Contextual information needs of people in life transitions struggling with obsessive-compulsive disorder

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Abstract

Introduction. Obsessive-compulsive Disorder (OCD) is a severe chronic mental health issue that significantly impacts people's everyday lives. This study aims to reveal the contextual information needs of the people living with OCD during life transitions and how these needs dynamically evolve across various transitional stages.

Method. The study collected 1,500 posts from an OCD online forum of a well-known Chinese social media platform, Douban. A subsequent content analysis was performed on 324 selected valid posts.

Analysis. Guiding by the information behaviour theory of transitions, two rounds of open-coding analyses were conducted on the posts.

Results. Preliminary findings indicate that people with OCD have various types of contextual information needs during different transitional stages, namely understanding, negotiating, and resolving, suggested by the existing theory.

Conclusion. Information needs are context-specific, complex and continuously changing during life transitions of people with OCD. Our conclusion can provide theoretical insights for future research exploring the dynamic information needs during the mental health transitions. Additionally, it serves as a preliminary conceptual framework for various stakeholders to offer informational support to people with OCD.

Introduction

Life transitions denote the specific phases that individuals grapple with, involving significant events such as illnesses, traumatic incidents, or bereavement (Ruthven, 2022). These transiting periods, laden with life challenges, herald disruptions to their daily routines and often culminate in a loss of control and meaning. To navigate this turmoil, individuals necessitate appropriate information to assist them in meaning-making (Park, 2010; Ruthven, 2019a).

In this ongoing study, we investigate the contextual information needs of people with obsessive-compulsive disorder (OCD) who experienced life challenges. OCD, a prevalent and chronic mental illness, manifests through intrusive thoughts and ritualistic behaviours (Mataix-Cols et al., 2005). Prolonged OCD symptoms significantly impact patients' mental well-being and social functioning (Stein et al., 2019). Adequate informational support is essential for people with OCD to understand the nature of the illness and develop coping strategies. However, people with OCD often have a sense of shame associated with their conditions which hamper their expression of information needs and lead to information poverty (Bronstein, 2014). Hence, it is critical to explore the information needs of people with OCD, in order to better provide them with informational support during life transitions. Furthermore, given that life transition is a dynamic process, which can be divided into multiple stages (Kralik et al., 2006), the information needs for supporting transitions at different stages are constantly changing (Willson, 2019). Therefore, we are also interested in how these needs evolve with the progression of OCD transitions.

Building upon the above discussions, we have proposed the following research questions:

RQ1: What are the contextual information needs of people with OCD?

RQ2: How do the contextual information needs evolve during different transitional stages?

Employing Ruthven (2022) 's information behaviour theory of transitions, we conducted a content analysis using data sourced from OCD online forums in China. Our preliminary findings dynamically illustrate the intricate information needs of people with OCD across various transitional stages.

Literature review

Ruthven posits, '*Information behaviours we use in everyday life may not be appropriate for obtaining useful information during a significant life change*' (Ruthven, 2022, p. 579). Therefore, individuals need to adopt specific information behaviours and practices to cope with the complex challenges in a transitional context. As the starting point of information behaviour (Wilson, 1981), information needs in transitional contexts exhibit complexity (Savolainen, 2012; Wilson, 2019). These needs are no longer about achieving the *mastery of life* in everyday contexts but rather coping with transitions in uncertainty and chaos (Savolainen, 1995; Westbrook, 2009). For instance, influenced by social stigma, information sources for infertile men have shifted from family and friends to online infertility communities. Anonymous communities better meet their private information needs during their life transitions (Patel et al., 2019).

In recent years, the Information Science field has witnessed a surge in research exploring information needs, behaviours, and practices within various complex transitional contexts (Haimson et al., 2021; Hicks, 2019; Ruthven et al., 2018). For instance, studies have delved into the information behaviour and practice among immigrants (Allard and Caidi, 2018; Bronstein, 2019; Du, 2023), LGBTQIA+ individuals (Huttunen and Kortelainen, 2021; Jia et al., 2024), early career academics (Alon, 2023; Willson, 2019), and refugees (Anderson et al., 2020; Lloyd et al., 2017; Oduntan and Ruthven, 2019). Only a few studies have examined how individuals with mental illnesses obtain information support during transitions. For example, Bao & Ke (2023) investigated the information practices of individuals coping with depression amidst the COVID-19 pandemic. Genuis and Bronstein (2017) detailed how people with OCD strive to establish a renewed sense of *normal* by employing information practices. However, these studies seldom

systematically investigate the information needs of individuals experiencing mental distress during life transitions, particularly few studies that specifically focus on the contextual information needs of people with OCD.

