

# Obsessive-Compulsive Disorder in People With Learning Disabilities: A Qualitative Study of Caregivers' Challenges and Strategies Practiced in Institutionalized Settings

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*Little is known about OCD in people with learning disabilities (LD) in general and in terms of current and professional support. In this study, we examined caregivers' perceived challenges and strategies practiced in institutionalized settings in managing OCD in people with LD and derived implications for research and practice. We studied individual cases of people with LD (n = 7). Each case included group discussions (n = 28) and semi-structured interviews with caregivers (n = 20). We used qualitative content analysis to analyze the data. Our findings reveal the following challenges for caregivers: recognizing and classifying ambiguous behaviors, recognizing emotional well-being and needs through nonverbal signals, finding and applying effective strategies, being unqualified regarding additional needs, managing inappropriate institutionalized conditions, and lacking external specialization. We identified five strategies for dealing with compulsive behavior: tolerating and allowing, accepting and supporting, involving, limiting the compulsive act, and stopping the act. Collaboration among psychiatric, therapeutic, and caregivers in institutionalized settings is critical for early identification and support of OCD. Challenges arise from caregivers' lack of training on the additional needs of people with LD and OCD, highlighting the urgent need for disorder-specific guidelines for identification and support.*

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**Keywords:** people with learning disabilities, obsessive-compulsive disorder, compulsive behavior, challenges, coping strategies, caregivers, professional support, qualitative research

## INTRODUCTION

Research focused on understanding the needs and conditions for appropriate professional support for people with learning disabilities (LD) and mental disorders is increasing (e.g., Durbin et al., 2017; Painter et al., 2018; Schützwohl et al., 2016). Among those with special needs, the largest subgroup of people with LD is characterized by a limited ability to learn, process, and interpret information. These individuals encounter challenges with

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various cognitive processes, such as reading (dyslexia), writing (dysgraphia), mathematical operations (dyscalculia), and other academic skills. They are often categorized as having a *learning disability*. In the United States and several other countries, this term is specifically used for those who show limited abilities in reading, writing, spelling, or performing mathematical calculations despite receiving conventional instruction, possessing adequate intelligence, and having sociocultural opportunities. In contrast, in the United Kingdom, a learning disability is not solely characterized by low academic performance but also denotes reduced intellectual ability, which is associated with difficulties in everyday activities, affecting an individual throughout their life. It involves significantly lower intellectual functioning than average and limitations in carrying out day-to-day tasks. The U.K. definition covers a broader spectrum of cognitive, social, and practical skills compared to the U.S. definition. In this paper, we employ the term learning disability in the U.K. sense. The global prevalence of individuals who meet the criteria for this condition is estimated to be between 0.05%–1.55% (Maulik et al., 2011; McKenzie et al., 2016) or 1%–3% (Patel et al., 2020).

People with LD are considered vulnerable to health-related problems (Allweiss et al., 2017; Perera et al., 2020), and they can develop the same mental health problems as people without LD, which is a major challenge for public health care and services (Deb et al., 2022). The frequency with which people with LD are treated in the mental health system is also increasing (Nieuwenhuis et al., 2017; Nieuwenhuis et al., 2021).

Despite the reported importance of mental disorders, there is limited evidence regarding the specific experiences of health care workers and caregivers in caring for people with LD and mental health problems in the field of mental health care (Chiang et al., 2022; Schmidt & Uman, 2020). Some of these studies focus on presenting people's experiences of mental health services (Kroese et al., 2013; Whittle et al., 2019) and psychotherapy (Evans & Randle-Phillips, 2020; Lewis et al., 2016; Ramsden et al., 2016). Other studies include investigations of the perspectives of caregivers, direct support staff, social workers, nurses, health professionals, mental health professionals, and therapists in general or in relation to mental health services and inpatient mental health care for people with LD (e.g., Araten-Bergman & Werner, 2017; Ee et al., 2021, 2022; Fredheim et al., 2013; Lee & Kiemle, 2015; Rose et al., 2012). Experience studies, however, tend to generalize about mental disorders rather than be specific to a particular disorder, and those involved in the mental health care of people with LD feel challenged (Ee et al., 2022).

Until now, we have underestimated the importance of disorder-specific experience studies in terms of their importance for research. As a result, we know little about current support practices and caregivers' specific experiences,

needs, and challenges in interacting with people with LD and comorbid OCD living in institutionalized settings. The reported prevalence of OCD is 0.7% to 3.5% in people with LD (Cooper et al., 2007; Deb et al., 2001; Vitiello et al., 1989), compared to 1%–2.3% in the general population (Fullana et al., 2010; Ruscio et al., 2010). Therefore, people with LD may have OCD as a comorbidity, and in particular, the heterogeneous group of people with LD and OCD places specific demands on the health care system in general and on caregivers in institutionalized settings.

