Julia Sorbara CPEG Fellowship Report

With the support of the CPEG Fellowship, I completed an MSc thesis project entitled: *Does Age Matter: Mental Health Implications and Determinants of When Youth Present to a Gender Clinic* (supervisor: Dr. Mark Palmert).

Background:

It is well known that gender incongruent youth experience high rates of mental health comorbidities. Gender-affirming medical care (GAMC) (i.e: the use of hormone blockers and/or gender-affirming hormones) has been shown to reduced emotional and behaviours problems and improve the psychological functioning of gender incongruent youth and adults. Despite these benefits, gender incongruent youth often present to GAMC at older ages and at later stages of puberty.

Study Aims

This study had three main aims as follows:

Aim 1: To assess the relationship between age at presentation to GAMC and rates of mental health comorbidities

Aim 2: To identify factors that influence when gender incongruent youth present to gender-affirming care

Aim 3: To determine whether youth who present to care at older ages face more barriers to care than those who present at younger ages.

Methods

Aim 1

A cross-sectional chart review was performed to assess the relationship between age at presentation to gender-affirming medical care and rates of self-reported mental health comorbidities. Patients were grouped based on age at presentation with those presenting at $\geq$15 years of age categorized as older presenting youth (OPY) and those presenting at <15 years of age classified as younger presenting youth (YPY). Data were extracted from documentation pertaining to the first clinic visit and included demographic variables, including age at first clinic visit, elements of the youth's gender journey, and details of the youth's mental health history. Rates of self-reported mental health comorbidities were compared between OPY and YPY. Binary logistic regression analysis was used to determined factors associated with various mental health comorbidities at the time of presentation to GAMC.

Aims 2 and 3

A sequential exploratory mixed-methods study was performed to explore factors that influence when gender incongruent youth present to GAMC and to determine whether youth who present to care at older ages face more barriers to care. This study design begins with the collection and analysis of qualitative data. These results form the foundation of a subsequent quantitative data collection phase which can be used to generalize or evaluate the findings from the initial qualitative phase. The rationale for this approach is that qualitative data can provide insight into

individual experiences while quantitative data can provide perspective on the degree to which elements of individual experiences are shared by a larger sample of the population under study

Aim 2: Aim 2 represented the qualitative strand of this mixed methods study. Youth and caregivers seen in the Transgender Youth Clinic (TYC) were eligible to participate in semi-structured interviews. As the goal of this aim was to inform the quantitative strand of this mixed methods study, interview sample size was determined *a priori*. A total of 24 semi-structured interviews were conducted with 6 OPY, 6 OPY caregivers (OPY-C), 6 YPY, and 6 YPY caregivers (YPY-C), lasting 12-37 minutes. Youth and caregivers were interviewed separately. The interview script contained open-ended prompts representative of topics that were considered, either on theoretical grounds or based on existing literature, to influence transgender youths' journeys to gender-affirming medical care. Audio-recorded interview data were transcribed verbatim.

Transcripts were analyzed in accordance with principles of thematic content analysis. Each transcript was coded by two independent coders for factors that were presumed, based on prior experience with this population, to influence timing of presentation to gender-affirming care. Codes were also applied to excerpts that represented additional ideas related to timing of presentation to care. The final code tree was developed in an iterative manner. Codes were then organized into themes that characterized factors influencing when transgender youth seek medical care. Theme case counts were used to determine whether themes were either present or absent in a given interview transcript, allowing for comparison of theme representation between OPY/OPY-C and YPY/YPY-C.

Aim 3: Aim 2 represented the quantitative strand of a sequential exploratory mixed methods study. Interview themes identified to be differentially represented between OPY/OPY-C and YPY/YPY-C were used to build a questionnaire, informing both questions as well as response choices. Separate questionnaires were designed for youth and caregivers (Appendix 5 and 6, respectively). Single- and multi- answer multiple choice, open-ended, and Likert-type scale questions were used based on what was considered most appropriate for the nature of the question. Questionnaires were reviewed and revised by both content experts and TYC patients and families for content analysis, face validity, readability, usability, time requirement, and appropriateness of language. The final versions of the youth and caregiver questionnaires contained 44 and 49 items, respectively, and required approximately 20-25 minutes to complete. Caregiver and youth questionnaires were administered on paper to patients seen in the TYC for follow-up over a 4-month period. Participation was anonymous and voluntary. Responses were compared between OPY and YPY and between OPY-C and YPY-C.

