

THEME ARTICLES:

A Qualitative Study of Young People's Perspectives on Receiving Psychiatric Services via Televideo

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Abstract

Objective: It is critical to consult young people about their experiences. This study addresses the paucity of research on the perspective of young people in general, and in paediatric telepsychiatry specifically. The goal is to understand the experience of young people receiving telepsychiatry. **Method:** Interpretive interactionism (Denzin, 1989) was used to interview 30 young people; immediately following the consultation and four to six weeks later. Analysis occurred via a series of steps in keeping with the interpretive interactionist framework. **Results:** Four themes arose repeatedly: the encounter with the psychiatrist and experience of having others in the room; the helpfulness of the session; a sense of personal choice during the consultation; and, the technology. Participants highlighted the importance of their relationship with the psychiatrist. Participant's narratives were replete with examples of ways that they actively took responsibility and exerted control within the session itself. **Conclusion:** Young people have a significant role to play in their own care. It is critical that telepsychiatry recommendations be explained and opportunities for young people to express their concerns and discuss alternatives are provided. Further efforts to include young people may include ensuring offering alternate treatments and/or negotiated when recommended treatments are unacceptable and/or resisted.

Key words: telepsychiatry, qualitative, televideo, interpretive

Résumé

Objectifs: Interroger les adolescents sur leur expérience. Constaté la rareté des travaux de recherche sur l'expérience des adolescents de la psychiatrie en général et de la télépsychiatrie en particulier. Présenter l'expérience des adolescents et adolescents qui reçoivent des services de télépsychiatrie. **Méthodologie:** Les données recueillies après interrogation de trente sujets ont été interprétées au moyen de l'approche interactionniste (Denzin, 1989), immédiatement après la consultation et quatre à six semaines plus tard. **Résultats:** Quatre thèmes revenaient régulièrement: la rencontre avec le psychiatre et l'expérience découlant de la présence d'autres personnes dans la salle; l'utilité de la session; l'impression de choix individuel pendant la consultation; la technologie. Les participants ont souligné l'importance de leur relation avec le psychiatre. Leurs narratifs comportaient souvent des exemples de la manière dont ils assumaient activement la responsabilité de la session et se l'approprièrent. **Discussion:** Les adolescents et adolescentes ont un rôle important à jouer dans leurs soins. Il est essentiel de leur expliquer les recommandations de la télépsychiatrie, de leur permettre d'exprimer leurs inquiétudes et de leur présenter les choix qui s'offrent à eux. Les futures études pourront porter sur les autres traitements et/ou sur les négociations lorsque les adolescents et adolescentes refusent les traitements recommandés ou font preuve de résistance à leur égard.

Mots clés: télépsychiatrie, qualitatif, télévidéo, interactionnisme interprétatif

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Background

Canada's child and youth mental health system has been described as fragmented and underfunded with a significant shortage of mental health professionals (Kirby & Keon, 2006). This is problematic as prevalence rates of psychiatric disorder in community samples of children and adolescents range from 15-25 percent (Parker, Steele, Junek et al., 2003). Rural and northern communities, in particular, suffer from a severe shortage of psychiatric expertise (Parker, Steele, Junek et al., 2003; Broder, Manson, Boydell et al., 2004). Geographic and professional isolation make rural communities less attractive to mental health workers, and it is a challenge to recruit and retain specialists, who tend to concentrate in larger urban locales (Boydell, Pong, Volpe et al., 2006). Most rural communities are too small to sustain highly specialized personnel. Consequently, the delivery of mental health services using new technologies is a

growing area of practice and research interest. Telehealth has been used in therapy, triage, and medicine in addition to psychiatric consultation, and by a broader range of mental health professionals, not just psychiatry. (Lingely-Pottie & McGrath, 2006; Reed, McLaughlin & Milholland, 2000). Telemedicine has been used in child and youth mental health services around the world and has been shown to fill a service gap inherent in remote and rural regions (Cruz, Krupinski, Lopez et al., 2005; Elford, White, Bowring et al., 2000; Meyers, Valentine & Melzer, 2007, 2008; Pesamaa, Ebeling, Kuusimaki et al., 2004).