To date, issues surrounding OCD in people with LD have received little scientific attention although it can be a comorbid condition. Specific guidelines and diagnostic manuals have been developed for the prevention, assessment, management, and treatment of mental health problems as well as challenging behaviors in people with LD (Bertelli et al., 2022; Deb et al., 2022; Gentile et al., 2018; National Collaborating Centre for Mental Health [UK], 2015; National Guideline Alliance [UK], 2016). Analysis of the guidelines shows that they do not specifically address the treatment of OCD in the context of LD, nor do they provide guidance on how caregivers can support treatment in daily life in a broader sense. In addition, guidelines and recommendations for the clinical diagnosis and therapeutic and medication treatment of OCD are available for the general population (Koran et al., 2007; UK, 2006; Reddy et al., 2017; Voderholzer, Rubart, et al., 2022). In this regard, treatment and medication strategies for people with OCD have been well researched (Skapinakis et al., 2016). For example, OCD is basically treatable, and treatment can lead to symptom reduction with guideline-based therapeutic support, such as cognitive behavioral therapy with or without pharmacotherapy in combination with other treatments (Berberich & Hoffmann, 2022; Voderholzer, Favreau, et al., 2022). Wahl et al. (2010) found that 70% of patients with OCD in outpatient care in the German general population were unrecognized and therefore untreated. Given the diagnostic difficulties (e.g., Gentile et al., 2018; Seidel, 2019), the situation is likely similar for people with LD. In addition to the undertreatment of OCD, the mistreatment of people with LD should be addressed.

### **PURPOSES OF THE STUDY**

Among other things, mental disorders in people with LD result in an additional and, if unrecognized or mistreated, often unmet need for psychiatric-psychotherapeutic care (Schützwohl & Sappok, 2020). Therefore, it is beneficial in this study to limit the focus to OCD in the mentioned guidelines as well as the lack of information on OCD support beyond treatment, that is, tasks for professional environmental support (e.g., caregiver). To better understand and provide mental health support and specific needs for people with LD and OCD, it is first necessary to understand the challenges and strategies of the people who

support them, including caregivers in institutionalized settings.

We derived the objectives of this study directly from the problems described above and address this important research gap by providing an in-depth view in this context of (a) perceived challenges and (b) strategies caregivers use in institutionalized settings.

As a result, we focus on two questions:

**Research Question 1:** What challenges do caregivers in institutionalized settings face when dealing with compulsive behaviors in people with LD?

**Research Question 2:** What strategies do caregivers use to manage the compulsive behaviors in people with LD in institutionalized settings?

We examine the findings with respect to professional caregiver support, relate them to existing knowledge, and summarize empirically based implications for research and practice. This study's results may provide guidance for the development of specific and practical recommendations for caregivers to meet the needs of people with LD appropriately in the context of OCD.

## METHODS

### *Participant Recruitment and Description*

We contacted by letter and/or email 20 medium to large institutions in three German states where people with LD live. We selected institutions on the basis of contacts with people in leadership positions. Inclusion criteria for the case study comprised a person with LD, diagnosis of OCD or severe compulsive behavior (i.e., six to seven times per week for more than 1 hr per day if uninterrupted), high need for support due to the compulsive symptoms, and unusual degree of compulsive symptoms. Exclusion criteria included (acute) somatic symptoms, compulsive behavior phenotypic for the disability (e.g., Cornelia de Lange syndrome, Prader–Willi syndrome), and behaviors that only disturb the environment (i.e., not pathological) or occur infrequently.

If an individual met the inclusion criteria in the first recruitment phase (32 short behavior descriptions), they submitted a short questionnaire for the second recruitment phase (selecting 11 from 32 descriptions). The two recruitment phases resulted in eight individuals with LD; these phases involved in-depth discussions with an OCD psychotherapy expert. Prior to the start of the study, Case Study 8 had to cancel due to illness. In total, seven case studies (4 males, 3 females, ages 40–71 years) explored the challenges and strategies caregivers use to manage OCD in people with LD. The participants' conditions covered all of the World Health Organization's (2021) severity levels of intellectual development disorders (6A00) except for the profound disorder (6A00.3). Among the subjects with LD, three had a diagnosis of OCD and four had suspected OCD.

Table 1 summarizes the participant composition, detailing the diagnoses of people with LD and the professional affiliations of other participants in the seven cases. The diagnoses are based on the 10th revision of the ICD, but to connect the study results, we translated them here based on the 11th revision.

