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# ORIGINAL ARTICLE

# 'Don't abandon me': Young people's experiences of child and adolescent psychiatric inpatient care supporting recovery described in blogs

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**ABSTRACT:** Child and adolescent psychiatric (CAP) inpatient care has the potential to support or hinder young people's mental-health recovery. Research describing inpatient care from the perspective of young people is rare. Personal blogs provide an opportunity to further understand how inpatient care relates to young people's recovery processes. This study aimed to explore young people's experiences of CAP inpatient care supporting mental-health recovery. The study is reported in accordance with the COREQ guidelines. Data were created during 2018 from twentyseven personal blogs describing first-hand experiences of being a patient in a CAP inpatient care facility in Sweden and analysed using a method for interpretive description. Information in blogs suggests they were written by women, a majority of which had experienced eating disorders. Findings describe young people's experiences of CAP inpatient care supporting mental-health recovery in an interpretive explanation with one theme, 'Don't abandon me', and three subthemes: 'Listen to me', 'Believe in me', and 'Allow me to feel safe'. This study adds to the growing body of empirical work suggesting the importance of the concept of recovery in young people's mental health. To support recovery, CAP inpatient care needs to focus on developing the content of care rather than minimizing the length of the stay. User experience should be at the heart of efforts aimed at improving services.

**KEY WORDS:** Blogs, Child and adolescent psychiatric care, Connectedness, Inpatient care, Mental-health recovery.

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## INTRODUCTION

This study used personal blogs to study experiences of child and adolescent psychiatric (CAP) inpatient care supporting personal recovery. Nurses in CAP inpatient care are responsible for establishing an environment that fosters self-management and is safe, structured, and supportive (Delaney 2017). Edwards et al. (2015) suggests that young people are at risk of dislocation and contagion when subject to CAP inpatient care. Inpatient care can hinder recovery as it contributes to stigmatization and difficulties in upholding and managing life outside the ward, and it can also be a place where young people develop harmful behaviours (Edwards et al. 2015). The application of the recovery

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model on young people's crisis care can be used to change an emphasis on shortening the length of stay in inpatient care to developing care focusing on respect and autonomy (Kaplan & Racussen 2013).

# Background

Young people's mental-health recovery

The concepts of personal recovery and recovery-oriented care are generating a growing amount of interest in the context of young people's mental health (Ballesteros-Urpi et al. 2019; John et al. 2015; Kaplan & Racussen 2013; Kelly & Coughlan 2019; Law et al. 2020; Naughton et al. 2020; Rayner et al. 2018; Schneidtinger & Haslinger-Baumann 2019). However, there is little research that focuses on the recovery experiences of young people (Rayner et al. 2018). The CHIME framework – describing connectedness, hope, identity, meaning/purpose, and empowerment as core elements of recovery (Leamy et al. 2011; Slade et al. 2012) - has also been found relevant for young people's recovery (Naughton et al. 2020). It has been suggested that young people's recovery differs from adult recovery in some aspects and that conceptualizations of young people's recovery need to acknowledge that young people are in a period of development (Kelly & Coughlan 2019; Law et al. 2020; Naughton et al. 2020; Rayner et al. 2018). Also, parents are believed to have a substantial impact on young people's recovery (Naughton et al. 2020; Schneidtinger & Haslinger-Baumann 2019). Young people's recovery should involve both the young person and their parents, rather than focusing on independent functioning, and should be more about young people re-engaging in day-to-day activities than rebuilding their lives (Naughton et al. 2020). Compared to adults, young people may have different and fluctuating recovery goals (Law et al. 2020). Their recovery may involve a stronger connection to receiving a diagnosis, achieving symptom reduction and having access to mental-health services (Law et al. 2020; Schneidtinger & Haslinger-Baumann 2019). Youth recovery processes include the development of self-belief and resilience; responsibility and personal agency; identity, awareness, and acceptance; connection; and hope and positive expectations (Rayner et al. 2018).

