ORIGINAL RESEARCH ARTICLE

Don't Forget the Caregivers! A Discrete Choice Experiment Examining Caregiver Views of Integrated Youth Services

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Abstract

Background The design and implementation of community-based integrated youth service hubs (IYSHs) is burgeoning around the world. This collaborative model of care aims to address barriers in youth service access by designing services that meet the needs of youth and caregivers. However, heterogeneity across models requires a better understanding of the preferences for key service characteristics.

Method A discrete choice experiment was conducted among 274 caregivers of youth aged 14–29 years with mental health challenges. The experiment consisted of 12 attributes with four levels each, representing different service components; additional measures were collected, including demographics and burden assessments. Utility values were calculated, representing the degree of preference for a given level of an attribute. Latent class analysis was conducted to understand subgroups with different service preferences, identifying three latent classes with differing IYSH service preferences.

Results The largest class ($n = 173$, 63.1%), entitled 'Comprehensive, Integrative Service Access', strongly valued practical aspects of service design, such as rapid access and support for a wide range of needs. The 'Service Process Features' class ($n = 67$, 24.5%) expressed a relative prioritization of process features of service access, while the smaller 'Caregiver Involvement' ($n = 34$, 12.4%) class most highly prioritized caregiver involvement in their youths' services. Similar demographic characteristics and caregiver burden were found across classes, although participants in the Caregiver Involvement latent class were supporting younger youth.

Discussion and Conclusions Caregivers have diverse youth service preferences and relative priorities that should be taken into account when designing services. System designers and service providers are encouraged to take caregivers' preferences and priorities into account, alongside youth priorities, whether designing service delivery models or an individual service plan for a youth.

Key Points for Decision Makers

It is important to consider the perspectives of caregivers when designing and scaling integrated youth service hub models.

This study identified caregivers' priorities regarding the components of integrated youth service hub models.

Caregivers as a whole prefer rapid access to a diversity of youth services during evening and weekend hours, with e-health services available and caregiver involvement in care.

Subgroups of caregivers highly prioritize aspects of access to comprehensive integrative services, service process features, and caregiver involvement in youth care.

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1 Background

Across a wide range of mental health and substance use (MHSU) disorders, first onset most often occurs during adolescence and young adulthood [1]. Furthermore, youth mental health disorder prevalence rates are rising [2]. Despite the high prevalence, only a minority of youth with such concerns access treatment, and the treatments available are often neither timely nor evidence-based, with considerable negative repercussions [3–6]. Youth face complex pathways into care, often through suboptimal routes with multiple service contacts [7, 8]. Additionally, youth and families experience many barriers in accessing services, such as long wait times, uncoordinated services, lack of access to appropriate specialists, age-based transitions, and stigma [9–13]. Attention to family members is also of particular importance, since family members of youth with MHSU challenges often experience caregiver burden [14, 15].

Integrated youth service hubs (IYSHs) are an emerging model of care that provide holistic, youth-focused services [16, 17]. They integrate MHSU services, physical health care, and other community and social services in a one-stop-shop setting within the community. IYSH models are rapidly being developed and scaled around the world. Examples in Canada [18] include the Foundry model in British Columbia [19], Youth Wellness Hubs Ontario (YWHO) in Ontario [20], and the pan-Canadian Access Open Minds project [21]. International examples include headspace in Australia [22] and Jigsaw in Ireland [23], among others.

IYSH models explicitly aim to address service access barriers in youth MHSU care. IYSH models typically define 'youth' as adolescents and young adults, including transitional aged youth who face particular service access barriers [24]. The models work by bringing together evidence-based services for multiple areas of need in an integrated manner, all in one youth-friendly setting, with walk-in or other rapid access models [25, 26]. IYSHs address a wide variety of youth needs, spanning the continuum from evidence-based treatments for discrete disorders to important social services, supporting young people in all areas of their lives through a social determinants of health and bioecological framework [18]. They do so in part by bringing various partner agencies together to provide comprehensive sets of services and increasing service integration, which has been lacking in youth services [27]. The goal is to provide holistic, developmentally informed services across the developmental transition from childhood to adulthood. Examples of types of services included in these models are psychotherapy, psychiatry, primary care, peer support, care navigation, and housing support.