Of particular note in these studies is the marked absence of the voice of young people. One exception is Grealish et al.'s (2005) study that examined adolescent perspectives regarding the quality of inpatient assessments and support via videoconferencing. Adolescents described heightened empowerment when using the equipment, and felt that they were spoken "to" rather

than “at”. They reported that telemedicine promoted the transfer of power and control by making them feel more comfortable about ending the consultation or walking out. They found the process more structured and felt better informed, which resulted in enhanced understanding of their problems and increased participation in health-care decision-making.

The importance of consulting young people about their experiences is identified in the literature on paediatric mental health services, and there is a growing commitment to listening to their voices (Borland, 2001; Buston, 2002; Claveirole, 2004). Traditional perspectives conceptualize young people as developing beings who are not yet able to speak in their own voices (Balén, Holroyd, Mountain et al., 2000). This perspective has led to data being collected either by proxy, from adults close to the child, or via objective measures where the child remains passive (Balén, Holroyd, Mountain et al., 2000; Claveirole, 2004). Although this approach has its place, it is controlled by adults and neglects the competence of young people to contribute. More recently, it has been recognized that children need to be given the opportunity to share their feelings and wishes about issues affecting them (Gladstone, Boydell & McKeever, 2006; Irwin & Johnson, 2005). This study addresses the significant gap in the literature, namely the paucity of research that focuses solely on perspectives of young people in research generally, and in paediatric telepsychiatry research specifically. The goal is to understand the experience of young people receiving psychiatric services through a paediatric telepsychiatry program. The Toronto Paediatric Telepsychiatry Program (TPTP) was initiated in 2000 by the Division of Child Psychiatry at the University of Toronto. The program is funded by the Ministry of Community and Social Services (currently the Ministry of Children and Youth Services) to function through The Hospital for Sick Children (SickKids). This Program uses televideo to provide psychiatric consultations, case consultations (professional-to-professional) and education to children’s mental health agencies (CMHA) and their clients in rural and remote Ontario. The mandate of the program is to provide bilingual (English and French) psychiatric consultations and education to under-served children’s mental health community agencies and their clients, utilizing interactive videoconferencing technology (ITV). As an academic site within the Division of Child Psychiatry at the University of Toronto, SickKids is also required to fulfil clinical, teaching, and research mandates.

Clinicians at the CMHAs are responsible for referring a young person for a consultation through SickKids. Referrals are typically not accepted directly from physicians. During the consultation, the young person’s case manager must be present to ensure that knowledge between the consultant and the young person is exchanged effectively, and for legal prudence. The consultant provides verbal feedback and recommendations at the end of the young person’s consultation, and a

written report is sent to the agency soon afterwards (Boydell, Volpe & Pignatiello, 2009; Pignatiello, Boydell, Teshima et al, 2008). The goal of this study was to explore the young person’s perspective on the experience of the psychiatric encounter, positive and negative aspects of receiving psychiatric services via televideo, and technological issues.

Methods

An interpretive interactionist framework was used to guide the study (Denzin, 1989). Interpretive interactionism is both a perspective and a method, and seeks to highlight the lived experience of individuals, collected through thick description and personal experience stories. A major aim of the interpretive interactionist researcher is to identify the subjective meanings of the individual positioned within a social context. Like other qualitative research methodologies, the epistemological posture taken by interpretive interactionism questions the possibility of value free inquiry, an objective researcher, and interpretation based on causality (Guba, 1990; Lather, 1990). It assumes that knowledge is socially constructed and the concept of truth depends on the perspective one takes in interpretation (Greene, 1990; Lincoln, 1990).

Study sites included seven rural and remote community child and youth serving mental health organizations in Ontario receiving paediatric telepsychiatry services. A theoretical approach to sampling was adopted using the following criteria: (a) young people aged seven to 18 years; (b) English or French speaking; (c) no history of Pervasive Developmental Disorders; and, (d) distribution across geographical regions. Thirty participants¹ were successfully recruited, 21 of whom completed a second interview. The age and sex of the participants are shown in Table 1. Eight participants had received a previous psychiatric consultation.

