

Real-Time Needs, Real-Time Care: Creating Adaptive Systems of Community-Based Care for Emerging Adults

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ABSTRACT

Research indicates a decline in mental health service utilization between the ages of 16 to 25, leaving emerging adults with mental illness at risk for worsening outcomes. The authors utilized a community-based participatory research (CBPR) approach to explore the mental health landscape for youth aged 16–25 in London, Canada. Interviews and focus groups ($n = 30$) with community and hospital system leaders, youth and caregivers were transcribed and coded using an approach informed by constructivist grounded theory. There was consensus regarding difficulties in the current system including wait times and crisis-driven services leading to powerlessness among youth and caregivers. Solutions include delivery of services through a flexible, real-time system that emphasizes patient and caregiver engagement, youth centric services and recovery-oriented care across the hospital/community continuum. The results highlight that disparate stakeholders agree regarding the need for transformational change shifting away from traditional medical models.

Keywords: transition, youth, emerging adult, community, youth engagement

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RÉSUMÉ

La recherche montre une baisse de l'utilisation des services de santé mentale chez les jeunes de 16 à 25 ans : les adultes émergents qui vivent avec une maladie mentale sont donc à risque de se retrouver avec des problèmes toujours plus graves. Les auteurs de cet article présentent la recherche participative communautaire qu'ils ont menée pour explorer la situation des jeunes de 16 à 25 ans, à London, en Ontario, en matière de santé mentale. Ils ont réalisé des entrevues et mené des groupes de discussion (n=30) avec des responsables de la communauté et du système hospitalier, avec des jeunes et avec des personnes soignantes ; ces conversations ont été transcrites et encodées à l'aide d'une approche qui s'appuie sur la théorisation ancrée constructiviste. Les auteurs ont observé un consensus en ce qui a trait aux difficultés qu'entraîne le système actuel, comme les longs temps d'attente et le fait que les services sont surtout offerts en cas de crises, ce qui laisse les jeunes et les personnes soignantes avec un sentiment d'impuissance. Pour régler ces problèmes, il faudrait que les services soient offerts grâce à un système flexible qui répond aux besoins au moment où ils se posent et qui met l'accent sur la participation des jeunes et des personnes soignantes ; ces services devraient également être axés sur les jeunes et sur le rétablissement, et offerts à la fois dans les hôpitaux et dans la communauté. L'étude montre que les différents participants et intervenants s'entendent sur le fait que le système actuel, basé sur les modèles médicaux traditionnels, doit être modifié pour s'en éloigner.

Mots clés : transition, jeunes, adultes émergents, communauté, participation des jeunes.

Mental disorders comprise a significant burden of illness for Canadians between the ages of 16 and 25. An estimated 10–20% of Canadian youth and young adults are affected by a mental illness or disorder—the single most disabling group of disorders worldwide (Canadian Mental Health Association, 2015). The mental health of emerging adults (EA) is a unique issue due to the developmental vulnerability to psychiatric disorders during this period. At least 75% of mental health concerns begin in childhood, adolescence or young adulthood and mental health and addictions issues lead to limited participation in the workforce and an increased economic burden (Carver et al., 2015). EA with psychiatric disorders between the ages of 16 and 25 face a fragmented system that does not adequately support either those transitioning from child and adolescent to adult systems or those experiencing the onset of psychiatric illness (Cairney et al., 2015). There is also a lack of successful engagement and retention of EA (Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008), compounded by a lack of coordinated strategy to address this issue (Mental Health Commission of Canada, 2015b). For example, Canada lacks a country-wide strategy to help these EA and no province or territory has implemented transition protocols or mandated specialist services for this population (Canadian Mental Health Association, 2015).

Despite the disproportionate impact of mental disorders on this population, there is little research on the service gap for EA, which include both transitions and first episode presentations (Sukhera, Fisman, & Davidson, 2015). Existing research has explored transition models for youth between child and adolescent and adult systems of care (While et al., 2004; Hovish, Weaver, Islam, Paul, & Singh, 2012; Muñoz-Solomando, Townley, & Williams, 2010; Cappelli et al., 2014; Singh, 2009; Singh, Paul, Ford, Kramer, & Weaver, 2008) or exclusively focused on first episode psychosis presentations (McGorry, Killackey, & Yung, 2007; Mihalopolous et al., 2007). While studies have examined models of care for first episode mood and anxiety

(Osuch, Vingilis, Fisman, & Summerhurst, 2016), there is little research on patient experience and engagement of hospital and community sectors as related to mental health services for emerging adults.

