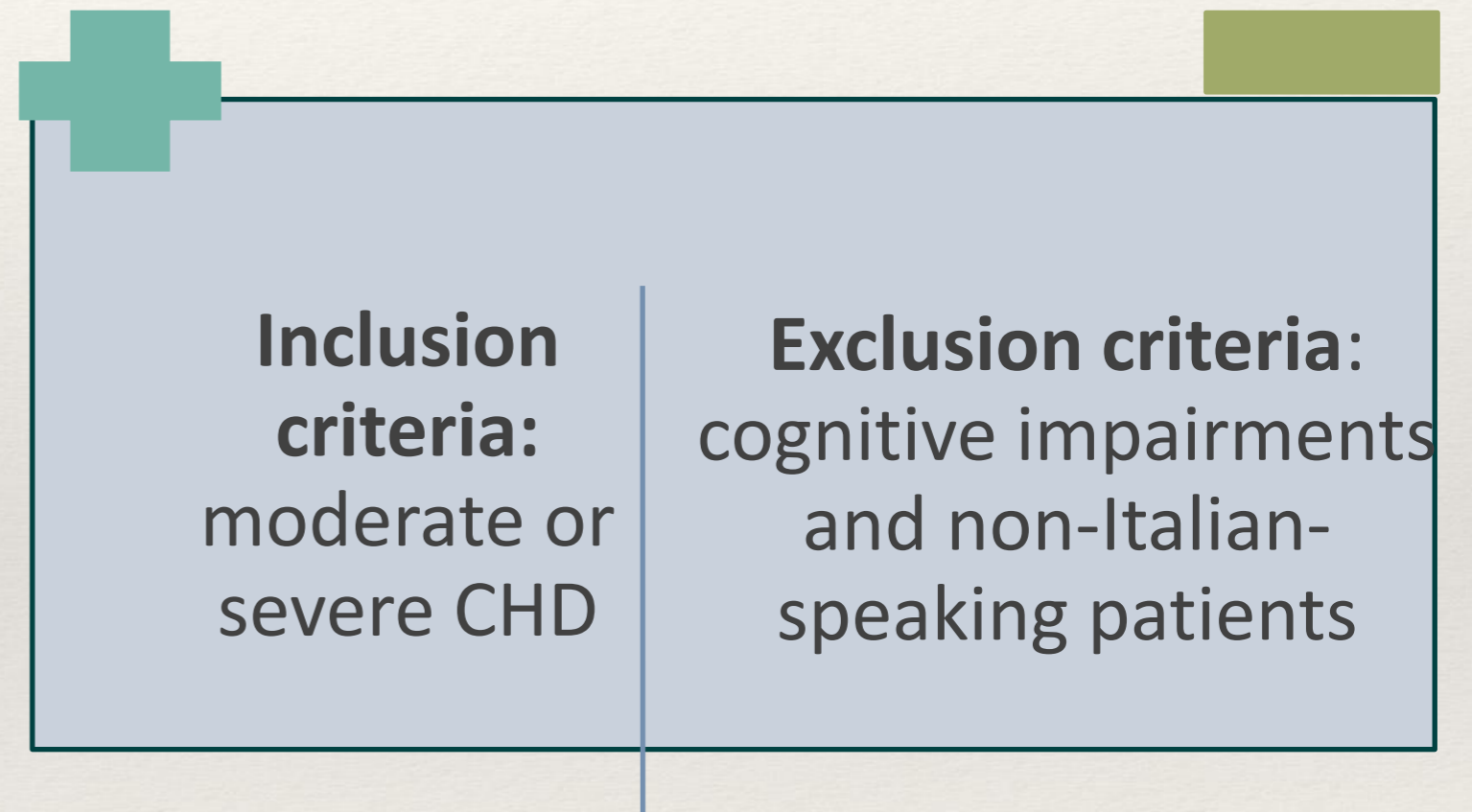
DESIGN

A pilot, two-arm, randomized, controlled, single-blind trial was conducted (follow-up: 3, 6, 9, and 12 months).



PARTICIPANTS

Twenty adolescents affected by CHD from 12 to 18 years old were enrolled



Experimental group received TC programs delivered four times
Control group received standard care.