**Table 1 . Summary of diagnoses and affiliations of participants in the seven case studies**

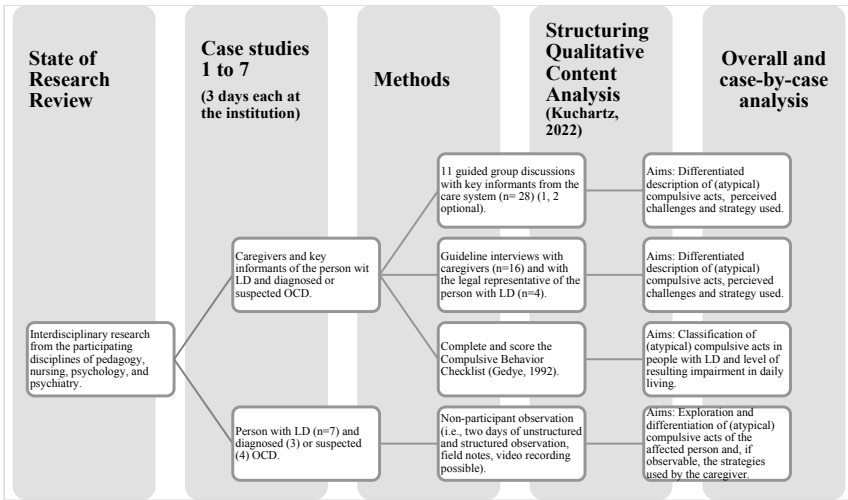
<b>Summary of ICD-11 diagnoses of persons with LD (n=7)</b>	<b>Summary of the composition of the first group discussion (n=28)</b>	<b>Summary of the composition of the individual interviews (n=20)</b>
<ul style="list-style-type: none"> <li>- Disorders of intellectual development: 6A00.0 (2), 6A00.1 (4), 6A00.2 (1);</li> <li>- Obsessive-compulsive disorder: 6B20 (3);</li> <li>- Other diagnoses: 6A20.Y (1), 6A23 (1), 6A02.5 (1), 8A60.9 (1), LB18 (1), 2F34 (1).</li> </ul>	<ul style="list-style-type: none"> <li>- Institutional Management (2);</li> <li>- Specialized Service (4);</li> <li>- Nursing Care Management (3);</li> <li>- Pedagogue (4), Curative Education Nurse (8);</li> <li>- Nurse (1), Geriatric Nurse (3), Nursing Assistant (3).</li> </ul>	<ul style="list-style-type: none"> <li>- Legal representation of the person with LD (4);</li> <li>- Specialized Service (2);</li> <li>- Nursing Care Management (1);</li> <li>- Pedagogue (3), Educator (1), Curative Education Nurse (3);</li> <li>- Nurse (2), Geriatric Nurse (1), Nursing Assistant (2), Medical Assistant (1).</li> </ul>

**Study Design**

The use of case studies is a common method in qualitative research (Priya, 2021). This qualitative study is exploratory in nature due to significant research gaps in this context. The strength of the case study design is that it allows for an in-depth description and analysis of one or more cases in their natural setting, thus providing an in-depth understanding of the research topic (Priya, 2021; Yin, 2018). The individuals with LD who participated in the study live in specialized residential settings, commonly referred to as institutionalized settings in Germany, where they receive daily support from caregivers. A total of seven case studies (four males and three females) explored the perceived challenges and the strategies caregivers use in this particular context. The overall

study design comprised the nonparticipant observation of the person with LD, group discussions with key informants of the support system ( $n = 28$ ), and semistructured interviews with caregivers and legal representatives of the person with LD ( $n = 20$ ). We also used caregiver scores on the Compulsive Behavior Checklist (Gedye, 1992). We analyzed the empirical qualitative data through qualitative content analysis (Kuckartz & Rädiker, 2023).

Group discussions and individual interviews with caregivers and key informants led to the findings we discuss in this paper. To help explain the study, Figure 1 shows a visualization of the study design.



**Figure 1. Visualization of the research process**

### ***Guided Group Discussions***

The strength of guideline-based group discussions lies in the effective facilitation of joint discussion of questions, which can provoke diverse opinions and perspectives (Vogel, 2022) that lead to differentiated descriptions of perceived challenges and strategies used. At the beginning of the first research day, each case study used the qualitative method of group discussion with key informants relevant to the person with LD. Due to the different time resources and group sizes of the key informants, we discussed content areas with different intensities. If the capacity of the institutions allowed it, we conducted a final group discussion with the same or a similar composition of participants on the third research day.

The groups of key informants were as heterogeneous as possible to obtain results relevant to the target group. We prestructured the following content areas using a discussion guide in five phases, including open-ended questions:

- clarification;
- the person: their biography and their position in the institution;
- support needs, challenges, and relevant situations related to compulsive behavior;
- practiced strategies and reactions; and
- additions, access to the person, and conclusion.

***Guided Individual Interviews***

In addition, we conducted guided individual interviews using a semistructured interview format (Misoch, 2019) with caregivers ( $n = 16$ ) with and without prior participation in group discussions and with legal representatives of people with LD ( $n = 4$ ). The guidelines served to capture the subjective theories on the topics and the everyday knowledge of the interviewees in a structured way, with as much openness as possible (Helfferich, 2022). A leading question introduced each content area, followed by in-depth questions about the topic area as appropriate. For the individual interviews, which we prestructured according to a guideline, the following topics were particularly suitable:

- introduction and entry,
- biographical reconstruction of the person with LD's history,
- insights into the daily life of the person with LD and the meaning of the symptomatology of OCD,
- requirements for professional roles,
- restrictions due to compulsive behavior,
- information about the subjective significance of compulsive behaviors in working with people with LD and relationship implications,
- situations in which compulsive behavior manifests itself,
- challenges in dealing with the compulsive behavior and help,
- strategies for managing the compulsive behavior of the person with LD, and
- conclusion.