Young people's perspective on inpatient care

A limited number of contemporary studies describe CAP inpatient care from the perspective of young people (Gill *et al.* 2016; Moses 2011; Reavey *et al.* 2017; Salamone-Violi *et al.* 2015; Schneidtinger & Haslinger-Baumann

2019). Gill et al. (2016) conducted interviews with twelve adolescent inpatients and described the importance of young people's feeling understood by others and the advantages and disadvantages of the inpatient environment being separate and different from life outside the facility. They also described the importance of young people's developing more confidence in themselves and their abilities and having hopes and fears about what would happen after discharge. Moses (2011) interviewed eighty adolescents after discharge from inpatient services. Interpersonal interaction with peers and staff, therapeutic interventions, psychoeducation, and being in a safe and structured environment was perceived as being helpful. Other experiences were perceived as unhelpful or harmful, including the environment being restricting and regimented, staff behaving unhelpfully and disrespectfully, and the young people not being listened to or involved in decisions regarding treatment (Moses 2011). Reavey et al. (2017) interviewed twenty young people who described inpatient care as predominantly containment rather than treatment, focusing on monitoring and controlling young people's behaviour instead of dealing with their mental-health difficulties. Building connections and trust and learning how to deal with emotions were perceived as crucial elements of inpatient care that were sometimes lacking (Reavey et al. 2017). Focusing on patient satisfaction, Salamone-Violi et al. (2015) interviewed eleven young people admitted to inpatient care. They described connection with staff or other patients as a crucial element of their experience in addition to the importance of being involved in decision-making. Inpatient care can be a place of safety, advocacy, therapy, and improved mental health, but it can also be a restricted environment where young people experience a dearth of information and activity (Salamone-Violi et al. 2015). Schneidtinger & Haslinger-Baumann (2019) reported findings from nine interviews with young people experiencing personal recovery who described ambivalent feelings towards inpatient care. Ward structure and rules could either be perceived as a relief or as constraining; similarly, peers could be seen as an important source for community and support or as having a bad influence (Schneidtinger & Haslinger-Baumann 2019). The constant presence and availability of staff provided a sense of security, but witnessing psychiatric emergencies involving peers was extremely stressful. Receiving visits and support from family during the stay was considered to be important. Supporting therapies were considered helpful, as was learning coping strategies and skills from staff (Schneidtinger & Haslinger-Baumann 2019).

## Blogs in nursing research

Personal blogs (short for weblogs) are described as a type of social media that might provide insight into lived experiences, including aspects of health (Eastham 2011). Blogs first appeared in 1999 and have since been a part of online culture (Hookway 2008). Personal blogs focusing on an individual's experiences of health, care, and treatment have been referred to as 'illness blogs' (Heilferty 2009). Blogs are considered useful for gaining a deeper understanding of the illness experience (Hookway 2008). The increasing amount of data available in blogs allows researchers to focus on specific health-related phenomena (Eastham 2011). To our knowledge, no previous studies have focused on personal blogs describing young people's experiences of psychiatric care or mental-health recovery.

#### Rationale

Personal recovery is a novel concept in young people's mental health. CAP inpatient care has the potential to support or hinder young people's recovery. First-hand accounts of experiences in CAP inpatient facilities can inform nursing research and practice, but research describing inpatient care from the perspective of young people is rare. Personal blogs provide an opportunity to hear directly from young people and further understand how inpatient care relates to young people's recovery processes. Knowledge on young people's recovery processes can inform treatment approaches and improve mental-health outcomes.

#### Aim

This study aims to explore young peoples' experiences of child and adolescent psychiatric inpatient care supporting mental-health recovery.

## **METHOD**

This is a qualitative descriptive study analysing personal blogs using a method for interpretive description (Thorne 2008). The study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ; Tong et al. 2007). The research team consisted of two women and one man, all experienced in psychiatric inpatient care. At the time of the study, the first author was working as a nurse in child and adolescent psychiatric care while achieving a master's degree in psychiatric nursing. The second and third authors were both working as assistant professors in nursing.

## Data creation

The data for this study were created from twenty-seven blogs describing one's personal experiences of being a patient in CAP inpatient care in Sweden. The use of blogs for data creation facilitates including participants with specific and diverse experiences that might be difficult to approach through other means (Eastham 2011). Blogs also allow for anonymity, which is believed to increase the honesty and depth of people's narratives (Hookway 2008).