Interventions of Experimental Group

- ❖ **I Pillar:** Tailored Health Education was provided through leaflets, brochures, and face-to-face discussions.
- ❖ **II Pillar:** Counseling professional, both for patients and families to support them by improving personal resources
- ❖ **III Pillar:** The Transition Coordinator who oversees the transition process, ensuring the achievement of goals and customizing specific needs through phone or in-person sessions

APPLIED IN THE OUTPATIENT SETTING
AT THE TIME OF ENROLLMENT

METHODS



INSTRUMENTS:

Healthcare Needs Scale - CHD -

COMPARATIVE ANALYSES:

- HEALTHCARE EDUCATION
- CLINICAL SUPPORT
- EMOTIONAL SUPPORT
- CONTINUUM OF CARE



DATA ANALYSIS «comparative test»

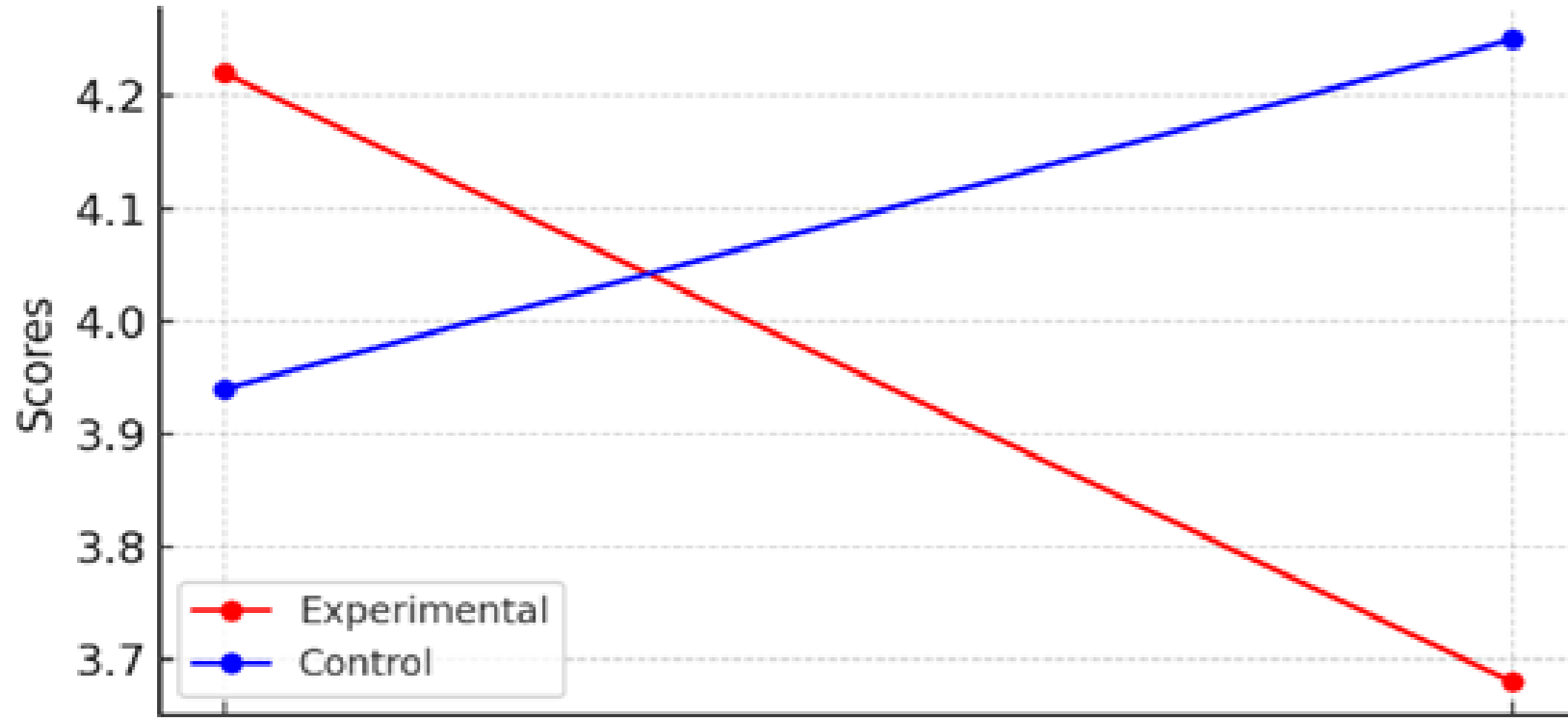
Wilcoxon and U-Mann Whitney

Results