Life transitions are a process during which information needs and behaviours continuously evolve (Ruthven, 2022). For example, Allard and Caidi (2018) developed a five-stage translocal meaning-making model, illustrating the intricate information practices during immigrant transitions. Naveh and Bronstein (2019) analyzed forum data to examine how information supports the construction of a normal sense for diabetic pregnant women in four stages. However, studies that depict the dynamic information activities across multiple stages of transitions remain scarce, possibly due to the absence of transition theories within the Information Science field. In recent years, Ruthven (2022) proposed the information behaviour theory of transitions as an instrumental guideline to explore information needs, behaviours, and practices during life transitional stages. The core essence of this theory categorizes transitions into three stages: *understanding*, *negotiating*, and *resolving*, following a chronological order. The general pattern for each stage is as follows: during the understanding stage, individuals engage in information seeking from various information sources, establishing preliminary understandings of situations. During the negotiating stage, individuals seek knowledge to address the issue, evaluating its value and engaging in information using behaviours. In the resolving stage, individuals construct meaning, develop new understandings of transitions, and influence others by sharing their narratives. Subsequently, this theory has been adopted and expanded to some extent by other scholars. For instance, Du (2023) integrated this theory with the information journey framework to investigate information practices among older immigrants during life transitions. Our research draws upon the theory to examine how information needs evolve across different transitional stages among people with OCD.

Method

Data collection

Online forum data provides immediate, wide-ranging insights into information needs (Ruthven, 2019b). This study utilizes data from 'My Obsessive-Compulsive Disorder (OCD),' a prominent Chinese online forum on Douban (https://www.douban.com/group/43017/), boasting over 60,000 members since 2007.

In order to conduct an initial exploratory study, we employed a web scraping tool, Web Scraper, to collect the latest 1500 forum posts. To specifically capture information needs, we selectively retained posts displaying evident inquiry tones. 324 valid posts were selected for subsequent data analysis.

Data analysis

This study uses content analysis to code data concepts and themes. Initially, two doctoral students independently applied open-coding to extract research concepts and themes from the data. Following this, two additional doctoral students, not part of the initial coding, collaborated in discussions to revise conflicting codes. Finally, three information behaviour experts, well-versed in the information behaviour theory of transitions, participated in a focus group discussion, contrasting coding results with the theory's core stages and providing interpretations on how information needs themes emerge among people with OCD across different transition stages.

Preliminary findings

Understanding: feeling, identity and attribution

The understanding stage reflects the initial stage for people with OCD, marked by a deep sense of dissonance compared to their former life. During this stage, information needs among people with OCD are illustrated in Table 1.

Information needs theme	Concept	Description	Number & Percentage (%)
emotional regulation	unhappiness fear tension despair irascibility	People with OCD have information needs to methods of alleviate negative emotions	74 (22.84%)
identity confirmation	diagnosis confirmation severity confirmation	People with OCD require informational support to confirm their condition and assess its severity.	15 (4.63%)
attribution knowledge	familial reason genetic reason personality reason cultural reason	People with OCD require informational support to help them determine the causes of their condition.	31 (13.25%)

Table 1. Contextual information needs during Understanding stage

Methods for *emotional regulation* stand as the most pressing information need for people with OCD at the understanding stage. However, it is like what Taylor (1968) described as *conscious information needs*—vague and challenging to operationalize. Still, it may serve as an intrinsic motivator for subsequent, more constructive information needs. As illustrated in this example:

'*This inexplicable fear—I'm a teacher, but why do I feel this intense fear when I step onto the podium? What's really going on here? Is it my mind or is there something wrong with my body?*'

Identity confirmation poses a challenge for people with OCD. Due to insufficient mental health education and a lack of policy guidance in China, the term 'OCD' holds ambiguity and is often treated with levity within Chinese culture, many individuals are unaware that it is a genuine mental health condition. Consequently, in OCD forums, many people seek validation regarding whether they truly have OCD, for instance:

'*Does checking each question meticulously five times or more count as OCD?*'

Attribution knowledge is vital during the understanding stage. Exploring OCD causes helps individuals redirect focus and understand subconscious connections with the disorder. Consequently, people with OCD aim to attribute the disorder to factors like family, genetics, emotions, personality, and Chinese ceremonial culture, leading to specific information needs. For instance, in the family context:

'*Do you feel your illness is related to your family of origin? I believe it's my parents' excessive protectiveness that reinforced my timid and sensitive nature.*'

Negotiating: Coping strategies and social connections

During the negotiating stage, people with OCD compare and weigh different treatment options, aiming to address OCD in a way that aligns with their personal psychological commitment while minimizing costs. In this stage, information needs among people with OCD are presented in Table 2.