The most frequent reasons for scheduling the telepsychiatry consultations were: querying the existence of a psychiatric disorder, medication suggestions or reviews, and dealing with aggressive behaviours. Participants either had a previous diagnosis confirmed or, more often, a diagnosis applied for the first time. The following diagnoses were confirmed: Oppositional Defiant Disorder (n=13), Attention Deficit/Hyperactivity Disorder

Table 1. Interviews: Participant Age and Sex
(Parentheses indicate number of second interviews completed)

AGE	MALE	FEMALE	Total
7-12 years	8 (6)	3 (1)	11 (7)
13-18 years	9 (6)	10 (8)	19 (14)
Total	17 (12)	13 (9)	30 (21)

¹A decision was made to halt recruitment after 30 interviews as saturation of thematic content had been achieved.

(n=9), Mood Disorder (n=9), Learning Disability (n=5), Anxiety Disorder (n=4), Conduct Disorder (n=4), Attachment Disorder (n=3), Developmental Disability (n=2), Fetal Alcohol Syndrome/Fetal Alcohol Effects (n=1), Personality Disorder (n=1), Psychotic Disorder (n=1), and Adjustment Disorder (n=1). More than half (16 of 30 participants) had more than one identified disorder. Two participants were noted to have substance abuse and dependence concerns. Thirteen participants also had psychosocial issues regarding relationship problems (n=9) and problems of abuse and neglect (n=6), with two participants having both of these as listed concerns.

An interview guide was developed (McCracken, 1988; Gubrium & Holstein, 1997) to obtain the perceptions and experiences of participating in a paediatric telepsychiatry consultation. Two interviews were scheduled with each young person. The first interview was conducted face-to-face between the young person and the researcher and took place immediately following the consultation. It was intended to solicit immediate responses and impressions of the telepsychiatry session. Second interviews were conducted via telephone 4-6 weeks later, after some time had passed. The most common reason for incomplete second interviews (N=9) was an inability to contact the young person due to a change in telephone number, a move out of the community, or unreturned phone calls, despite several attempts. Three participants in the study declined a second interview. All interviews took an average of 30 minutes to complete.

All interviews were audiotaped and transcribed verbatim. Transcripts were analyzed via a series of steps – bracketing, construction and contextualization – in keeping with the interpretive interactionist framework (Denzin, 1989). Bracketing involves isolating the essential elements under investigation. Data were bracketed by repeatedly reading transcripts in order to develop a detailed coding system. Analysis meetings ensued to discuss the categories identified and agree upon common terms. The next stage, the process of construction, classifies orders and reassembles the phenomenon back into a coherent whole. This involved taking some of the more discrete categories or codes (such as psychiatrist understanding of problems, valued qualities in the psychiatrist) and reassembling into a larger analytic category (such as comfort with the psychiatrist). Contextualization, a process in which greater meaning is sought across individual experiences, followed. Strategies to ensure procedural rigor included prolonged engagement with the study material, sampling to saturation, an audit trail, reflexive journal, and peer review in the form of regular co-investigative meetings (Erlandson, Harris, Skipper et al., 1993).

Results

Four key areas arose repeatedly in the analysis of transcripts: the encounter with the psychiatrist and the experience of having others in the room; the perceived

helpfulness of the session; a sense of personal choice and individual responsibility (or lack thereof) during the consultation; and, the technology itself as a key aspect of the psychiatric consultation.

The Encounter

An important objective of the interview was to identify perspectives regarding the televideo encounter with the psychiatrist delivering the consultation. Many references were made to the expertise of the psychiatrist, his/her valued qualities, the fact that the psychiatrist listened to them and “did their homework”. Several commented that they felt that they were able to “open up” despite admitting that they don’t usually talk about their personal troubles.

It was nice to actually get to talk to somebody, like somebody professional about what's going on and what I might be able to do to make things easier on myself.
(F, 15)

Though initial discomfort with the technology was the principal source of anxiety for young people, the experience of meeting a psychiatrist seemed to make some participants nervous as well. This was often related to their fear that they would get into trouble if they said something “bad”. However, invariably, this had a temporal aspect to it as levels of discomfort were replaced by comfort fairly quickly and most certainly by end of session.

Young people seemed divided about having others in the room with them at the time of the consultation. As mandated by the Paediatric Telepsychiatry Program, every young person is required to have an agency-based case manager present during the consultation (as the official ‘client’ of the telepsychiatry program), but many also have their parents and/or other family members with them, as well as school personnel (e.g. teacher, principal). Some young people spoke about being uncomfortable with other people in the room at the time (despite the fact that their consent was often obtained beforehand) and indicated that they wanted to keep their discussions private.