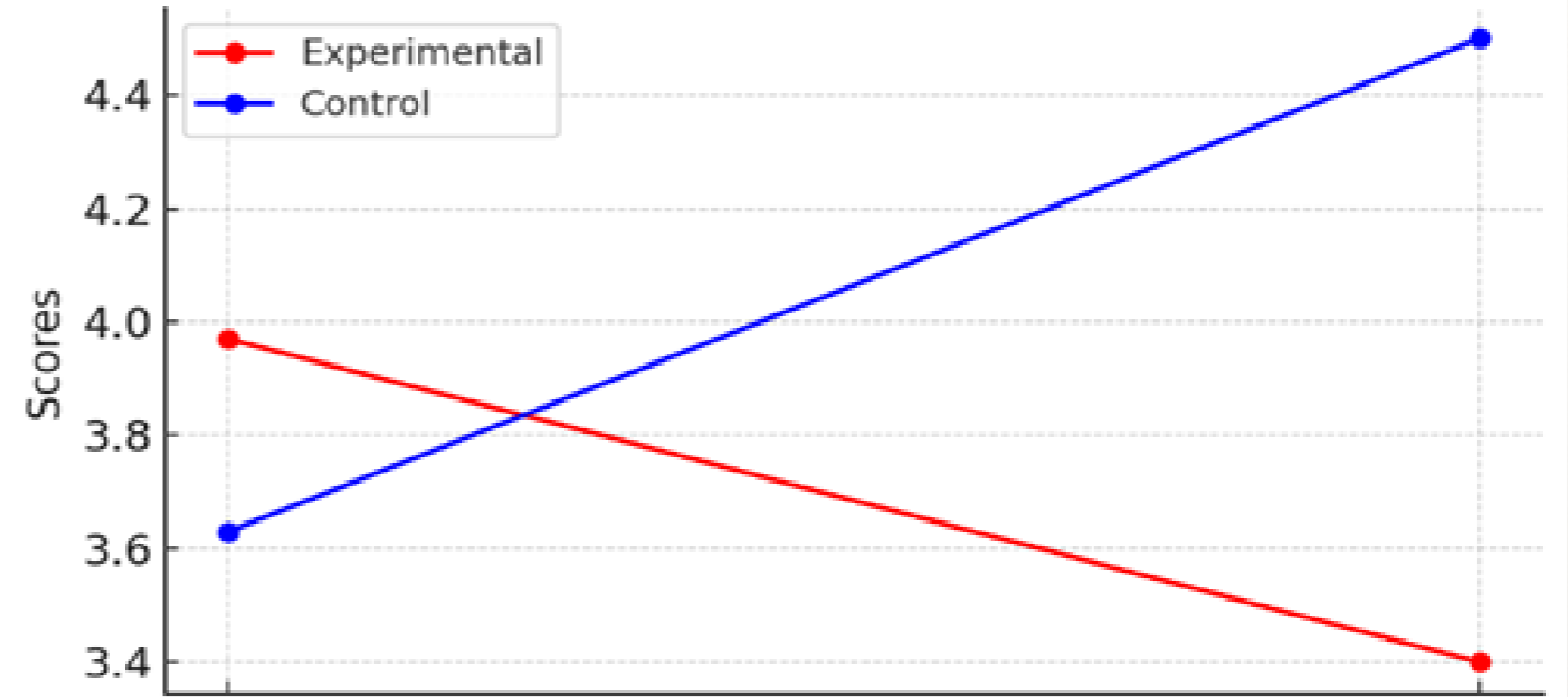
ANALYSIS FACTOR	ARM 1 <u>EXPERIMENTAL</u> group		ARM 2 <u>CONTROL</u> group		wilcoxon	U-test Mann-Whitney "P"
	T0 M(±DS) Range (Min-Max)	T4 M(±DS) Range (Min-Max)	T0 M(±DS) Range (Min-Max)	T4 M(±DS) Range (Min-Max)		
HEALTHCARE NEEDS SCALE FOR YOUTH WITH CHD (HNS-CHD)	4.22 (0.53) 3.40-5	3.68 (1.05) 2.20-5.00	3.94 (0.69) 2.80-4.80	4.25 (0.87) 3-5.00	< .001 (0.001)	0.342 (0.461)
HEALTHCARE EDUCATION	3.97 (0.62) 3.33-5	3.40 (1.52) 2-5	3.63 (0.88) 2.33-5	4.50 (0.79) 3.33-5.00	< .001 (0.001)	0.381 (0.368)
CLINICAL SUPPORT	4.37 (0.74) 2.67-5	3.53 (1.46) 1.33-5.00	3.93 (0.72) 2.67-5	4.08 (0.83) 3-5	< .001 (0.001)	0.155 (0.711)
EMOTIONAL SUPPORT	3.63 (0.78) 2.67-5	3.47 (1.32) 1.67-5.00	2.97 (0.69) 1.33-4	4.17 (0.88) 3-5	< .001 (0.001)	0.114 (0.461)
CONTINUUM OF CARE						