Information needs theme (Host's post)	Concept	Description	Number & Percentage (%)
coping strategies	medicine intervention hospital intervention psychological intervention informal spiritual information treatment plan conflicts	People with OCD have numerous information needs regarding coping strategies for OCD.	78 (33.33%)
social connections	seeking geographical peers seeking symptomatic peers	People with OCD seek to connect with others who share geographical or experiential similarities.	102 (43.59%)

Table 2. Contextual information needs during Negotiating stage

Coping strategies for OCD become the primary information need in this stage, with a prominent focus on information regarding medication as a treatment strategy. Apart from information needs on drug use and efficacy, people with OCD express information needs to assist them in weighing options and risk-reward scenarios during treatment, such as:

'I *want to stop medication for pregnancy preparation, but I'm afraid of a relapse. What should I do?*'

In addition to the information needs related to formal medical treatments, people with OCD have informal spiritual information needs. These spiritual insights assist people with OCD in introspecting their inner selves and in perceiving mental illness from 'higher' and 'deeper' spiritual dimensions (Nangia & Ruthven, 2023), such as:

'What are the core ideas of the 'Shurangama Sutra'? Why is it said to be capable of alleviating anxiety?'

Building *social connections* enhances community belonging and facilitates treatment information exchange for people with OCD. They strongly seek connections with nearby peers and those with similar symptoms.

'*Are there any girls with OCD in Jiangsu? I hope we can become friends.*'

'Is *there anyone who likes adjusting volumes to odd numbers?*'

Resolving: can OCD achieve complete recovery?

The characteristic of the resolving stage involves individuals constructing a new landscape of meaning, resolving or letting go of long-standing issues (Ruthven, 2022). During this stage, the information needs of people with OCD are presented in Table 3.

Information needs theme (Host's post)	Concept	Description	Number & Percentage (%)
standards for recovery	Correctness of recovery direction reduction of cognitive echoes elimination of physical symptoms	People with OCD focus on recovery details and aim for complete healing.	8 (2.47%)
coexistence plans	feasibility efficacy longevity	People with OCD seek viable coexistence strategies with their condition	16 (4.94%)

Table 3. Contextual information needs during Resolving stage

Information needs during the recovery phase are minimal. First, people with OCD grapple with the *standards for recovery* from the disorder. They may seek confirmatory information to evaluate how to return to a state of *no OCD*. However, this obsessive insistence on confirming information is not a positive sign, as it is driven by the disorder itself. This could exacerbate their condition, even leading them back to previous stages. A post mentioned:

'I *feel like I don't have OCD, but I'm really struggling with how to quickly alleviate the symptoms of vegetative nerve disorder, and it's really confusing me.*'

Second, many people acknowledge the difficulty of treating OCD, and mention a term called *living with anxiety*. They no longer cling to coping strategies but seek long-term *coexistence plans* with the condition. For instance:

'I've *come to accept reality; it's like a shadow I can't shake off. I want to know how to coexist peacefully with it.*'

Discussion

This study, based on the information behaviour theory of transitions, employed a qualitative research method to explore the contextual information needs of people with OCD. The research illustrates the dynamic development of information needs among them during different stages of OCD transitions (see Figure 1).
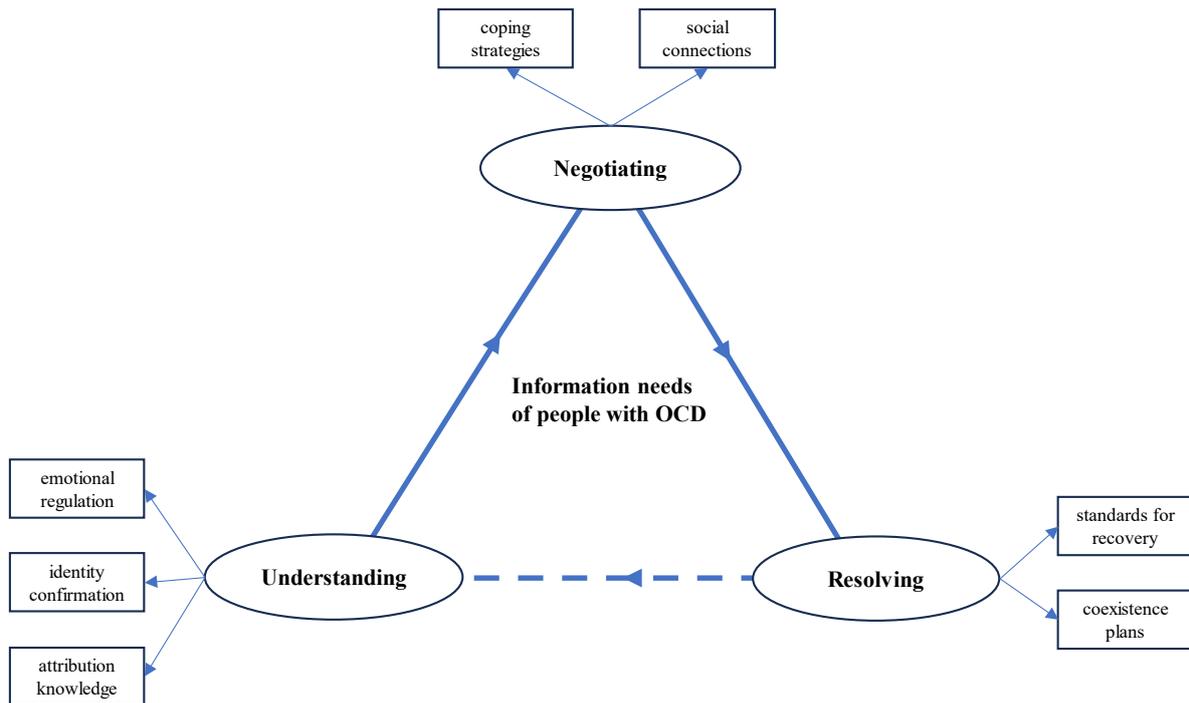
Figure 1. Contextual Information needs of people with OCD.