I didn't like the fact that my parents were there. I don't know, there were some things that I would have preferred discussing without my parents' presence.
(F, 13)

Others found it reassuring to have people present with them, often explained to be a result of feeling supported by a positive figure during the stressful consultation.

Helpfulness

Young people discussed the degree to which they found the telepsychiatry consultations helpful. Responses ranged from those who felt that the consultation had been very helpful, to those who were more equiv-

ocal, finding it of limited value to themselves, or uncertain about its overall or long-term helpfulness. The opportunity to release pent-up emotions and thoughts, and having them understood by the psychiatrist were identified as being important. Others noted that the psychiatrist's ability to listen without being judgmental was a positive aspect of the consultation.

I felt that I was able to open up. I usually don't talk about that kind of thing. (F, 15)

Many participants who found the session helpful mentioned new knowledge gained around diagnosis, medications, and advice and coping mechanisms.

I think he understood me really well because at the end he did a whole summary of what we were talking about and my experiences and that, and he just got it right on. (F, 18)

In their second interview, young people often identified that they had the opportunity to use coping strategies suggested in the consultation.

Whenever I'm getting in an argument, I just try to walk away and play with another one of my friends...and, I haven't wrecked my room in a very, very, very very, very long time. (M, 8)

Some participants believed that the session might be helpful for others who were in the room during the consultation, but not necessarily for them directly. They mentioned that their parents or case workers may have benefited from increased insight into the issues they were grappling with. In cases where young people believed their session to be of limited helpfulness, their reasons included the single-session consultation model, as well as the associated relatively short period of contact with the psychiatrist during the consultation, which is typically 1.5 hours in length. They acknowledged that they can feel different from day-to-day and these mood shifts would be difficult for the psychiatrist to understand in a single meeting ("especially for teenagers, we're in different moods everyday"). Many indicated that this brief encounter did not allow sufficient time to form a helping relationship. As noted by one 14-year old female,

You don't really know the person. You can't really judge by that...how can you help someone that you don't really know?

There was often contradiction in the narratives, wherein they initially stated that the consultation was unhelpful, but would later identify components which they believed might have been helpful. One example comes from an interview with an 18-year old female, who early in the interview noted,

Well, I think it could be useful but it would have to be more repetitive because just an hour, it's not enough. It didn't help me.

This participant later went on to acknowledge: I don't think it was completely not useful...like for some points it was useful...because I knew I would not have other contact with her, I could ask her some direct questions.

For some, it was difficult to ascertain what they thought of the experience and its overall or long-term helpfulness. One 16-year old male alluded to the potential helpfulness of the session when he stated that, "it could help". Uncertainty was often related to denial of a problem in the first place. This lack of knowledge (or acknowledgement) of the problem was also evident in other interviews, as was the tendency to minimize the problem, as one 14 year old female stated "well compared to what we see everywhere, and what I know about other people, things like that. According to me, my problems are not as important as a lot of people."

In the first interview, conducted immediately following the telepsychiatry session, the recency of the consult made it difficult for young people to state whether or not it had been helpful. As one participant reflected, "Well it did not bring me further, but... I don't know if it helped me so far, I don't know sometimes just talking about it is helpful, but it's too recent for me to tell if it helped." (F, 18). At the time of the second interview, many youth remained uncertain of the helpfulness of the experience. Some, particularly younger ones, stated that they had forgotten all about the consultation and required several probes to stimulate their recall.

Personal Choice

A recurrent theme throughout the interviews was the sense of personal choice and responsibility (or lack thereof) and the importance of feeling in control during the session. Young people's narratives were replete with examples of the ways in which they were able to exert 'control' within the encounter.

If you don't want to talk about this subject, you don't talk about it. (F, 14)

Many participants indicated that they were opposed to taking medication and, in fact, chose not to follow through on recommendations made in this area.

She recommended medication, but I don't want that. I don't want to be like strange because I never liked feeling different...always trying to blend in with my friends. (M, 13)

Some young people described their feelings of lack of control over the situation, as a result of being coerced to attend the session, or feeling that they could not speak up during the encounter to voice their opinion, particularly when they did not agree with someone in the room.