***Description of Overall and Individual Case Analysis Procedures***

After completing seven case studies, we transcribed and analyzed empirical data from qualitative surveys using qualitative content analysis (Kuckartz & Rädiker, 2023). We developed an inductive–deductive category system. Instead of a following consensual coding process (Kuckartz & Rädiker, 2022), we coded the transcripts from Case Study 1 using MaxQDA software

and with a second coding pass, as Kuckartz and Rädiker (2022) suggested. A comparison of coding passes revealed minor differences, requiring only a few category definition adjustments: For the content analysis of perceived challenges, we changed the category “diagnosis and differential diagnosis” to “recognizing and classifying ambiguous behavior” due to the demands placed on caregivers. In addition, we split the text segments previously grouped in this category into “recognizing and classifying ambiguous behavior” and “information about emotional well-being and needs through nonverbal signals.” We renamed the category “discipline-related requirements for changing needs” as “nonqualified to address the additional needs of the person with LD” based on the analysis of the coded text segments. In terms of strategies practiced, we split the category “tolerating and accepting” into “tolerating and allowing the compulsive act” and “accepting and supporting the compulsive act” for further analysis of the data. In addition, “stopping the compulsive behavior” combined successful stopping and attempts to stop the behavior because attempts to stop the compulsive behavior were more common in the data. By combining qualitative methods from the case studies, we obtained case-related and cross-case findings through qualitative content analysis.

### ***Ethical Considerations and Consent of Participants***

In Germany, according to local laws and the institutional criteria of the University of Cologne, an ethics committee consultation is not mandatory for nonmedical social or ethnographic research projects. Vulnerable persons with LD in the broader sense participated in this part of the study; that is, they were reported through interviews and discussions with caregivers and key informants. However, given the involvement of human subjects, especially vulnerable people with LD, our study strictly adhered to recommended research ethics guidelines. We followed the German Research Foundation guidelines (2022) and the German Interdisciplinary Society guidelines for promoting research on people with intellectual disabilities (2020). Based on these guidelines, we developed a self-reflection and research reflection framework with eight procedural steps to ensure ethical harmlessness, including risk assessment, respect for rights, and crisis intervention strategies.

An information letter provided clear and transparent information to all subjects about the purpose of the study, study procedure, data protection, anonymity, retention obligation, voluntary participation, and publication. All involved participants provided informed written consent (Kiegelmann, 2020), including legal representatives of the person with LD, key informants, and caregivers, without withdrawal. The study complied with the Data Protection Act of North Rhine-Westphalia. For risk assessment and respect of rights, we agreed on crisis intervention strategies and had crisis intervention plans in place for six of the seven participants with LD. Each institution had a specialist



trained in crisis prevention, intervention, and aftercare. Ongoing consultation was intended to prevent incidents, with the study ready to stop if necessary.

## RESULTS

The results in this paper focus on the qualitative findings. Therefore, the sequence of main codes is arranged not by their frequency but in a logically comprehensible order of categories. Additional quantitative details on code frequencies, provided after each main code, should not be viewed in isolation but rather alongside the qualitative statements (Kuckartz & Rädiker, 2022).

The category frequencies result from the group discussion and individual interview analysis units. When we quantify the results of the qualitative content analysis, however, “high category frequencies in an interview do not necessarily go hand in hand with a high significance of the category for this case” (Kuckartz & Rädiker, 2022, p. 117).

### *Perceived Caregiver Challenges*

#### **Recognizing and Classifying Ambiguous Behavior**

The data reveal challenges for caregivers in recognizing and classifying the ambiguous behaviors (code frequency: 64) of people with LD. This information provides the specification necessary for the conceptual development of practice guidelines. Classifying OCD in people with LD is a significant challenge from a caregiver perspective. This leads to the specific differentiation challenge for caregivers in distinguishing symptoms of OCD in people with LD from (a) other mental or neuropsychiatric disorders, (b) autism spectrum disorder, (c) medication influences, (d) rituals and habits, and (e) behaviors related to the intellectual disability (e.g., stereotypes). In this study, the nonspecific behavior of the person with LD, considered in isolation, is found to be a central reason. This results in behavioral ambiguity for caregivers and hence the need to (safely) differentiate and classify behavior through observation, as the following two statements show:

It’s also difficult because everything is actually based on this observation, these descriptions. I can’t take a blood sample and say, “Oh, you have depression or you have schizophrenia.” That would be nice if it could be done that way ... and also many mixed forms. I find everywhere a little bit of, he has a little too much of each or something. He has a little bit of autism, a little bit of borderline, a little bit of [schizophrenia].... For each one, I could say, “Oh, he has that too, he has that too, and he has that too, like this.” (Case Study 1, group discussion, Pos. 216–218, Speaker B4, registered nurse)

That’s really difficult with intellectually disabled people, to recognize, to define these mental illnesses. So that is, everyone

has difficulty because you don't know if it is a mental handicap or ... if it is a mental illness.... So always with the diagnosis now to determine exactly whether this is really a mental illness in addition, and that he really shows the symptoms of a mental illness. And that is the great difficulty in this area really have no verbal language then. (Case Study 3, group discussion, Pos. 110, Speaker B1, specialized services)