Results

Aim 1

Three hundred nineteen new patients were seen in the TYC during the study time periods and 300 met inclusion criteria for the chart review, 184 OPY and 116 YPY. YPY recognized their gender incongruence earlier in life than OPY (5.8 years, [IQR 3.0, 11.0] vs. 9.0 years, [IQR 5.0, 13.0], $p<0.001$). YPY also reported coming out about their gender identity at younger ages compared to OPY (12.0 years [IQR 11.0, 13.0] vs.15.0 years [IQR 13.0, 15.0], $p<0.001$). Social transition occurred earlier in life for YPY compared to OPY (13.0 years [IQR 12.0, 13.4], 15.00 years [IQR 14.0, 16.0]. $p<0.001$). However, the time from recognition of gender incongruence

to first TYC visit was similar between OPY and YPY (6.77 years [IQR 3.5, 11.9] vs. 7.4 years [IQR 3.1, 10.4], p=0.11).

Upon presentation, more OPY than YPY reported a diagnosis of depression (46% vs. 30%), had self-harmed (40% vs. 28%), had considered suicide (52% vs. 40%), had attempted suicide (17% vs. 9%), and required psychoactive medications (36% vs. 23%), all $p < .05$. After controlling for covariates, late puberty (Tanner stage 4 or 5) was associated with depressive disorders (OR 5.49 [95% CI: 1.14, 26.32) and anxiety disorders (OR 4.18 [95% CI: 1.22, 14.49]) while older age remained associated only with psychoactive medication use (OR 1.31 [95% CI: 1.05, 1.63]).

Aim 2

Six themes and 13 subthemes related to timing of presentation to gender-affirming medical care were identified as being differently represented or expressed by OPY/OPY-C and YPY/YPY-C. Identified themes fell into 3 main categories: individual factors, environmental factors, and health care factors. Individual factors were elements of the care-seeking experience related directly to the youth's gender identity or gender journey that impacted the timing of presentation to care. These included the perceived validity of the gender journey, based on gender expression and concerns of external influences, as well as barriers to gender journey exploration. Environmental factors included school system interactions, LGBTQ+ community members, family, and peers. Finally, healthcare system factors that impacted presentation to care were perceptions around medical therapy, particularly a sense of urgency related to assessment and initiation of treatment, as well as the nature of health care system interactions prior to presenting to the TYC.

Aim 3

A total of 299 questionnaires were distributed to all eligible youth and caregivers attending follow-up appointments at the TYC. Respondents were subsequently categorized as OPY, OPY-C, YPY, or YPY-C based on the age at their first clinic visit ($\geq$15 years or < 15 years, respectively) and their role (youth vs. caregiver) as indicated by the questionnaire responses. Forty-six caregivers and 50 youth opted not to complete the questionnaire. A total of 101 caregiver questionnaires were completed (50 by OPY-C and 51 by YPY-C), giving a response rate of 68.7%. 102 youth completed questionnaires (56 OPY and 46 YPY) for a response rate of 67.1%.

OPY/OPY-C did identify a greater number of barriers to care than YPY/YPY-C. Significantly more OPY-C reported identifying with a specific religion compared YPY-C (50.0% vs. 29.4%, p=0.04). Similarly, more OPY than YPY indicated a familial religious affiliation (53.6% vs 28.2%, p=0.01). Personal religious affiliation was similarly endorsed between OPY and YPY (26.8% and 26.1%). The majority of both OPY and YPY who felt their family's religious affiliation impacted their access to care felt that this delayed their presentation to the TYC. Most youth and caregivers had at least one connection to the LGBTQ+ community prior to the first clinic visit. YPY were more likely to report having LGBTQ+ family members compared to OPY (45.7% vs. 19.6%, p=0.006).