While IYSH models generally include specific evidence-based interventions, they also include other services and components packaged together in unique, integrative ways and settings that have less evidence behind them. Our scoping review [25] found many similarities across models in terms of key components and principles (e.g. rapid access, evidence-based services, service integration), which might be presumed to be universally important; however, we also found important inconsistencies across models (e.g. means of access, setting, range of service providers). Models are developed locally using collaborative teams, a service development approach, and available resources. They tend to include components thought to support youth in engaging with their services, such as an accessible location, the offer of evening and weekend hours, and the provision of 'youth-friendly' services and features [12] that are responsive to youth and family contexts. However, an evidence gap emerges regarding the components that are most critical and should be the highest priorities for model development and scale.

When designing patient-centred health services to meet the needs of service users, understanding the perspectives of that population is essential [28, 29]. It is not surprising that youth and caregivers want their preferences to be heard when developing treatment plans [30]. By hearing and accounting for their preferences at an earlier stage, such as at systems design, it is possible to create patient-centered care service pathways that are responsive to youth and family needs, i.e. services that fit with the preferences of service users [31]. For youth services in particular, understanding preferences of both youth and caregivers is essential because of the key role that caregivers play in facilitating service utilization [32–34]. Ensuring that the services match the preferences of both youth and caregivers has been found to increase youth service acceptability and use [31, 33]. Unfortunately, the perspectives of youth and caregivers are rarely integrated in service planning, development, and research; this leaves a gap in terms of optimizing service design through patient-oriented research and care [35].

This study expands on the emerging literature on IYSH models of youth MHSU service delivery. We take an empirical approach to identifying the core characteristics and features that an IYSH model should contain. We look beyond evidence-based treatments, to include the other service components and characteristics incorporated to make such models responsive to service user needs. The complete programme of research examines the perspectives of caregivers, youth, and service providers regarding the most important service characteristics to include in an IYSH model. This paper presents the findings regarding caregiver perspectives.

1.1 Research Questions

This study aims to identify (1) the IYSH service characteristics most important to caregivers of youth with mental health and/or substance use challenges, and (2) whether different latent classes of caregivers have different youth service preferences, and, if so, what defines these classes.

2 Method

2.1 Discrete Conjoint Experiment

The Discrete Conjoint Experiment (DCE) methodology asks respondents to select product or service preferences packaged together in complex hypothetical scenarios. Drawn from marketing research methodologies, DCEs identify the relative importance of different service preferences, as well as participant subgroups with different preference sets.

This study followed the guidelines of the International Society for Pharmacoeconomics and Outcomes Research taskforce's report on Good Research Practices for Conjoint Analysis [36]. Guided by our scoping review of IYSH services [25], the team collaboratively developed DCE attributes and levels. The literature review was used to identify components of IYSH settings (attributes), and team discussions were used to establish levels for each attribute. Iterative versions were refined through team meetings and informal surveys. Internal team surveys were developed using REDCap software [37], presenting draft attributes and levels; research team members scored their appropriateness and provided open-ended feedback to refine them. A consultation meeting was held with six caregivers to further refine the attributes and levels. During this caregiver consultation, the DCE process was described and the full set of attributes and levels was presented, as well as DCE choice set examples; attributes and levels were discussed and feedback was collected. From each of these steps, the feedback obtained was integrated in order to create the DCE survey used in the next step. This tentative DCE survey was then pilot tested among four caregivers in two Ontario locations (one large city and one rural area) for finalization. The process consisted of, first, a researcher describing the study and overall attribute and level concepts, then the caregivers completing the survey with research staff and voicing their questions, concerns, or comments. This pilot testing resulted in the refining of the instructions and practice exercise to better guide participants through the DCE survey, as well as adjustments to the demographic survey. For example, based on the pilot testing, the number of practice exercises was reduced from three to one, as the DCE process was clear to pilot participants and the practice exercises were considered redundant. As a whole, pilot participants understood the survey and no major changes were required at this stage.