## Sampling

We used purposeful sampling as we wanted to find blogs describing a variation of experiences of CAP inpatient care. Purposive sampling allows researchers to use their judgement to include participants with specific characteristics or features (Higginbottom 2004). Blogs were included in the study if they contained first-hand accounts of experiences of being a patient in a Swedish CAP inpatient care facility if they were freely accessible and not restricted by passwords or membership in a certain community.

## Web search

Potential blogs were identified through Google searches performed during November and December 2018 and then screened by the first author. Searches used keywords pertaining to blogs and CAP inpatient care. Searching ceased when we were unable to identify any more relevant blogs.

## Blog characteristics

The information available in the blogs suggests that they were written by twenty-seven women who experienced CAP inpatient care during the period of 2010–2018 when they were 12–18 years old. A majority of the bloggers described experiences relating to eating disorders. Reasons for admission disclosed in the blogs varied but would typically involve risk for suicide related to anxiety and depression.

#### Data extraction

Blogs included in the study were read through by the first author. Passages describing experiences of inpatient care supporting or obstructing recovery were identified and collated into a single document of  $\sim 12~500$  words. We chose to include passages describing positive experiences of inpatient care supporting recovery as well as negative experiences relating to these same topics. For the purposes of this study,

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recovery was understood to be any experience relating to the development of connectedness, hope, identity, meaning/purpose, and empowerment (cf. Leamy *et al.* 2011; Slade *et al.* 2012). Each passage was given a numerical code allowing the authors to trace it back to the original blog post.

# Analysis

Data were analysed using a principle-based and iterative method for interpretive description (Thorne 2008; Thorne et al. 2004). We also employed techniques and concepts of qualitative content analysis (Graneheim & Lundman 2004). While this study focus on experiences of child and adolescent psychiatric inpatient care supporting mental-health recovery, the analysis used an inductive approach, that is we sought to navigate 'within and beyond the original theoretical scaffolding' (Thorne et al. 2004, p. 5) in order to reach 'a coherent rich interpretation that allows a priori theory to be changed by the logic of data' (Thorne et al. 2004, p. 6). Thus, while our initial understandings of recovery as related to the development of connectedness, hope, identity, meaning/purpose, and empowerment provided guidance in the data creation phase of the study, the analytic phase sought to challenge these understandings through critical reflection and discussion. The first author conducted the formal analysis. Findings were continually discussed and revised by the third author. Bloggers were not presented the opportunity to provide feedback on the findings.

The selected passages were considered as a whole and read through several times. Meaning units corresponding to the aims of the study were identified, condensed, and coded. This was followed by what Thorne et al. (2004) calls the critical phase of the analysis, involving the interpretation of findings through the identification of patterns and creation of themes. Coding facilitated bringing meaning units describing similar experiences together in groups and allowing them to be considered in contrast with other groupings. The analysis resulted in the creation of one theme and three subthemes forming the basis for an interpretive explanation.

# Ethical considerations

The use of social-media content as data poses an ethical challenge that calls for reflection on the issues of integrity and consent (McKee 2013). Social-media content can be viewed as a form of naturally occurring data (Hilton 2017). We chose to only use pre-existing,

widely available material as we considered this to be public and not private. In the interest of confidentiality, we have however taken steps to avoid the identification of specific blogs. We have chosen not to disclose the keywords we used when we searched for blogs. Also, researchers using online material are advised that the use of direct quotes poses a threat to participants anonymity as quotes can readily be copy-pasted and used to identify the original posting through search engines (Eysenbach & Till 2001; McKee 2013). After careful deliberation, we did chose to include direct quotes in the results section, following the assessment that the connection of quotes to specific blogs will be difficult as the quotes have undergone translation from Swedish to English. The study was approved by the regional ethics committee in Umeå (id: 2018/264-31).

# Rigour and credibility

Rigour and credibility in interpretive description is evaluated in terms of moral defensibility, disciplinary relevance, pragmatic obligation, and contextual awareness (Thorne 2008). We consider this study to be morally defendable as it provides knowledge that can benefit both young people experiencing mental-health problems and recovery and nurses working in CAP inpatient care. It is relevant for the discipline of nursing as it focuses on the connection between care and recovery and values the subjective experiences of young people. The study demonstrates contextual awareness as the research process emphasizes reflexivity in planning, data creation, analysis, and reporting. We believe our findings to be credible and transferable, and thus, the study fulfils the pragmatic obligation requiring researchers to consider the practical applications of their findings.