The Technology

The majority of participants expressed excitement in

recalling the experience of speaking to a psychiatrist over televideo, and suggested that the novelty of the experience was the “*best part*” of the process. “*Cool*” was used repeatedly in the interviews to describe the overall experience with telepsychiatry. Participants were enthusiastic about the technology’s ability to connect them, both aurally and visually, with someone relatively far away. As one young person expressed,

I got to speak to the um, I got to speak into a T.V. and um, talk to someone and that, I've never really done that before and it was so exciting to do it. (M, 8)

Several participants alluded to the fact that the consultation caused them to feel somewhat “*removed*” from the process, likened to “*feeling like watching a show*”.

You kind of zone out because you think he's not always there, like, you think he's just a television program. (M, 13)

Many articulated their preference for the consultation to be held over televideo, suggesting that this format alleviated some of their anxieties regarding the meeting. They explained that meeting mental health professionals in person is intimidating, arousing more anxiety than what they had experienced during the consultation over televideo.

It's sure that face-to-face is harder according to me because she's right there and on the T.V. you can say like I don't mind, you don't know her and you won't see her again. I prefer it that way.” (F, 17)

Participants also identified the benefit of having the psychiatrist in a distant location, making it unlikely that they would encounter the doctor in their community, close to home. In the words of the previous participant, “*You won't see her in town!*” (F, 17). Some believed this anxiety arose from the fear of “*judgements*” being made by the psychiatrist and meeting over televideo seemed to dampen their concerns regarding this.

Participants made only very brief comments about the quality of the technology during the session. Some spoke about difficulties with picture and sound quality, but most problems were considered to be short in duration. Even when the duration was longer than several minutes, participants did not seem to believe that these difficulties adversely affected the session as a whole.

Discussion

These results offer important messages for all [child] psychiatry encounters/consultations. In talking about the telepsychiatry session itself, all participants highlighted the importance of the relationship between the psychiatrist and young person. Shattell and colleagues (2007) noted three commonalities with mental health service recipients’ expressions of elements of a positive therapeutic relationship: feeling “*related*” to (interpersonally

connected), feeling “*known*” as a person (as opposed to a number, diagnosis, etc.) and feeling that the problems which brought the clients into care were being addressed. Young people in our study identified these factors as being critical to a successful telepsychiatry session.

The young people who indicated that their session was helpful identified the psychiatrist’s expertise and ability to make recommendations, concrete suggestions for coping with presenting symptoms or issues, and understanding the problem or issue being discussed. They explained that they appreciated the opportunity to release pent-up emotions and express them to someone who was listening. Much like the questionnaire responses presented by Grealish and his colleagues (2005), young people also noted that they felt understood and respected by the psychiatrist, and felt they had a better understanding of their problems.

Some young people expressed reservations about the degree of helpfulness of their telepsychiatry consultations. This was directly associated with the temporal aspect of the consultation, namely, that it was one-time only. Participants suggested that more than one meeting with the psychiatrist would allow the psychiatrist the opportunity to understand them better, provide a more informed perspective of what is going on in their lives and their issues before being provided with a diagnosis and/or recommendations for treatment. Shattell and colleagues (2007) also noted the essential need for service providers to take time with care recipients. Those who believed that the consultation was helpful often noted that they felt respected and understood by the psychiatrist, but many expressed that they were unsure that it was going to be of help to them because it was a one-time event. They often believed this to be the case because of a lack of regular and ongoing contact with the psychiatrist. This suggests that the relationship between the young person and his/her consulting psychiatrist needs time to develop, ideally by including multiple sessions.

It is important to also highlight youth comments regarding the room layouts, ambience, etc as these are concrete suggestions that can be readily addressed. Action has already been taken vis-a-vis making changes to the physical and aesthetic structure of the video conference rooms in keeping with suggestions of young people. For example, they requested that the set up be less formal and that the table between the televideo and themselves be removed. Young people are routinely exposed to the room and the technology before the consultation session, and consultants are encouraged to provide some information about themselves as ‘a person’.