Since effective user engagement is considered an essential element of developing mental health services for EA (Carver, Davidson, & Cappelli, 2011), user-led system improvement is an important area for exploration for this population. Several health system leaders have called for leveraging health service change through social movements and “bottom-up” approaches (Bate, Robert, & Bevan, 2004). Existing literature on patient engagement in mental health system design is specific to either pediatric or adult systems, and fails to capture a broad cross-section of youth, caregivers, service providers, and system leaders across hospital and community sectors.

Multiple authors have described how user-led service redesign benefits participants and communities (Davidson et al., 2010; Pelletier, 2014; Pelletier, Rowe, Francois, Bordeleau, & Lupien, 2013). Community-based participatory research (CBPR) is a useful method to engage disparate stakeholders and transform mental health practice. CBPR aims to equalize the power structure and facilitate an action-oriented research process. It stresses social action and change and is an ethical approach to research within the historical context of discrimination against disadvantaged communities (Israel, Eng, Schulz, & Parker, 2005). CBPR has been successfully adapted for health services research with underserved populations (Pieh-Holder, Callahan, & Young, 2012; Tataw, Bazargan, & James, 2011). A review of CBPR in child health found that it offers a unique approach for translating evidence-based models and research into effective and sustainable interventions (Vaughn, Wagner, & Jacquez, 2013). This study utilizes CBPR to explore system leader, youth, and caregiver perspectives on the system of care for EA between the ages of 16–25 with mental health challenges who are either transitioning from child and adolescent to adult systems of care or experiencing a first episode of illness. Our goals included engaging service users, caregivers, community/hospital providers, and leaders in consultation regarding mental health system redesign.

METHODS

Setting

The study takes place in a mid-sized Canadian community with numerous community-based mental health agencies and a large academic health science centre.

Design

As part of existing efforts to improve community and user engagement in mental health service design, hospital-based mental health leaders consulted with key informants from the community service sector, community mental health agencies, education and health sectors utilizing a CBPR framework. An advisory council was formed with broad representation which conducted an informal needs analysis, identifying the need to further explore and engage around the specific issue of EA mental health services. The council assisted in developing the study design and sampling strategy and was consulted regarding key discussion questions, providing regular feedback during the process of analysis and interpretation.

Since CBPR emphasizes an equal partnership between researchers and community members, gaining the trust of the community is a common challenge (Christopher, Watts, McCormick, & Young, 2008). At every step of the process, the researchers acted respectfully towards community members as key informants and considered local tensions and hierarchies. These included funding differentials between hospital and community mental health sectors as well as privilege and power differentials among researchers, providers, and study participants. The team strived for a cooperative relationship between researchers and the community. Researchers advised participants that an analysis of their responses would be presented to them for further input, and that their participation would inform the design and implementation of change efforts. This was achieved by regular advisory council meetings and one-to-one consultation with key informants. The research team emphasized that authentic engagement of community and user perspectives was a core philosophy that guided their work and were informed by existing research on youth engagement including Roger Hart (2013).

Our study was also informed by constructivist grounded theory. Constructivism assumes that people, including researchers, construct the realities in which they participate, and grounded theory is a way to learn about the worlds we study and a method for developing theories to understand them (Charmaz, 2014). Constructivist grounded theory provides a useful approach to learn about service challenges and build theory to inform change (Charmaz, 2014). We felt that CBPR and constructivist grounded theory were complementary approaches that aligned with our efforts to promote partnerships between researchers and community members.

Participants and Recruitment

Representation from several groups was sought to gain a broad perspective of the scope and nature of mental health services for EA with input from the advisory council. Four core community agencies were identified along with a local academic health science centre and were engaged in the recruitment via multiple routes (e.g., posters, emails) of key informants from community and hospital systems, EA service users and caregivers. There was partial overlap between key informants involved in study design and EA service users and their caregivers. We excluded service users who were not between the ages of 16 and 25, and any service users or caregivers who were experiencing significant active mental health symptoms warranting inpatient hospitalization, were employed by the hospital organization, or could not communicate in English were also excluded.