In the final DCE, there were 12 attributes, each with four levels. A sample choice task is shown in Fig. 1, and all attributes and levels are shown in electronic supplementary Fig. 1. The attributes contained four levels each, representing (1) Core Health Services; (2) Other Services; (3) Peer Support; (4) Cultural Sensitivity; (5) E-Health Services; (6) Location; (7) Information Sharing with Caregivers; (8) Caregiver Involvement; (9) Age Range Served; (10) Time of Appointments; (11) Wait Times; and (12) Youth and Caregiver Engagement. For the complete set of attributes and levels, see electronic supplementary Fig. 1. Some overlap can be observed in the levels within some attributes, such as in the types of services offered; however, these were designed to reflect the multicomponent service options offered within IYSH settings. Using a partial profile design to minimize participant burden given the large number of attributes and levels [38], DCE tasks consisted of three service options, each containing one level of three attributes. Participants selected the most preferred option for youth (aged 14–29 years) with MHSU challenges. A balanced DCE algorithm optimized orthogonality and attribute/level balance. Random attribute and level combinations ensured that each participant's survey version was unique. Sawtooth Software's SSI Web [39] was used to administer the survey, hosted on a secure server at the Centre for Addiction and Mental Health (CAMH), in Toronto, ON, Canada. Recruitment occurred over a 4-month period from late 2019 to early 2020. Based on simulation analyses, the target sample size was 350 [40]; however, data collection was terminated at $N = 274$ due to research shutdowns associated with the coronavirus disease 2019 (COVID-19) pandemic. With 274 participants, the design strength was 258.1. Comparatively, with a target number of 350 participants, the design strength was 331.1, for a d-efficiency ratio of 78.0.

2.2 Participants and Procedure

A total of 274 caregivers were recruited over 5 months. Caregivers, or family members, were defined as individuals self-identifying as being the primary caregiver of a youth aged 14–29 years with MHSU challenges. Recruitment occurred by circulating a study flyer with a web link to Ontario youth-serving MHSU organizations, with a request to forward the flyer on to prospective participants. Median response time was 23 min. Caregiver participants were offered the optional entry into a random draw for gift cards if they chose to provide their contact information, which was not linked to the survey data. Research Ethics Board approval was obtained from CAMH.

2.3 Measures

In addition to the DCE choice tasks, we collected demographic information, for both the participant themselves and for an index youth for whom they were providing care. Caregivers also completed the Burden Assessment Scale (BAS) [41], a 19-item scale that measures the amount of

Fig. 1 Sample choice task

Question 1. Thinking about services for youth (aged 14-29) with mental health and/or substance use challenges, what do you think is the best option?			
	Option 1	**Option 2**	**Option 3**
Core Health Services	Mental health and substance use counseling, and medication management.	Only mental health counseling.	Mental health and substance misuse counseling, medication management, and physical/sexual health.
Peer Support (youth with experience with mental health and/or substance use challenges)	Recreational activities led by trained peer support worker.	Mental health groups run solely by a trained peer support worker.	Can talk to a trained peer support worker, upon request.
Service Sensitivity to Culture (i.e., LGBTQ, Black, Indigenous, and People of Colour, Religion, Spirituality)	Culturally-based services are available for cultures common to the local area.	Can ask for a service provider with a certain cultural background, when available.	Can ask for a service provider with a certain cultural background, when available.
	TM	TM	~

burden experienced by caregivers supporting a loved-one with mental health challenges. The 19 items are answered on a 4-point scale, where higher scores indicate a higher level of caregiver burden. The BAS yields a Total Burden Score, as well as two subscales: Subjective Burden (9 items, current alpha = 0.85) and Objective Burden (10 items, current alpha = 0.91). Total and scale scores were calculated as mean scores. The BAS has demonstrated acceptable content and construct validity [41]. It has been validated among caregivers of adults, as well as caregivers of children and adolescents [41, 42]. In a validation study among Canadian caregivers of children and adolescents with mental health and behavioural challenges, total average burden scores were 49 out of a maximum of 76 [42], which equates to a mean score of 2.6 on a 4-point scale. All measures were completed in English.