Participant’s narratives were replete with examples of ways that they were able to actively take responsibility and exert control within the consultation session itself, whether it was offered to them or not. Grealish and colleagues (2005) noted that young people found that telemedicine promoted the transfer of power and control

by allowing them to feel more comfortable about ending the consultation or walking out. The sense of feeling that they could leave at any time was also expressed by a few participants in this study. Young people also demonstrated their capacity for decision-making regarding the uptake of recommendations made for them. As Prout (2000) suggested, children are actors participating in social processes, and are not simply outcomes of these processes. He states that 'whilst, like all social actors, children can be seen as shaped and constrained by the circumstances of their lives, they also shape them and are enabled by them. They are limited by the social conditions of their lives, but also find ways of creatively managing, negotiating and extending the possibilities' (p.7).

The denial of a problem by some young people may represent an attempt to feel in control of the situation or perhaps could be a response to the stigma related to mental illness. It is possible young people are in denial, but it is also possible they simply disagree with how adults have defined the problem, or responded to it. This suggests that an emphasis be placed on asking young people about the ways in which they define the problem, recognizing and accounting for the issue of stigma and discussing it with them. An inclusive view of children must address the issue of their perspectives and their needs and desires; 'the right to have [their] definition of reality prevail over other people's definition of reality' (Rowe, 1989, p.16). This encapsulates the typical power relationships between adults and young people, that is, it is the adult view of the world that is most frequently the framework for understanding (John, 2003, p.47).

This study supports earlier research on uptake of telepsychiatry recommendations which addressed the importance of buy-in from both family members and young people themselves (Boydell, Volpe, Kertes et al., 2007). Clearly, young people have a significant role to play in their own care, including adherence to suggested medication. It is thus critical that such recommendations be thoroughly explained and that there is an opportunity for young people to openly express their concerns and discuss possible alternatives. Further efforts to include young people may include ensuring alternate treatments are offered and/or negotiated when recommended treatments are not acceptable and/or resisted.

Young people in this study explained that the most positive facet of their telepsychiatry consultations was the opportunity to be exposed to a new form of technology. They referred to the novelty of the experience as the "best part" of the process for them and repeatedly used the term "cool" to describe their encounter. Consequently, it would be useful to capitalize on the novelty aspect by highlighting the cutting edge technology used in the session. Although some young people were initially uncomfortable with the technological aspect of the consultation, they noted that this feeling abated very quickly, after about ten to fifteen minutes. After this period, par-

ticipants indicated that the technology was the most positive aspect of their consultation. Some also expressed an initial discomfort and sense of nervousness regarding meeting the psychiatrist, however, very basic strategies for overcoming this, such as having the psychiatrist talk to the young person directly about non-mental health related issues and some information about the psychiatrist as a person, could help alleviate this nervousness.

Since this is the first study we know of to qualitatively explore the perspectives of young people who receive help via a paediatric telepsychiatry program, further studies need to be undertaken with young people in other geographical locales and cultural contexts. For example, conducting qualitative inquiry with a sole focus on young Aboriginal people who receive help through this program, as well as recruiting a sample of individuals who live in more remote communities, would be a fruitful next step in understanding how young people view being a part of these consultations. The adult telepsychiatry literature (e.g., Shore, Savin, Novins et al., 2006) suggests that cultural formulations during telepsychiatry consultations may require the psychiatrist to attend to different types of concerns and questions.

Given that many of the research interviews were of limited duration and younger participants in particular often indicated that they were ready to terminate the interview soon after it began (are we done yet? and can I go now?), it might be fruitful to explore new methodologies that offer more opportunities for engagement. Our own recent (as yet unpublished) experience with arts-based methods indicates that many young people find working with the arts as a way of exploring phenomena under study highly satisfying. Another area of research could employ qualitative methodology to explore the similarities and differences between young people's experiences of conventional, face-to-face psychiatric consultations with those conducted over televideo. This might provide researchers and practitioners a more specific understanding of how the technology itself influences the manner in which young people are involved in these consultations.

Recent data has shown that parents endorsed high satisfaction with their children's telepsychiatric care, with increasing satisfaction upon return appointments (Myers, Valentine & Melzer, 2008). This, coupled with our findings that there is a strong desire on the part of young people to have a more extended relationship with the psychiatrist, suggests the need to further explore this option. In addition, longitudinal investigations are needed to understand the temporal nature of telepsychiatry on young people, their families and the communities served. It would provide an opportunity to address the multiplicity of factors in the lives of young people, of which telepsychiatry is just one component.

Acknowledgements/Conflict of Interest

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