## **FINDINGS**

Our findings are presented as an interpretive explanation incorporating the theme and sub-themes. In the following, the theme is presented followed by the subthemes.

## Don't abandon me

This theme was representative of participants' experiencing feelings of connectedness and being in community related to being accepted and recognized as a unique person. The theme also represents participants' experiencing feelings of abandonment and discon-

nection related to the staff on the ward not being available and not attending to their needs. The theme included three sub-themes representing participants' experiences of inpatient care as it contributed to aspects of personal recovery. To experience feelings of connectedness and community, young people in CAP inpatient care need to be listened to, believed in, and allowed to feel safe.

#### Listen to me

CAP inpatient care can support recovery when young people experience being listened to and taken seriously. Bloggers described a need to be seen, heard, and recognized by staff. When staff members took the time to really listen to them, young people reported that they themselves began realizing how they actually felt. This was important as it made young people feel validated. Bloggers described how temporary staff were the ones who really engaged with patients and allowed them to talk when needed.

Being listened to was a prerequisite for care to be adequate for and relevant to young people. Being given the requisite time with staff was important for young people to be able to express their innermost thoughts and feelings. Being able to confide in staff allowed them to have care adapted to their needs. One blogger described the value of staff being available and non-judgemental like this:

The best thing about CAP is that they don't get angry when you have anxiety. At [other mental health service], they would stand in the doorway yelling about getting it together and stop screaming, but here they think it is a good thing to let out the anxiety as long as you don't hurt yourself or others. They are more concerned about finding personal solutions and really stay with you during every anxiety attack and in between. If you want to talk, they always have time.

#2

Not being listened to would hold negative consequences for young people's recovery. Staff not listening gave rise to feelings of powerlessness resulting in them acting out in order to gain the staff's attention. Staff not listening would also result in inadequate decisions about young people's care. One blogger described how she felt powerless and desperate after being discharged and was left wondering what she could have done to get noticed. The experience of not being listened to was related to feelings of staff not caring. The staff's not trusting them or taking them seriously when they felt distressed or expressed instances of suicidal ideation was perceived as a betrayal. Bloggers described

the experience of CAP inpatient care as being at war and fighting to regain control of one's own life. Not having their thoughts, feelings and experiences noticed or taken seriously would lead young people to stop confiding in staff. One blogger wrote:

Imagine if staff had realized the power behind my struggle and my wish to keep on living even when I thought I wanted to die; then they could have helped me instead of working against me.

#16

## Believe in me

CAP inpatient care can support recovery when young people experience being believed in by staff. Bloggers express a need for the staff to be there and not give up on them and describe how this would contribute to young people's feeling hope. They describe feeling that someone had confidence in them and their abilities as instilling hope. This could mean staff working collaboratively with them and not giving in but believing in them and their future, even when they themselves could not.

Being believed in also involved young people perceiving that staff treated them like people and made the effort to meet their needs. Signs of commitment involved standing up for patients' rights and having individually adapted care. Being treated as a thinking and feeling person instills hope. One blogger wrote:

That time the doctor didn't give up but kept on seeing me every day of the week to find a solution. To understand me. He didn't just stick to the protocol for my treatment; he allowed me to be involved in shaping and finding a way that works for my body and soul. He has brought hope for life. That I actually have a chance at a normal life.

#24

Young people may experience a lack confidence and hope that can be reinforced by inpatient care. For example, being told that they had 'failed' while on leave from the ward meant that they would lose trust in both themselves and in staff. Feeling better and recovering was counteracted by staff members' expressing the opinion that it was up to young people themselves if they wanted to be helped by inpatient care and that if young people did not want help they would not get it. Bloggers also wrote about staff displaying a lack of trust in the young people's abilities or their next of kin's.

## Allow me to feel safe

CAP inpatient care can support recovery when young people perceive that they are being given the time and

space to feel safe. This was described as necessary to accepting being admitted to the ward, wanting to stay there, adjusting to ward life, and being able to accept care. One blogger wrote:

I woke up early this morning and actually felt quite happy. I had settled in and accepted the thought of being admitted throughout the week and even longer. I had come to terms with the idea of being an inpatient. Not that I enjoyed being an inpatient.