The Research Ethics Board (REB) at Western University approved the study (#105552). Participant recruitment occurred between 2013 and 2015. Community and hospital agencies on the advisory council comprised the system leaders ($n = 5$). These agencies assisted in recruiting youth ($n = 16$) and caregiver participants ($n = 9$) through the dissemination of electronic materials and posters in high traffic clinical areas within both community and hospital settings. All participants ($n = 30$) were provided with a letter of information and an oral explanation of the study, including an explanation that participation was voluntary.

Throughout the study, findings were presented to several study participants by the study coordinator to engage in a triangulation process (Gilchrist & Williams, 1999). Overall, participants agreed with the findings.

Data Collection

Data collection included semi-structured, individual interviews with system leaders from community and hospital agencies ($n = 5$), youth service users ($n = 16$) with three focus groups (two with four participants and one with three participants) and five individual interviews, and caregivers ($n = 9$) with one focus group (with six participants) and three individual interviews. Service user and caregiver interviews were held outside of the hospital and during evening hours whenever possible. Participants were provided with nominal gift cards. Participants completed questionnaires to obtain basic demographic information. At the beginning of the sessions, the study coordinator read a standardized introductory statement and used a discussion guide that was adapted depending on the group involved. Questions centred around transition from child to adult services, first time mental healthcare experiences, ease of care access, avenues for change or improvement, experience with hospital admission, necessary components for youth-friendly care and what additional supports may be needed.

The focus groups and individual interviews were recorded using a digital audio recorder and transcribed utilizing a professional transcription service prior to data analysis. Before coding, all identifying information was removed from the transcripts and each participant was assigned a number.

Data Analysis

Once transcribed, the study coordinator reviewed the texts together with the audio recordings and notes taken during the focus groups to ensure that transcripts correctly reflected the focus groups and interviews. Strategies used in grounded theory analysis include the simultaneous collection and analysis of data, a two-step coding process, constant comparison, analysis through memo writing, and theoretical sampling to refine ideas, which all aid in concept development (Charmaz, 2014). According to Charmaz (2006), during the coding process, constructivist grounded theory was used to derive salient concepts. The authors individually coded transcripts and then met to reach consensus on their coding. Data was collected and analyzed through simultaneous coding until saturation occurred. Coding was completed by group, and key themes from each group were based on both frequency (within an interview and across participants) of the theme and frequency across participants. Prominent codes were consolidated and further organized into categories and subcategories. Codes were then developed into overarching themes and axial coding was conducted to explore relationships between themes using nVivo software (version 10). Reflexivity is a key component of many aspects of this study and includes examining how the researcher's interests, positions, and assumptions influenced their study (Charmaz, 2014). Care was taken to include a reflexive stance to inform how the researchers conducted their research, related to the research participants, and represented them in written report (Charmaz, 2014).

RESULTS

Limitations of Current System: Crisis Driven Access and Fragmentation leading to Powerlessness and Exclusion

There was overwhelming consensus across all participants regarding limitations of the current mental health system. Key areas of agreement included crisis driven access to care, hospital focused assessments/interventions, wait lists/times, lack of options, lack of choice, and lack of engagement.

Crisis driven access care, with the emphasis on hospital-focused intervention, was a key theme for all three participant groups:

...it's either a big admission to the hospital or be on your way. There is absolutely no middle ground. (EA service user)

We begged them [the hospital staff] to keep her. They would not. They said "has she ever tried to kill herself before?" No. "Oh well, that's what's required to get into be an inpatient." I was, like, really? Like you're going to wait for her to attempt that? (caregiver)

[It's] frequent trips to the hospital...and then they are discharged and they either don't access community supports [or] that they haven't been set up...[EA service users] keep accessing service because of emergencies...they stabilize and then they're out again and then it's, you know, repetitive, over and over again. (system leader)

Another key area of agreement was on the challenge of wait times to access services:

Everything was like a really long wait...and it [the waiting] was just really hard to do. (EA service user)

...there's this fantastic program that's going to change her world and it's going to be amazing...but we can't let you have it right now. (caregiver)

I think that our wait lists can really interfere with people being able to move forward with their own life goals. (system leader)

EA service users and caregivers reflected a feeling of powerlessness and exclusion that included not feeling helped, lack of choice, experiencing stigma, feeling judged, burden, frustration, and worry while reflecting the need for both self and parent/caregiver advocacy. When caregivers and their EA service users access mental health services, many left the encounter without having benefited.