### ***Information about Emotional Well-being and Needs through Nonverbal Signals***

The seven people with LD in the study had little or no verbal language, which led to the challenge of how to capture information about emotional well-being and needs through nonverbal signals (code frequency: 42). This required the caregivers to observe and interpret ambiguous nonverbal behavioral signals (gestures, facial expressions, and behaviors) of the person with LD and adjust their actions accordingly. In terms of recognizing and managing additional mental illness in the person with LD, two specific needs for caregivers emerge from this study. The nonverbal expressions of the person with LD challenged caregivers to derive relevant information about the person's current emotional well-being and needs and to assess the degree of subjective impairment caused by the compulsive act:

I know what she wants from her gestures, but I don't know what's actually going on inside her. That she enjoys it, that she likes it ... but if she has any other wish and can't express it ... [which makes things] difficult. Can you only hear from the staff because of her behavior, that sometimes you get behind what it is. (Case Study 2, Interview B5, legal representative of the person with LD, Pos. 58)

Another respondent states, "That's what I try to do and make, but I just don't get positive or negative feedback. That is, most of the time you notice it then, of course, when he spreads the stool or when he has wetted the bed, that something didn't fit." (Case Study 5, Interview B4, assistant, Pos. 76)

### ***Finding and Applying Effective (Coping) Strategies***

Another challenge that emerges in the study is finding and applying effective (coping) strategies (code frequency: 95) in dealing with the compulsive behavior in the person with LD. For the seven individuals with LD diagnosed with or suspected to have OCD, caregivers use five strategies individually and in combination. From the caregiver's perspective, the strategies used to cope with the OCD, including those classified here approximately as disorder-specific, had little or no influence on the affected person's behavior; they lead to a reinforcement of the compulsive action or to a shift to other objects. For example, in Case Study 3, the limitation of the number of light switches to turn

on and off leads to a shift to the repeated closing of doors and windows. We therefore discuss the question of the fundamental ability to influence behavior. The caregiver's uncertainty about how to respond appropriately to compulsive behaviors directly relates to this, as the following statement shows: "To the extent that I let their compulsion act out now, does it then multiply even more that is then not always so [quieter], not so easy" (Case Study 2, group discussion, Pos. 36, Speaker B4, geriatric nurse).

Moreover, caregivers report that the person's compulsive actions change and that new ones develop, which means that the team has to agree repeatedly on new action strategies. One problem in the decision-making process regarding the appropriate coping strategy is the caregiver's fear of aggressive reactions from the person with LD when they stop the compulsive act, which some caregivers consider unpredictable, "I worry about, also about the employees ... because he is so unpredictable.... You just don't know. You can't assess it. It's so unpredictable because otherwise, we could take stuff out" (Case Study 1, Interview B6, nursing assistant, Pos. 54)

### ***Not Qualified to Address the Additional Needs of the Person with LD***

A challenge in pedagogical and care institutions, as mentioned by caregivers, is that they are not qualified to address the additional needs of the person with LD (code frequency: 98) in terms of recognizing and dealing with mental disorders in people with LD in general and with OCD in particular due to their heterogeneous professional orientation (e.g., pedagogical staff, care staff, unskilled staff). First, caregivers have various levels of theoretical and/or practical knowledge about people with LD, depending on their profession and previous field of work:

That's when I grew into it, but of course, the employee of the specialist service is the specialist because, of course, a nursing specialist does not go to the training courses with mentally handicapped people and autism. So, then I have to slowly educate myself again a little bit because it's more care in which I did the training and everything. In school, something like that doesn't happen at all, background knowledge like that. (Case Study 3, Interview B2, Pos. 6)

Second, the lack of training and the little or no further training regarding mental disorders with a focus on people with LD leads to a challenge in that caregivers have to deal professionally with an additional need of the person with LD for which they are not (sufficiently) qualified. This leads to uncertainty among caregivers in dealing with compulsive behaviors in people with LD: "To what extent do I let their compulsion act out now, does it then multiply even more, that is then always not so, [quieter] not so easy" (Case Study 2, group discussion, Pos. 36, Speaker B4, geriatric nurse).

### ***Inappropriate Institutionalized Conditions***

The data reveal that, from the caregiver's perspective, the specific environments and institutional structures are inappropriate institutionalized conditions (code frequency: 139) for recognizing and managing compulsive behaviors in people with LD; they are unsuitable at several levels. At the structural level, this relates to the number of objects that could be relevant to the person with LD (e.g., large numbers of rooms, doors, light switches). At the task level, there are various statutory service priorities of the institutions where the person with LD lives (e.g., long-term care services, inclusion services, protective housing option). At the staff level, it is the heterogeneous composition of the staff (e.g., pedagogical staff, nursing staff, educators, unskilled staff) and the availability of staff resources (e.g., different tasks and perspectives, staff shortage, need for one-to-one care). For example, this exchange occurred during an interview:

Interviewer: Have you ever tried to stop that, so to speak?