One circumstance described as contributing to feelings of safety was the presence of staff on the ward. Staff being there when you needed them provides a sense of security to the young people. By adapting to the young people's individual needs, staff could further contribute to feelings of safety. Bloggers stated that their stay was made easier when staff, knowing how important it was to have a private room, made the effort to reorganize the ward based on individual needs. However, staff could also be perceived as a threat to young the people's safety. Having the staff violate their dignity would lead to distress and to young people experiencing the ward as a non-caring environment. One blogger wrote:

Being forcefully restrained and then pushed through the corridor for all patients to see, while staff members tried to joke with me was degrading, and I felt violated.

#14

Another aspect of inpatient care helping young people to feel safe was the overall ward environment. Bloggers described a need for a calm and pleasant environment. Their stay on the ward was facilitated by a homey environment and the opportunity of being active. A circumstance adding to a positive experience of being admitted was the existence of routines contributing to a predictable environment. Bloggers attributed this to regular staff who took it upon themselves to uphold the ward's structure.

Features of inpatient care invoking feelings of uncertainty made it difficult for the young people to feel safe. Not knowing what was happening in their own care was upsetting and made them feel excluded. Some describe being discharged just when they started feeling at ease with the thought of staying on the ward. This then contributed to an overall negative experience of inpatient care. Also, a fear of being discharged was a recurring negative feeling amongst young people being cared for in CAP inpatient care. Bloggers also wrote about a lack of future planning and an overwhelming fear of not being able to make it outside the ward.

Some bloggers described having expressed suicidal ideation still being discharged and not understanding why. One blogger wrote:

They discharged me even though I told them I was feeling unbelievably bad. The meeting that should have lasted fifteen to thirty minutes dragged on for about three hours. I screamed and cried, and I left when it became too distressing (I don't usually make a scene, but I couldn't handle the situation). I told them that I thought I might take my own life if they discharged me. The doctor yelled at me.

## **DISCUSSION**

Our findings describe young peoples' experiences of CAP inpatient care supporting mental-health recovery in an interpretive explanation with one theme, 'Don't abandon me', and three sub-themes: 'Listen to me', 'Believe in me', and 'Allow me to feel safe'. These findings reinforce an understanding of connectedness as a core element of recovery (Leamy et al. 2011; Slade et al. 2012) and calls attention to the development of connection as a youth recovery processes (Kelly & Coughlan 2019; Rayner et al. 2018). Corresponding with Salamone-Violi et al. (2015), our findings suggest that a feeling of connection might be crucial for young people's overall success with inpatient care. While staff support is but one of many avenues for developing connectedness in recovery (Leamy et al. 2011), our findings suggest that the development of connection between staff and the young people plays an important role in supporting or hindering young people's recov-

The findings regarding the sub-theme 'Listen to me' highlight the necessity of CAP inpatient care being collaborative care in order to support young people's recovery. Lynch et al. (2020) identified trust and confidentiality, supportive rapport, and collaborative treatment as core components of the helping relationship in the context of young people's mental health care. Involving young people in their own care is especially important when it comes to discharge planning (Salamone-Violi et al. 2015). Staff not listening to patients is a known barrier to recovery in psychiatric inpatient settings as it prevents care from focusing on the individual needs of patients and thus tends to become meaningless from the perspective of patients (Hyde et al. 2015; Looi et al. 2015; Marklund et al. 2020). As described by Simonds et al. (2014) being listened to makes it possible for young people to express their needs; however, it is also a healing process in itself involving expressing one's suffering and receiving validation. Young people describe the importance of professionals having the skills to understand their reasoning, be able to read between the lines, and support them in expressing their emotions and feelings with follow-up questions (Lindgren *et al.* 2015).

However, not being listened to might also hinder young people's recovery in another aspect. Rayner et al. (2018) describe the development of confidence, self-efficacy and self-belief and an accompanying resilience as a key recovery process allowing young people to take on challenges in their lives. Our findings describe how not being seen and recognized as an aspect of not being listened to and taken seriously leads to negative feelings including feeling powerless. Thus, staff not listening to young people may be understood as disempowering in several aspects.