Discussion/Conclusion

These data suggest that gender incongruent youth who present to gender- affirming care later in life, as defined by later in age or later in puberty, experience higher rates of mental health comorbidities than those who present to care earlier in age and puberty. In particular we have shown that rates of depressive and anxiety disorders as well as psychoactive medication use are higher in youth who present to care later in puberty and age, respectively. We suspect that mental health statuses of transgender youth decline with increasing age and progression through puberty and that earlier presentation to care and timely initiation of gender- affirming therapy interrupts this downwards trajectory.

Our findings suggest that the most important determinant of when transgender youth present to care is the age at which they recognize their gender incongruence. We did not find that older presenting youth faced more barriers to care than younger presenting youth. There appear to be differences in the care-seeking experiences of youth who present to care earlier and later in life. However, a delaying effect of these differences was not supported by the quantitatively similar gender journey timelines exhibited by both groups. Familial religious affiliations and the presence of LGBTQ+ family members emerged as factors that may affect when youth seek care. We presume this is via their influence on when youth recognize their gender incongruence.

Finally, our findings provide further support for the notion that gender-affirming care is time sensitive and that efforts should be made to facilitate access to care of this population, such as enhanced education of primary care providers. Furthermore, community- and school-based interventions may help to support youth in recognizing their gender identities, leading to timely medical care.

Endocrine Society 2020 Abstract (acceptance pending):

DOES AGE MATTER? MENTAL HEALTH IMPLICATIONS AND DETERMINANTS OF WHEN YOUTH PRESENT TO A GENDER CLINIC

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Background/Aims: Gender incongruent (GI) youth experience high rates of mental health comorbidities. While gender-affirming medical care (GAMC) provides psychological benefit, GI youth often present to care at older ages. The goals of this study were to 1) assess the relationship between age at presentation to GAMC and rates of mental health comorbidities, 2) identify factors influencing when youth present to GAMC, and 3) determine whether older presenting youth face more barriers to care.

Methods: We performed a cross-sectional chart review of patients presenting to GAMC. Subjects were classified a *priori* as younger presenting youth (YPY): <15 years of age at presentation or older presenting youth (OPY): ≥ 15 years of age. Self-reported rates of mental health comorbidities and medication use were compared between groups. Binary logistic regression analysis was used to identify determinants of mental health comorbidities. Covariates included pubertal stage at presentation, social transition status, and assigned sex. Next, we performed a sequential exploratory mixed-methods study. Factors influencing age at presentation to GAMC were explored through 24 semi-structured interviews with OPY, YPY, and their caregivers (OPY-C and YPY-C). Thematic analysis identified themes with differential representation between OPY/OPY-C and YPY/YPY-C. From these themes, a questionnaire was designed and distributed to youth and caregivers presenting for follow-up. Responses were compared between OPY and YPY and between OPY-C and YPY-C.

Results: Of 300 youth, there were184 OPY and 116 YPY. Upon presentation, more OPY than YPY reported a diagnosis of depression (46% vs. 30%), had self-harmed (40% vs. 28%), had considered suicide (52% vs. 40%), had attempted suicide (17% vs. 9%), and required psychoactive medications (36% vs. 23%), all $p < .05$. After controlling for covariates, late puberty (Tanner stage 4 or 5) was associated with depressive disorders (OR 5.49 [95% CI: 1.14, 26.32) and anxiety disorders (OR 4.18 [95% CI: 1.22, 14.49]) while older age remained associated only with psychoactive medication use (OR 1.31 [95% CI: 1.05, 1.63]). Six themes were identified from interviews that influenced age at first clinic visit, including individual, environmental, and healthcare system factors. 101/152 youth and 102/147 caregivers completed questionnaires. While OPY/OPY-C did not endorse more barriers to care than YPY/YPY-C, more OPY than YPY had religious families (54% vs 28%, p=.01) while more YPY than OPY had LGBTQ+ family members (46% vs. 20%, p=.006).

Conclusions: Older age and late pubertal stage are associated with worse mental health among GI youth presenting to GAMC. Our findings emphasize the importance of timely access to GAMC for GI youth and highlight familial environment as a factor that influences when youth present to gender-affirmative care.