B3: Yes, of course you try, but you can't do it because you would always have to stand next to her, and that's why you can't manage that. (Case Study 2, Interview B3, geriatric Nurse, Pos. 18–19)

Another respondent stated,

Yes, we exchange. We talk to each other a whole lot. And when five people sit there, sometimes there are five different insights about the same situation. And there, I have sometimes said, "Either I am now wrong, not wrong, or have a different perception than my colleagues. We were yet in the same place, and the place is often like this. (Case Study 1, Interview B4, registered nurse, Pos. 11)

The caregivers in this study did not consider the working hours and procedures (e.g., shift work, scope of tasks, time resources, lack of observation resources, limited presence, incomplete information sharing) in institutionalized settings adequate because they allow the caregivers to perceive only snippets of the behavior and its intensity, as the following statement illustrates:

Even if someone really spends time with him intensively, observes him with all the trimmings, there you could also conceptually work even further, like one is there in the morning, one is there in the afternoon, one writes this down, the other this, the other that, and if handovers occur and several take care of one, information also gets lost. (Case Study 1, Interview B1, specialized services, Pos. 58)

The seven people with LD included in this study live in institutions that are referred to as "special forms of housing" in Germany. There, the affected persons with LD live in apartments shared with up to eight other people with LD. The other people with LD are at risk due to or are restricted (e.g., in their

freedom of decisions and movement) by the affected person's compulsive actions. The caregivers mentioned that it is challenging to consider the needs of the other persons with LD in addition to the needs of the affected person, focusing on the affected person and neglecting the other residents: "It doesn't restrict him personally; it restricts the group in some things ... so it doesn't restrict him at all. He's happy the way it is." (Case Study 5, Interview B3, nurse, Pos. 30)

Another respondent said,

Many residents have to make cutbacks because of him. First, because some of our residents can't talk, except for two female residents. And I think we have to close some of the room doors; we have to close the windows. In the summer, the residents partly sweat because the windows are closed. I think if the residents could talk and also fight back ... it wouldn't be easy for [the person with LD]. (Case Study 3, group discussion, Pos. 131, Speaker B2, nursing care management)

### ***Lack of Specialization in the External Mental Health Care System***

Another challenge that emerges from the caregiver's perspective is the lack of specialization in the external mental health care system (Code frequency: 21) regarding the needs of people with LD and additional mental disorders in general and in relation to compulsive behaviors in particular. In the context of (outreach) primary care, limited time resources for face-to-face contact with the person with LD were mentioned as a challenge. Other external support is related to the psychiatric–psychotherapeutic support system. In acute psychiatric care, people with LD are quickly discharged without resolving the problem and return to institutions. In crisis situations, caregivers face long waiting times in psychiatric hospitals, especially in the more distant special psychiatric units for people with LD. Caregivers report that in some cases, psychopharmacotherapy is required as a permanent medication or as medication on demand. However, caregivers find such a medication regimen challenging and often unhelpful. Medication management focuses primarily on reducing aggression, tension, or agitation and is perceived as a balancing act between improving and worsening the quality of life of the person with LD, considering the side effects and interactions.

Furthermore, in this study, there is a lack of collaboration, cooperation, and exchange between the pedagogical support system and the mental health care system, such as with the psychiatric hospital described in Case Study 1:

That's just the way it is; the man is very difficult to adjust with medication. You can't really manage it at all. The only thing that really works for him is a sedative [medication with a calming and activity-dampening effect] so that he comes down again. That's it. Otherwise, if you start him on

Citalopram [antidepressant], he'll be up-regulated to a dose that's no longer actually approved, but for the QT interval and so on, it all still fits, which of course on the other hand is again drive-increasing, which is counterproductive to the aggressive outbursts, but it's supposed to help with the compulsion. He was also in the hospital in this regard. The psychiatrist came the other day [laughs] to the psychiatric hospital; now, the dose should be critically reviewed by the hospital. We refer to the hospital, from them, this came, so it's very, very difficult, exactly [laughs]. (Case Study 1, group discussion, Pos. 223, Speaker B6, nursing assistant)

Access to the psychiatric–psychotherapeutic care system is considered difficult to nonexistent. Moreover, there are no specializing psychotherapeutic services for people with LD.

### **CAREGIVER STRATEGIES FOR MANAGING COMPULSIVE BEHAVIOR IN PEOPLE WITH LD**

#### **Tolerating and Allowing the Compulsive Act**

One strategy that caregivers in this study use to cope with the compulsive behavior of people with LD, individually or in combination with other strategies, is tolerating and allowing the compulsive act (code frequency: 62). Under this strategy, the summarized ways of dealing with the behavior indicate nonpathological motives for the behavior. These include trivialization (e.g., distinct personality trait), emphasizing the necessity of the compulsive act for the person with LD (e.g., providing guidance in the context of disability specificity), and classifying the compulsive act as a job (e.g., keeping rooms tidy). For example, one respondent stated, “And then, it's in the obsessive person's head, and you won't be able to change that. That's just, I think now, a piece of her” (Case Study 2, B3, geriatric nurse, Pos. 13). Another stated,

I would maybe, I don't know, build a light switch in his room or somehow indicate that he is busy. He can play or ... I don't know, can move chairs. I've also thought about throwing 20 pillows in his bed, which he can then sort—something like that. That he is simply employed.... I also sometimes leave doors open or windows open. Then he is busy. (Case Study 3, Interview B4, medical assistant, Pos. 108)

However, there are also caregiver response patterns that indicate shutting down situations related to the compulsive act. These include ignoring the compulsive act as a caregiver, leaving the relevant situations, and keeping a distance from the person with LD. In both directions, the compulsions of the person with LD are tolerated, nothing is done about the compulsions, and the behavior is allowed.