The preliminary findings of our study are as follows:

- During the understanding stage, people with OCD have information needs related to emotional regulation, identity confirmation, and attribution knowledge.

- During the negotiating stage, people with OCD seek information regarding coping strategies for the condition and maintaining social connections with peers.

- During the resolving stage, people with OCD express information needs about standards for recovery and coexistence plans.

This study provides several theoretical contributions. First, this study uncovered the complex information needs of people with OCD, offering a preliminary analysis of various needs that build upon Bronstein (2014)'s initial research on information poverty in this population. Meanwhile, this study is among the first to explore the information needs of OCD population in an Eastern cultural context. Given the differences in factors such as religious beliefs and family norms between East and West, the findings also exhibit some differences. For example, unlike Bronstein's (2014) study, this paper did not find information needs related to economic or self-protection aspects among OCD population but emphasized their informal spiritual information needs, which may be associated with the *spiritual practices* advocated by Buddhism and Taoism unique to Eastern context (Jeung et al., 2015). This inspires future research to explore people with OCD' information needs from a cross-cultural perspective and through the lens of the relationship between spirituality and physical well-being.

Second, employed information behaviour theory of transitions, we explored the information needs at various transitional stages, presented the dynamic evolution of information needs. This aligns with Willson's (2019) perspective on *changing information needs* in the context of immigration transitions. During the understanding stage, emotional discomfort, identity ambiguity, and a desire for understanding drive the information needs of

people with OCD, aligning with past information behaviours related to emotional fluctuations and identity construction during the initial stages of transitions among transgender transitions (Huttunen et al., 2020). During the negotiating stage, people with OCD start seeking specific treatment plans and social connections, which parallels the challenges in practices and community norms experienced by LGBTQIA+ individuals in the mid-stage as described by Jia et al. (2023). During the resolving stage, the most prominent information needs of people with OCD is the pursuit of coexistesnce, as they seek to embrace *living in anxiety* as a new way of life, which is similar to the perspective of OCD individuals seeking a *new normal* as highlighted in the study by Genuis and Bronstein (2017). Overall, our study provides valuable insights for future exploration of multi-stage information needs during transitions.

Finally, our study is an attempt to apply the information behaviour theory of transitions to the context of OCD. As a novel theory exploring information activities in life transitions within the Information Science field (Ruthven, 2022), further expansion is needed for its application and validation (Du, 2023). This study can serve as a reference for future research on chronic illness or mental health transitions that aim to utilize this theory.

Our research also offers practical guidance for a non-clinical approach, encouraging online OCD communities, healthcare institutions, and families to provide appropriate informational support for people with OCD.

Limitations and Future Research

Our study has some limitations. First, it was conducted within the context of China, lacking cross-cultural data to compare the differences in OCD information between Eastern and Western cultures. Future research could deepen understanding by examining data from OCD forums in diverse cultural contexts. Second, our study relies on secondary data from forums, which means our interpretations of information needs across different transition stages are based on expert knowledge. In the future, integrating primary data methods such as interviews and interpretative phenomenological analysis for more contextual results are necessary. Finally, our study merely presents the information needs of people with OCD without delving into how fulfilling these needs can assist them in meaning-making. Future research could analyse responses in forums to explore how meeting their diverse information needs through information practices at different transition stages could be achieved.

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