2.4 Data Analysis

We described the sample using descriptive statistics. Utility estimates were then calculated for each participant's DCE responses, using the hierarchical Bayesian method with Sawtooth Software [39]. With standardized, zero-centered utilities, the average utility range of attribute levels is set to 100 [43], where higher utility values indicate that a level has a higher relative value relative to the other levels of that attribute. The relative importance of each attribute is indicated by its proportional utility as a function of the total utility of all attributes. The utility value is the distance between the largest and smallest estimate of a level within the attribute. Using latent class analyses in Sawtooth Software's Latent Class module [39], we identified classes of caregiver participants with similar service preferences, assigning each participant a probability of belonging to a given latent class. Five replications were calculated for each latent class solution, using different starting seeds. Convergence was assumed for

log-likelihood decreases of 0.01 or less. Latent class solutions were compared using the Bayesian Information Criteria (BIC), Akaike Information Criteria (AIC), and Akaike's Bayesian Information Criterion (ABIC), in conjunction with class sizes and interpretability (see electronic supplementary Table 1 for fit indices). For the retained three-class model, a descriptive presentation of the attribute rankings is provided. Names for the latent classes were established through team discussions informed by (1) their relative importance scores, particularly those that were orthogonal or distinct in priority/rank compared with other classes (Table 2), and (2) the level endorsements for each attribute, particularly those preferred levels that are orthogonal or seem distinct compared with other classes. The remaining analyses were conducted using SPSS version 25 [44]. The latent classes were compared based on demographic characteristics and BAS scores. We examined rankings of the importance scores for the levels comprising the attribute.

3 Results

3.1 Demographic Characteristics

Demographic characteristics are presented in Table 1. The univariate majority of participants were female, educated, employed full time, financially stable, urban, and Caucasian, with good to excellent physical and mental health; however, only 33 (12.0%) participants met this full multivariate demographic profile, demonstrating some diversity and intersectionality in the sample. The mean age of youth rated by the caregiver sample was 20.72 years (standard deviation [SD] = 4.32). Youth rated by caregivers comprised 41.4% boys/young men, 49.1% girls/young women, and 9.5% transgender or gender diverse. Only

Table 1 Sociodemographic characteristics of caregiver participants and the index youth who they reported supporting (n = 274)

Sociodemographic characteristic	Youth, as rated by caregivers n (%)	Caregivers n (%)
Gender		
Man/boy	113 (41.4)	21 (7.8)
Woman/girl	134 (49.1)	245 (91.4)
Transgender or gender diverse	26 (9.5)	2 (0.7)
Ethnicity		
Asian	12 (4.4)	15 (5.5)
Black	3 (1.1)	3 (1.1)
Indigenous	5 (1.8)	3 (1.1)
Caucasian	213 (78)	232 (85.0)
Another ethnicity	40 (14.7)	20 (7.3)
Socioeconomic status		
Live comfortably	NA	155 (59.6)
Meet needs, with a little left	NA	61 (23.5)
Basic expenses met or less	NA	44 (16.9)
Employment		
Full-time	27 (10.4)	149 (57.8)
Part-time	63 (24.3)	26 (10.1)
Unemployed	157 (60.6)	36 (14.0)
Other	12 (4.6)	47 (18.2)
Education level		
High school or less	174 (67.2)	12 (4.6)
Some college/university	55 (21.2)	39 (15.0)
Graduate college/university	30 (11.6)	209 (80.4)
Region size		
Rural/small (population 0–30,000)	NA	40 (14.8)
Medium (population 30,001–99,999)	NA	49 (18.1)
Large (population over 100,000)	NA	182 (67.2)
Born in Canada		
Yes	241 (93.1)	216 (84.4)
First language		
English	250 (96.5)	233 (90.7)
Physical health		
Good/very good/excellent	162 (62.5)	226 (86.9)
Fair/poor	97 (37.5)	34 (13.1)
Mental health		
Good/very good/excellent	33 (12.7)	191 (73.5)
Fair/poor	227 (87.3)	69 (26.5)

12.7% of caregivers rated their youth's mental health as 'good' or better.

3.2 Overall Preferences Irrespective of Class

Observing preferences within each attribute irrespective of latent class or relative importance between attributes, caregiver latent classes universally indicated that models without caregiver involvement or information sharing with caregivers would not be desirable. Caregivers also preferred that rapid access be provided, including evening and weekend hours, in a specialized mental health setting. Caregivers endorsed that some level of e-health services be integrated in conjunction with in-person services. Overall, they preferred settings offering a diversity of services across core services and additional social service supports; legal support services were not a priority. They collectively negatively endorsed situating services in a school setting. Levels within other attributes were mixed across classes.