Comparative Analysis of TC Impact on Healthcare Perceptions Over Time

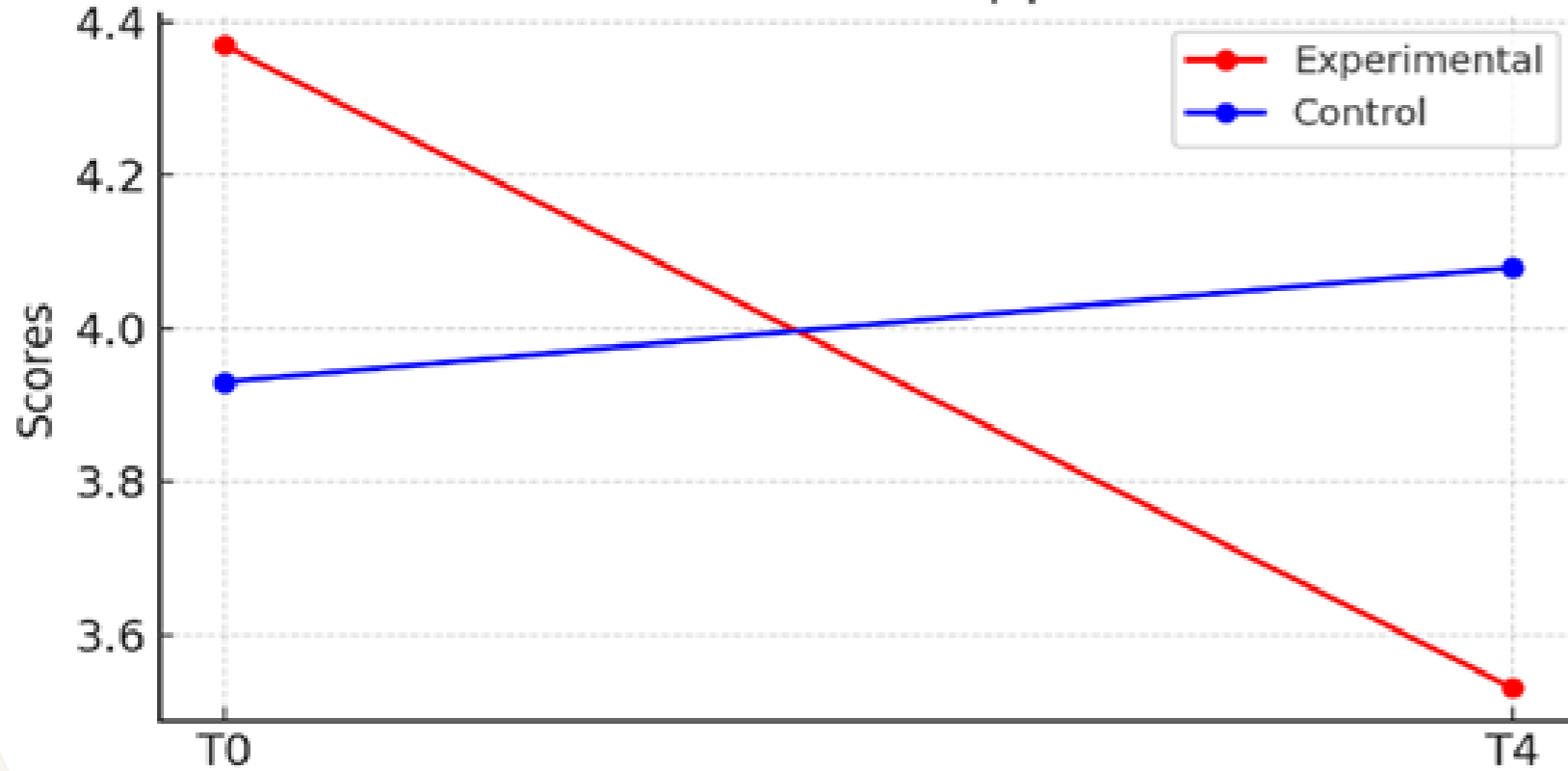
Healthcare Education