Oh no, they weren't listening to me at all...It was, "we are the physicians, we are the nurses, we are the team and this is our job. We do this every day and how dare you to tell us how to do it." (caregiver)

I was struggling and I wasn't even getting any help so I just stopped attending. (EA service user)

Service users also often indicated they experienced stigma and felt judged:

I was a hundred percent honest with my doctor, too, and...it screwed me over because I was like, yeah, I am a user, and I'm an addict, and I don't want to be going through the sickness that I'm going through. And I said I would stop using if I had something to help alleviate the withdrawals...[but] when I was honest with them I felt like I was damning myself. (EA service user)

Parents/caregivers experienced a high level of caregiver burden, frustration, and worry while working through the system with their EA service user:

The doctors are huge, especially on the floor... [I said] “how dare you tell me that my son has been diagnosed; I make the diagnosis, I give the medication.” (caregiver)

Solutions Include an Adaptive Recovery-Oriented and Real-Time System of Care That Integrates Hospital and Community Sectors

While study participants described problems with the current systems, they also had innovative ideas about how to transform the system. A need for greater flexibility emerged as a key finding along with the concept of real-time immediate services as a necessary shift from the traditional medical model.

One system leader describes how their organization has become more flexible to better meet the needs of EA service users:

So we have changed the way we engage [with EA service users]. So instead of coming into programs and then the expectation is we meet you ongoing until you’ve met your goals, it’s when you need us. You connect, we rapidly engage with you and then disconnect, and when you need us you can re-enter. It’s a quick...re-engagement period for as long they need; it’s usually a situational crisis. (system leader)

The unique concept of real-time care was identified by both system leaders and caregivers as an innovation that can address service user needs:

It’s one thing to say “Okay, I have arranged somebody for you for next Tuesday at 11:30.” Well, before Tuesday chances are they’re not going to follow through, you know, unless you physically take them. (system leader)

Doing all the issues, and doing it real-time, that is the biggest thing; he was ready to go now. (caregiver)

System leaders and EA service users emphasized the recovery-oriented concept of involving youth in their own care and the effort required to develop a connection between youth and their provider.

I always say the most important person is the person who engages with you. And that’s not always the doctor or the nurse or the social worker... Really, what you need is someone to listen to you and validate your feelings. (system leader)

My overall experience getting help was difficult...but very helpful when I found a main doctor that didn’t change and was persistent. (EA service user)

In addition to youth/caregiver engagement, system leaders emphasized the need for youth-centric services and the use of peer support to enhance youth involvement in the system:

We need to repurpose certain programs, groups to be geared to be engaging with this population, and that means really changing how we deliver...that [it] is driven by the person, not by us as it meets our policies and procedures. (system leader)

Some people are going through the same things I’m going through and some people are going through even more. It gives me a good sense of reality a little bit, seeing that there are people out there like me. They are struggling with the same things I’m struggling with. (EA service user)

These services should also be community based with a strong relationship between the hospital and the community to provide services along the care continuum with lower level supports being available:

When I think about mental health, it's on a continuum and so there's a lot that would be happening in the community, hopefully, before they would land at our doors [at the hospital]. So I see us as owning a piece but not the whole thing. (system leader)