3.3 Latent Class Analysis

Electronic supplementary Table 1 presents latent class fit indices for models ranging from one to five classes. Considering model fit, class size, and interpretability, we retained the three-class model. DCE attribute rankings and importance scores are presented in Table 2. The importance scores indicate the proportion of the total importance represented by each attribute for each latent class (see the detailed results in electronic supplementary Fig. 1 regarding the level values within each attribute).

3.3.1 Comprehensive, Integrative Service Access

Latent class 1 represented the majority of the sample ($N = 173$, 63.1%). This class most highly prioritized the attributes E-Health Services, Wait Times, Information Sharing, and Other Services. This latent class was distinct for their preference for access to comprehensive, integrative services. The least prioritized attributes were youth and family engagement in services, the time of appointments, and the age range served.

Caregivers belonging to this class prioritized a model in which e-health services provide a 24/7 supplement to in-person care. They also wanted the ability to schedule appointments via email, text, or online, and endorsed that services should be accessible either immediately or after about 72 h. In the Other Services attribute, members of this latent class prioritized that a choice of service options be available to support youth in areas of education, employment, housing, income support, and legal issues. For the Information

Sharing attribute, caregivers in this latent class endorsed that youth and service providers should work together to decide which information to share with caregivers. There was some endorsement of a model in which information is available to caregivers with youth consent and in which service providers decide which information to share, but caregivers in this latent class were opposed to a model in which there was no information sharing with caregivers.

3.3.2 Service Process Features

The second latent class, comprising 67 participants (24.5%), was labelled Service Process Features. This latent class prioritized a family-based, holistic approach to care, favouring service characteristics that might be considered 'youth friendly'. Specifically, they most strongly prioritized the following attributes: Information Sharing, Age Range, Caregiver Involvement, and Time of Appointments. The attributes with the least relative priority levels were Cultural Sensitivity, Engagement, and Core Health Services.

Members of the Service Process Features latent class prioritized either service providers deciding which information to share with caregivers, or youth and service providers working together to make this decision. They had a strong negative utility value for a service model in which there was no information sharing with caregivers. This latent class endorsed that services be delivered to an age range of 12–29 years, with services for those aged over 29 years also available. Participants were less likely to endorse more restrictive age ranges and service settings open to younger children, but endorsed flexible hours—either 24/7 or with

Table 2 Caregiver attribute importance scores and rankings for components of integrated youth service hubs for each of the three latent classes of participants

	Comprehensive, integrative service access [n = 173]		Service process features [n = 67]		Caregiver involvement [n = 34]	
	I	R	I	R	I	R
Core health services	7.74	8	4.86	10	5.43	10
Other services	10.10	4	8.35	7	3.66	12
Caregiver involvement	9.30	5	11.47	3	14.72	2
Peer support	7.42	9	5.84	8	5.82	8
Cultural sensitivity	7.65	6	2.40	12	4.13	11
E-health services	12.81	1	5.46	9	5.80	9
Age range	6.96	10	12.04	2	6.29	7
Time of appointments	5.07	11	10.84	4	7.93	6
Wait times	11.34	2	10.05	6	8.85	5
Location	8.73	7	10.79	5	11.47	3
Engagement	1.89	12	2.53	11	11.03	4
Information sharing	10.99	3	15.38	1	14.86	1

R Rank of each attribute's importance score within informant and segment. *I* Importance score of each attribute. Relative importance scores represent a percentage of value assigned to each attribute relative to the other attributes

evening and weekend hours. They also prioritized the option of being involved in family counselling with youth or being involved in counselling decisions with youth, and were less likely to choose a service delivery model in which caregivers received their own counselling or in which there was no caregiver involvement.

3.3.3 Caregiver Involvement

The third latent class accounted for 34 caregivers, or 12.4% of the sample. This smaller proportion of participants most strongly prioritized a high level of involvement in the care of their youth, irrespective of the types of services offered, leading to this class being called Caregiver Involvement. The attributes most strongly endorsed in this latent class were Information Sharing, Caregiver Involvement, Location, and Engagement, while the attributes with the least relative priority were Other Services, Cultural Sensitivity, and Core Health Services.