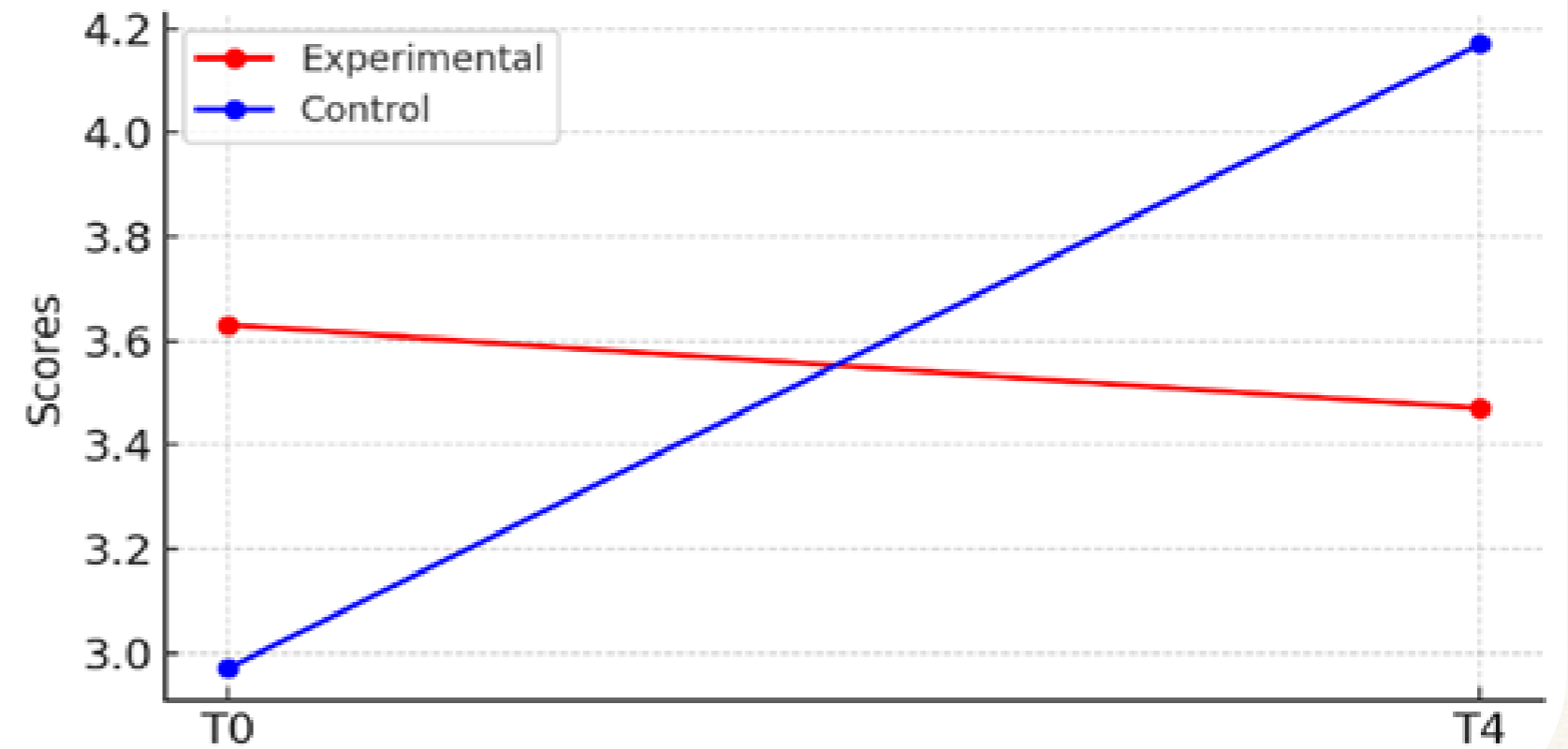
Clinical Support



Emotional Support



Continuum of Care



Time Points

*Thank You
for your attention*