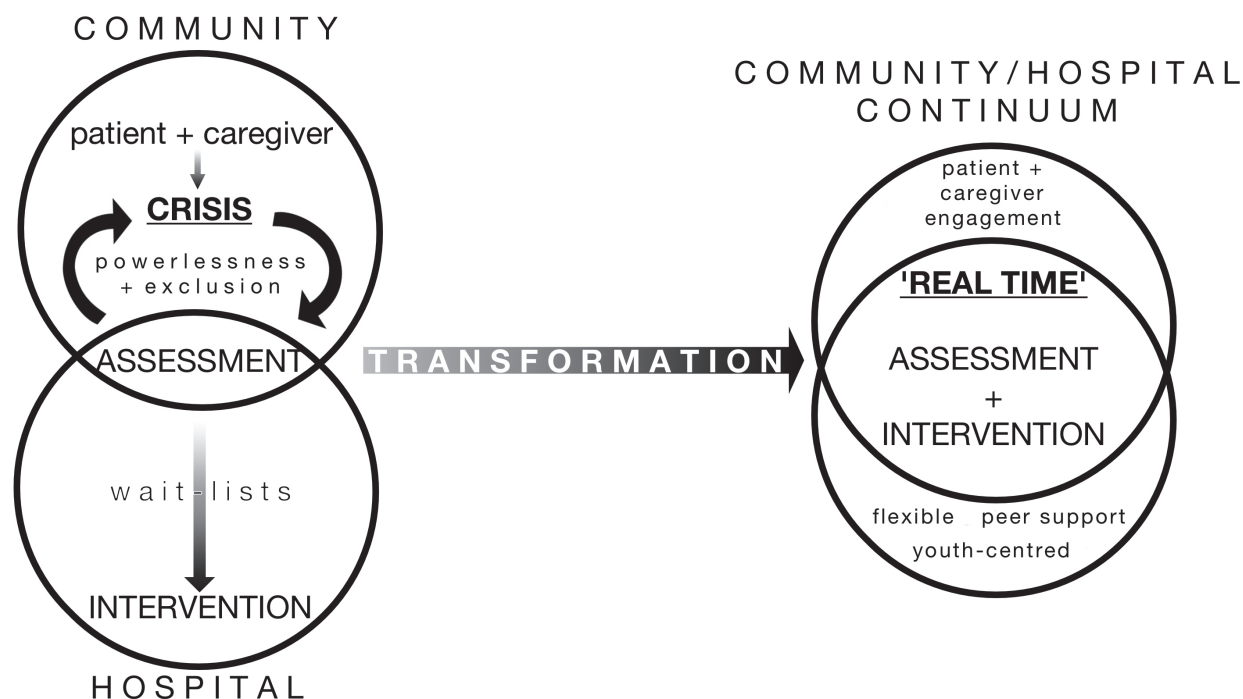
I would say that in an ideal world there wouldn't be any such thing as different mental health agencies, it would just be one cohesive thing and maybe there would be different locations... And if that's seeing a social worker once a week for coffee then that's seeing a social worker once a week for coffee. If you think you seriously need to be an inpatient [that would be available as well]. (EA service user)

DISCUSSION

Key findings in this study include broad agreement regarding difficulties that EA encounter in the current mental health system such as wait times, crisis-driven services, and feelings of powerlessness and exclusion among EA service users and caregivers. There is also agreement regarding the elements of ideal services including authentic youth/caregiver engagement and delivery of services through a flexible, real-time system of care that emphasizes prevention and recovery-oriented community-based services. The model derived from the results (Figure 1) can inform system redesign by highlighting features of the current system that can be ameliorated by a shift to a real-time adaptive model of care with improved community hospital integration.

Figure 1

Transformation to a Real-Time Adaptive Model of Care With Improved Community Hospital Integration



An existing model for prevention-focused and community-based mental health services is found in the literature on early intervention programs for psychotic disorders. Several authors suggest that the development of early intervention services that provide accessible and effective health care has the potential to reduce the burden associated with mental health problems (Chanen et al., 2009; McGorry, Killackey, & Yung, 2007; Stafford, Jackson, Mayo-Wilson, Morrison, & Kendall, 2013; Wade, Johnston, Campbell, & Littlefield, 2007). A successful example is the Australian National Youth Mental Health Foundation (Headspace), which is based on research evaluating early psychosis prevention programs and has demonstrated significant cost savings (McGorry et al., 2007; Mihalopoulos, Harris, & Henry et al., 2007; Mihalopoulos, McGorry, & Carter, 1999). Orygen Youth Health is a specialized version of a similar model in Melbourne, Australia (Ryall et al., 2008). Considerable funding was also required for implementation, which may limit the utility of this model in a chronically underfunded mental health system.