For the Information Sharing attribute, participants in the Caregiver Involvement latent class prioritized caregivers having access to youth personal information (with youth consent as per the level provided) or preferred that youth and service providers work together to decide which information to share. There was a large negative utility value for no information sharing with caregivers. They also strongly endorsed that caregivers should be involved in decisions regarding youth counselling or that caregivers should be involved in family counselling with youth. Little value was placed on caregivers receiving their own separate services or counselling, and there was a strong negative reaction to the prospect of no caregiver involvement. Participants preferred that youth and caregivers play a leadership role in making decisions for the organization, or that they should be on an advisory group. This latent class also prioritized housing the services in a youth café and recreation centre or an office that specializes in mental health services, as opposed to a hospital, doctor's office, or school environment.

3.4 Participant Characteristics by Latent Class

None of the demographic characteristics of caregivers were significantly different across classes (Table 3). Youth rated by caregivers were also similar across latent classes in gender, physical health, and mental health; however, caregivers in the Caregiver Involvement class were reporting on younger youth compared with those in the other two classes. Total levels of the BAS did not differ among latent classes (F (2, 254) = 1.087, p = 0.34). All latent classes reported similar total burden scores (Comprehensive, Integrative Service Access: M = 3.07, SD = 0.60; Service Process Features: M = 2.94, SD = 0.70; Caregiver Involvement: M = 3.10, SD = 0.63). Similarly, no significant

differences were found in the objective burden subscale (F (2, 254) = 1.020, p = 0.36). All classes featured similar levels of this subscale (Comprehensive, Integrative Service Access: M = 3.14, SD = 0.65; Service Process Features: M = 3.00, SD = 0.75; Caregiver Involvement: M = 3.14, SD = 0.65). Subjective burden was also not significantly different (F (2, 254) = 0.829, p = 0.44) across latent classes (Comprehensive, Integrative Service Access: M = 2.99, SD = 0.66; Service Process Features: M = 2.88, SD = 0.81; Caregiver Involvement: M = 3.05, SD = 0.67).

4 Discussion

This study examined caregivers' perspectives on the service characteristics most important for IYSH settings. As a whole, caregivers preferred a diversity of services, with rapid access, e-health services, and caregiver involvement, in a specialized mental health setting. Three latent classes of caregivers emerged. When making trade-offs between service components, the first class most strongly prioritized practical aspects of access to comprehensive services; the second latent class most strongly prioritized service process features; and a third, small latent class most highly prioritized caregiver involvement in diverse aspects of the youth's care. Despite somewhat high levels of caregiver burden in the sample as a whole compared with previous research [42], the latent classes were similar in terms of burden and demographic characteristics.

A recent small qualitative study from The Netherlands examined caregiver preferences in integrated service contexts [45]. That study found several themes that reflect the current study's quantitative findings: families wanted rapid access to family-centered, holistic, collaborative services, with smooth transitions, strong privacy policies, and parental involvement in decision making. These findings largely overlap with the current study and provide confirmation of those findings from a quantitative perspective, with international generalization. This study adds to those findings by demonstrating the existence of different constellations of preferences across caregivers, with some of these preferences being of different relevant importance than others.

In the current study, caregivers' prioritization of rapid access to services, when making trade-offs among various service features, comes as no surprise given the long wait times in the field [6] and the broad literature indicating wait times as a barrier [11, 45–48]. This finding supports the ongoing development of IYSH models with walk-in or other rapid access models as a key priority as the models are scaled. However, some caregivers did not highly prioritize the diversity of core or supplementary services; some caregivers appear to want access to services that they can be involved in, irrespective of what those services might be.