This strategy reflects the caregiver's assessment that the compulsive act should not be stopped, should not be stopped permanently, or should never be stopped. Caregivers' reasons for tolerating and allowing the compulsive act include the absence of danger to self or others, the nonharmfulness of the behavior to the person with LD or others, the compulsive behavior's unchangeability, and the fact that the person with LD would always find a way to perform the act:

He can live out his compulsions for all I care. As long as he doesn't endanger himself or others, he can do that. He can open and close the closet door 120 times for all I care because I don't think it's going to get him down. (Case Study 1, Interview B1, specialized service, Pos. 80)

### **Accepting and Supporting the Compulsive Act**

Accepting and supporting the compulsive act (code frequency: 108) is another strategy caregivers use to cope with the compulsive behavior of the person with LD, either alone or in combination with other strategies. This strategy includes accommodating or integrating the compulsions into the caregiver's existing work routines and adjusting daily routines to meet the needs of the person with LD. In terms of the caregiver's time management, this strategy is evident in the deliberate scheduling of delayed and unstructured times for the performance of the compulsions through the rescheduling or quick implementation of hygiene measures. At the level of general conditions, this strategy includes caregivers' adherence to constraint-specific rules and procedures, relieving individuals by allowing them to rest, reducing or foregoing tasks, avoiding excessive demands by minimizing change or pressure, or initiating special arrangements. For example, one respondent stated, "That's gone because everything else that he has in terms of constraints can otherwise be easily incorporated into everyday life" (Case Study 1, Interview B6, nursing assistant, Pos. 78). Another stated,

"No matter what we do, he needs to live out the compulsions, and that's why we tried, as far as possible, as the colleague said, to adapt life to him" (Case Study 3, group discussion, Pos. 125, Speaker B1, specialized service).

Furthermore, in three case studies, during the execution of the compulsive act, attempts were made to create a pleasant atmosphere for the person with LD through physical touch, praise, or thanks:

Every now and then, I sweep something away, or sometimes I thank him and say, "You've tidied that up pretty well now. It's nice that it's clean. Thank you," just to look at it a little more normal than it actually is. Yeah, maybe he feels taken more seriously there or something. (Case Study 1, Interview B6, nursing assistant, Pos. 44)

Reasons for acceptance and support identified in this study include caregivers' assessments that stopping the compulsive act would result in danger to self or others or increase the person's stress level, or they want to ensure that the person with LD is comfortable: "We try to let him have his way to prevent this aggression so he feels reasonably comfortable in his skin" (Case Study 3, group discussion, Pos. 105, Speaker B3, pedagogue).

### **Being Involved in the Compulsive Act**

In this study, being involved in the compulsive act (code frequency: 24) of the person with LD is another strategy caregivers use individually or in combination with other strategies. This strategy includes caregiver approaches that we refer to in this study as involvement in the form of accompanying, assisting, taking over, or coexecuting the compulsive act:

I see that argument: You're all codependent up there. I see that, and yes, that's probably true, but I don't want to make me or [the person with LD] have a terribly tense day. If that's because of a cup lined up somehow or otherwise lined up, then I'm happy to do that. (Case Study 5, Interview B1, curative education nurse, Pos. 40)

This strategy reflects the caregivers' assumption that their involvement, such as by participating in the compulsive act, allows them to build a better relationship with the person with LD and that the person with LD feels better or more normal:

I had the feeling that if I take on a few of his—I'll succinctly call them quirks—that this is sympathetic to him or that he feels more comfortable there or simply thinks, "Oh, look. She has the same damage as me. I like her." That I simply got better access or more closeness through it. At least that's what I tell myself... I simply also touch these signs and look at them ... simply to make it look a little more normal than it actually is. Yes, maybe he feels taken more seriously or something." (Case Study 1, Interview B6, nursing assistant, Pos. 44)

### **Limiting the Compulsive Act**

Limiting the compulsive act (code frequency: 77) is another identified caregiver strategy and includes limiting the compulsive action in terms of time, space, subject matter, or number before or during the implementation of the compulsive action. Response modes to the compulsive action of the person with LD include planned limitation by the caregiver prior to the performance of the compulsive action, such as preportioning food in the context of completeness compulsion, stimulus reduction in control compulsion, and maintaining an object's position in order compulsion. Meanwhile, the limitation for the caregivers during the implementation of the compulsive action occurs situationally or uniformly in consultation with the team. Response



modes include compromising by limiting the number, duration, or location; announcing and enforcing consequences; and allowing the compulsive act as a reward for an imposed activity. In addition, offering an alternative behavior, distracting and redirecting, and planning alternations between performing the compulsive action and insisting on performing other activities are all classified as strategies of limitation. For example,