Our findings align with the concept of a recovery framework that can reform mental health systems of care. Recovery-oriented practice is a concept derived through input from individuals with lived experience with mental health problems and emphasizes multiple concepts that integrate towards user-centred service design (Mental Health Commission of Canada, 2015a). Health services with a recovery orientation are evaluated on several core domains including areas such as connectedness, hope/optimism, identity, meaning/purpose, and empowerment (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). When service users and health providers were asked about their perspectives on recovery-focused practice, they emphasized hope, person-centred care and consideration of service-user perspectives (Leese, Smithies, & Green, 2014). The Mental Health Commission of Canada (2015a) has affirmed that recovery involves a shift from medical models towards person-oriented care and authentic partnerships with individuals and communities. Such a shift complements a shift from hospital to community-based services and can help foster improved trust in order to address the powerlessness and exclusion that EA patients and their caregivers currently face.

Improving youth and community engagement was both part of our study process and results. According to Monson and Thurley (2011), consumer participation in EA mental health service design, delivery, and evaluation is an essential component of early intervention services. Research by Coates and Howe (2014) has found that EA engaging with mental health services generates benefits for both the EA and the community. In addition to fostering new skills and promoting social connectedness and self-efficacy, participation can promote social inclusion through supportive relationships, involvement in group activities and civic engagement (Glover, Robin, Emami, & Arabscheibani, 1998; Hayes, Gray, & Edwards, 2008; Walker, Verins, Moodie, & Webster, 2005). While traditional methods of emerging adults' participation in service design includes institutionally driven councils or advisory bodies, there is a risk of tokenizing youth participation (Matthews, 2001). Consideration of adult privilege is an important consideration that is relatively unexplored in health services literature. There is emerging research that suggests youth-centred models that address issues of power and hierarchy can challenge traditional discourses and lead to promising results (Bell, Vromen, & Collin, 2008; Black, Walsh, & Taylor, 2011; Howe, Batchelor, & Bochynska, 2011; Ramey & Rose-Krasnor, 2015). Improved engagement between and among youth, caregivers, and community and hospital providers is necessary to transform current models into an adaptive system.

Perhaps our most interesting finding relates to the concept of real time adaptive care. Research by England, Lester, and Birchwood (2009) suggest that developing flexible teams and organizations that are

responsive to youth's needs may be effective in addressing tensions between the child and adolescent system and the adult system. Our participants suggested that existing medical models with waiting lists and difficult to access services are not responsive enough to a generation of youth that look for immediately accessible and flexible services. Single-session and walk-in therapeutic models have demonstrated promising results (Barwick et al., 2013; Hymmen, Stalker, & Cait, 2013; Horton, Stalker, Cait, & Josling, 2012). Some research suggests that walk-in services may be uniquely suited to an EA population who are traditionally disengaged in services (Wilf-Miron, Sikron, Glasser, & Barell, 2002). Additionally, an explosion in smartphone technology has the potential to enhance real-time care by leveraging mobile mental health applications to improve clinical outcomes and engagement (Tourous, Staples, & Onnela, 2015; Hollis et al., 2015).

Our study has several limitations including the difficulty in recruiting caregivers and ensuring that our qualitative research approach recognizes sources of potential bias. Despite efforts to solicit an advisory committee with multiple stakeholder representatives, hospital-based staff conducted this study. We also recognize the considerable and daunting challenge of adult privilege and risk of tokenizing youth participation. Despite our best efforts, we also were unable to recruit any participants who reflect First Nations' perspectives or issues related to cultural complexity. While this manuscript was developed early in our work, this research has facilitated further engagement with participants and efforts to pilot innovative clinical services informed by user-input and participation that are, in turn, informed by the model derived from our results. Research is underway to evaluate the effectiveness of our pilot on consumer engagement and clinical effectiveness.

CONCLUSION

Achieving cultural change by challenging traditional discourse in system design is not accomplished easily. Transformational reform is required to foster authentic youth and community engagement and work towards a truly patient-centred system of care. Our study provides evidence that youth, caregivers, community and hospital leaders agree both on the challenge of EA mental health and the key elements of the solution. Imminent action is needed to implement innovative models of care for youth transitioning between child and adult systems and those with their first episode of psychiatric illness. Further research is needed specific to this EA population who are faced with a system of care that provides the least amount of support during a particularly vulnerable, developmental period. A better understanding of their challenges and robust evaluation of potential solutions may serve to create a system of the future that is responsive to their needs.

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