The findings pertaining to the sub-theme 'Believe in me' reinforces an understanding of hope as a core element of recovery in general (Leamy et al. 2011) and the youth recovery process specifically (Rayner et al. 2018). Hope is described as a precondition for creating and experiencing a meaningful life (Tutton et al. 2009). Inspiring hope is a fundamental aspect of mentalhealth nursing (Fitzgerald Miller 2007; Tutton et al. 2009). In mental-health nursing, inspiring of hope is grounded in the interpersonal relationship between a nurse and the person in need of hope (Cutcliffe & Koehn 2007). Cleary et al. (2016) describe nurse-patient conversations as a collaborative exploration of possible roads to recovery and record how nurses' not giving up contributes to a feeling of connectedness that forms a foundation for patients' experiencing hope.

Findings regarding the sub-theme 'Allow me to feel safe' describing the importance of providing sufficient time and a safe space add to previous research (Glick et al. 2011; Kaplan & Racussen 2013) that challenges the primacy of short stays in CAP inpatient care. Young people's descriptions suggest that inpatient care is not necessarily a bad thing; rather, it can be a place for experiencing connection, acknowledgement, and hope. Staff need to appreciate young people's need to connect with others as part of their mental-health recovery process and as part of being in this particular period of development while realizing that this also can and should be manifested in everyday life on the ward. If staff fail to engage and connect with young people, it is no surprise if these patients lose hope of recovery. In accordance with Salamone-Violi et al. (2015), our findings suggest that being in circumstances that enable them to feel safe and accept care is perceived as more

important for young people's recovery than any specific type of treatment.

# Study strengths and limitations

Through the study of personal blogs, this study presents direct reporting from young people of actual inpatient care experiences. We believe that the included blogs constitute a rich collection of material describing a wide variety of young people's experiences in CAP inpatient care. However, there are limitations to the study that must be considered when interpreting the findings. As indicated by the content of the blogs, the study is likely to have included women only and predominantly young women experiencing eating disorders. It is possible that the results would have been different should we have been able to identify blogs written by young men or people identifying as non-binary, and people representing a wider variety of mental-health conditions. As we chose not to consider characteristics other than gender and mental-health condition, we are also not able to determine if our material represent a variation in terms of ethnicity or socio-economic status. It should be noted that the use of blogs for data creation means that this study is limited to describing experiences of young people who are willing and able to share their experiences in this format. This excludes people with limited ability to express themselves in writing as well as people whit limited digital literacy or limited access to the technology necessary for blogging.

## CONCLUSION

This study of CAP inpatient care adds to a growing body of empirical work that suggests the relevance of the concept of personal recovery for young people's mental health. The use of blogs offers the opportunity to hear directly from young people. To support recovery, CAP inpatient care need to focus on developing its content of care rather than on minimizing its average length of stay. Inpatient staff need to engage and connect with young people on CAP wards and be present, supportive, and non-judgemental in order to empower young people and instil hope. More research is needed to further understand the characteristics of young people's mental-health recovery and how recovery processes can be supported. Future research should also focus on developing and evaluating interventions supporting recovery-oriented practices in CAP inpatient

## RELEVANCE FOR CLINICAL PRACTICE

While CAP inpatient care have the potential to support young people's recovery, there are descriptions in the findings of humiliation, violation, exclusion, and coercion. This further stresses the relevance of CAP inpatient care adopting a recovery orientation, to which a focus on patients' rights as well as needs is integral.

This study emphasizes that minimizing the length of inpatient stays must not be paramount to meeting the needs of young people in crisis. Our findings suggest that applying a recovery orientation can guide inpatient staff in understanding what their patients' primary needs are. While interpersonal engagement is considered to be a critical element of inpatient care, it often goes unrecognized and unarticulated (Delaney *et al.* 2017). Our findings strongly support emphasizing staff engagement in CAP inpatient care.

This study also demonstrates the significance of understanding experiences of mental-health recovery and CAP psychiatric care from the perspective of young people. Thus, it stresses the importance of recognizing psychiatric and mental-health nursing as a reflective practice (Goulet *et al.* 2016), and the need for staff to be able to reflect on their practice from a multitude of perspectives. User experience should be at the heart of efforts aimed at improving services.

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