Table 3 Sociodemographic characteristics of participants across the three latent class

Caregiver characteristics	Comprehensive, integrative service access n = 173 n (%)	Service process features n = 67 n (%)	Caregiver involvement n = 34 n (%)	P value	φ
Gender[a]					
Man	9 (5.4)	8 (12.1)	4 (12.1)	0.144	0.12
Woman	158 (94.6)	58 (87.9)	29 (87.9)		
Ethnicity					
White	149 (86.1)	54 (81.8)	29 (85.3)	0.705	0.05
Non-White	24 (13.9)	12 (18.2)	5 (14.7)		
Socioeconomic status					
Lives comfortably	102 (62.2)	35 (54.7)	18 (56.3)	0.535	0.07
Lives less than comfortably	62 (37.8)	29 (45.3)	14 (43.8)		
Employment					
Employed	136 (83.4)	49 (76.6)	24 (77.4)	0.426	0.08
Unemployed/other	27 (16.6)	15 (23.4)	7 (22.6)		
Region size					
Rural/small urban	52 (30.6)	27 (40.3)	10 (29.4)	0.323	0.09
Large urban	118 (69.4)	40 (59.7)	24 (70.6)		
First language					
English	147 (91.3)	56 (87.5)	30 (93.8)	550	0.07
Born in Canada					
Yes	125 (83.3)	52 (83.9)	29 (90.6)	0.579	0.07
Education level					
High school/some post-secondary	30 (18.3)	16 (25.0)	5 (15.6)	0.431	0.08
Graduated post-secondary	134 (81.7)	48 (75.0)	27 (84.4)		
Physical health					
Good or better	147 (89.6)	55 (85.9)	24 (75.0)	0.077	0.14
Fair or worse	17 (10.4)	9 (14.1)	8 (25.0)		
Mental health					
Good or better	123 (75.0)	44 (68.8)	24 (75.0)	0.617	0.06
Fair or worse	41 (25.0)	20 (31.3)	8 (25.0)		
Youth characteristics					
Age, years					
<18	48 (28.6)	15 (22.7)	16 (48.5)*	0.013	0.22
18–24	86 (51.2)	30 (45.5)	15 (45.5)		
25–29	34 (20.2)	21 (31.8)	2 (6.1)*		
Gender[a]					
Man/boy	66 (38.2)	32 (48.5)	15 (44.1)	0.575	0.07
Woman/girl	88 (50.9)	29 (43.9)	17 (50.0)		
Transgender/gender diverse	19 (11.0)	2 (5.9)	5 (7.6)		
Ethnicity					
Caucasian	135 (78.0)	53 (80.3)	25 (73.5)	0.741	0.05
Another ethnicity	38 (22.0)	13 (19.7)	9 (26.5)		
Employment					
Employed	61 (37.4)	25 (39.1)	10 (31.3)	0.747	0.05
Unemployed/other	102 (62.6)	39 (60.9)	22 (68.8)		
Education level					
High school or less	114 (69.9)	38 (59.4)	22 (68.8)	0.638	0.10
Some college/university	30 (18.4)	17 (26.6)	6 (18.8)		

Table 3 (continued)

Caregiver characteristics	Comprehensive, integrative service access	Service process features	Caregiver involvement	P value	φ
	n = 173	n = 67	n = 34		
	n (%)	n (%)	n (%)		
Graduate college/university	19 (11.7)	9 (14.1)	4 (12.5)		
Physical health					
Good/very good/excellent	96 (58.9)	42 (65.6)	24 (75.0)	0.192	0.11
Fair/poor	67 (41.1)	22 (34.4)	8 (25.0)		
Mental health					
Good/very good/excellent	17 (10.4)	9 (14.1)	7 (21.9)	0.188	0.11
Fair/poor	147 (89.6)	55 (85.9)	25 (78.1)		

* $p < 0.05$

[a]Transgender and gender diverse genders were not analysed due to small cell sizes

Caregiver involvement in the treatment process emerged as a strong priority, at different levels for different participant groups. Previous work has shown that caregivers often feel excluded from their youth's or young adult's care, which they consider a considerable barrier and driver of dissatisfaction [7, 11, 13, 47, 49]. Caregiver involvement can be a facilitator of treatment retention for young people [48]. Whether through family-focused treatment with the youth and caregiver together or through interventions aimed at the parent themselves, youth and caregivers can benefit from involvement from a whole-family approach [48–50]. In terms of information sharing, caregivers expressed wanting opportunities to communicate with service providers about their youths' care and to understand their care [7, 13]. Somewhat paradoxically, but importantly, youth have expressed that confidentiality is a premise of youth-friendly services [12, 51]. Since strong caregiver involvement is a leading priority for a small proportion of caregivers, and a moderate priority for others, this is an important area of ongoing negotiation between the youth, service provider, and interested caregivers, as the youths' service needs evolve.

Many caregivers also prefer aspects of services considered to be 'youth friendly' [12]. For example, rapid access and the use of technology to book appointments, locating services in a youth-accessible setting, providing holistic services, reducing age-based transitions, and offering convenient hours are all preferred components [11–13]. Providing services and settings that reduce or facilitate age-based transitions is a particular priority of some caregivers [7]. By making services responsive to youth needs and preferences, it is hypothesized that service access and retention will increase, improving outcomes [12]. Caregivers appear to recognize this, and many are ready and willing to express their preferences to help shape services. However, the attributes and levels were designed to capture caregivers' perspectives on the service components most important for their youth; results may have been different if the study specifically queried caregivers on service components most important to caregivers themselves.

These findings provide valuable insights to support the design of IYSH settings that correspond with the preferences of caregivers. Caregivers are an important stakeholder in youth services, given their close involvement with the youth [52]. For some youth, caregiver support for service access, and service designs that are appealing to caregivers, increase the likelihood that the youth will use services [11, 33]. Taking caregiver preferences into account in the design and scale of IYSH models is important to ensuring an appealing and accessible model of care.

Most importantly, service developers are encouraged to engage youth and caregivers in the design and development of youth-oriented services. Engagement is a core component of IYSH development and is considered key to developing services that are responsive to youth and family needs [25]. While not all caregivers prioritize engagement as a key design preference, some are ready and willing to engage with organizations, at both the decision-making and service levels, to help optimize services for a broad range of families seeking services [53]. Caregivers should be engaged, alongside youth, in the development of both the service pathways and evaluations of service impact, as their important voices can help improve both the services and evaluation projects.

In sum, to meet the needs of the caregivers supporting young people, IYSH service developers are encouraged to continue to prioritize rapid access to a diversity of services in accessible environments, in line with their current orientation. They are also encouraged to expand the incorporation of technology into services, an area of work that is not yet fully optimized at a broad scale. Another area for further policy and procedural development within IYSH settings is information sharing with caregivers; IYSHs are encouraged

to establish clear opportunities and guidelines for the involvement of those caregivers who wish to be involved in their youth's services, with flexibility to meet the diverse needs of all those involved. There must also be a structure in place to guide conversations with the youth about caregiver involvement in order to come to person-level decisions that best meet everyone's needs.

4.1 Limitations

While the online survey was open to any caregivers of youth with mental health or substance use challenges across Ontario, it did not specifically utilize a strategy to recruit a sample representative of the population of Ontario caregivers, and the results may therefore not be generalizable; however, consistency with previous research suggests some level of generalizability. Despite substantial intersectionality in demographic profiles, a larger, more diverse sample would provide more information about the preferences of different subgroups. Caregivers without internet access would not have been reached by the current study. It is important to note that these findings represent the service priorities of predominantly educated and financially stable, Canadian-born, Caucasian female caregivers with internet access. Future research should examine the preferences of other population subgroups from an equity and diversity standpoint.

In addition, the strengths of the relative preferences is dependent on the service characteristics that comprised the DCE attributes and levels. While a substantial development process took place, it is possible that some priorities were missed, and overlap between attributes and levels may have influenced the findings. For example, the levels representing the types of core health services progressively built on each other, which may have affected the ability to detect specific preferences for one specific service component. In addition, priorities for service characteristics may change sustainability due to the effects of the COVID-19 pandemic, which is currently having major impacts on service design models and exposing youth and caregivers to new service models.

5 Conclusions

Understanding caregiver preferences is important in designing services that youth will access and benefit from. While caregivers have a diversity of preferences, considering the role of the caregiver in the services is an important aspect of these services. Providing easy-to-access services that address a range of youth needs and acknowledge the role of caregivers in the youth's care is important. System designers and service providers are encouraged to take caregivers' relative priorities into account, alongside youth priorities, when designing service delivery models and when developing service plans for an individual youth.

Declarations

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