All theory is gray. I was once in an advanced training on constraints. There, it was said that one should try to replace it with something else, which is perhaps more meaningful, but for him, it makes some sense. We limited him with the light switches. He had to tolerate that.... Only we can work the switch. He has accepted that but has just then looked for the only one who goes and also found. We deliberately left it that way ... a middle ground between letting him go and paying attention to the others. He would turn the light on and off in the group room while watching TV. You really noticed that he was told three times not to do it, for example. It is a compulsion. He has done it again and again. At some point, the other residents also became restless. It got on their nerves. (Case Study 3, Interview B3, pedagogue, Pos. 68 and 70)

### **Stopping the Compulsive Act**

Another strategy that caregivers use is stopping the compulsive act (code frequency: 105) and attempting, with only a brief or no effect, to stop the compulsive action of the person with LD. For example, this exchange occurred:

B2: [The person with LD] already has a real disorder. I say obsessive-compulsive disorder. And we try to take him out of this predicament. He can then just count for hours, just count, stand and count, and of course, we try to do that.

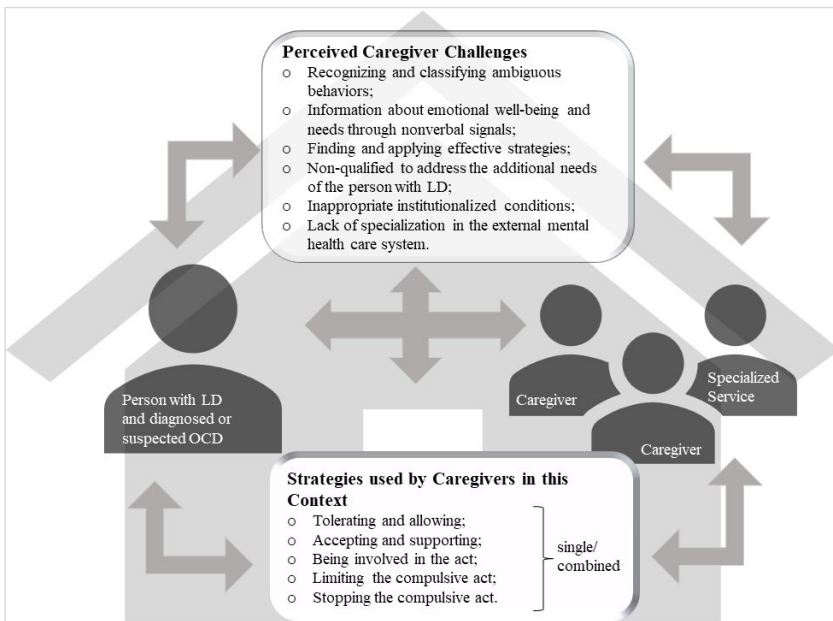
B3: To prevent it.

B2: To make it as good as possible so he then gets out. (Case Study 4, group discussion, Pos. 20–22, Speaker B2, geriatric nurse, Speaker B3, pedagogue)

Caregiver strategies include removal or elimination of the relevant object, one-to-one attendance, monitoring, and close guidance with insistence on the performance of any task. With the intention of ending the compulsive act, freedom-restricting strategies are also used. These actions consist of temporary separation from group situations, a crisis intervention plan, the administration of prescribed permanent and acute medication, limited use of a legally approved hand restraint belt, and in the case of danger to self or others, admission to a psychiatric hospital. For example,

My wish for him is that he gets a better position, quite simply. And he'll get it, so I'll do my best to make sure that happens. Even if it first has to be with mechanical aids.... This will also increase the quality of life again if that is what he wants. (Case Study 1, Interview B1, specialized services, Pos. 94)

This strategy follows from the caregiver's premise that the compulsive behavior of the person with LD should be stopped only if it presents a risk to self or others and the person's well-being could be improved by doing so. When in doubt, the behavior should not be stopped. Figure 2 presents our key findings regarding the perceived challenges and strategies caregivers use in dealing with OCD in people with LD and their potential interactions in institutionalized settings.



**Figure 2. Key findings on perceived challenges and strategies practiced by caregivers in dealing with OCD in people with LD**

## DISCUSSION

### *Perceived Caregiver Challenges*

To date, researchers have conducted comparatively little research to examine the specific experiences, challenges, and coping strategies of professionals dealing with the mental health problems of people with LD, focusing on mental health and primary care professionals (e.g., psychiatrists, therapists, physicians,

and nurses). In addition, researcher interest has tended to be cross-disorder rather than disorder-specific (e.g., Chiang et al., 2022; Ee et al., 2022; Schmidt & Uman, 2020). As a result, very little is known about the cross-disorder and disorder-specific experiences of the immediate support system in day-to-day care in dealing with the mental health issues of people with LD.

The results of this qualitative study clearly indicate that the caregivers were overwhelmed or felt challenged by the demands people with LD and additional compulsive behaviors place on them. We identified six main areas to describe the challenges that caregivers face in this context. The range of challenges includes the demands for professional support and the conditions under which these demands should be met.

The findings outline the following spectrum of key challenges: recognizing and classifying ambiguous behaviors, information about emotional well-being and needs through nonverbal signals, finding and applying effective strategies, inappropriate institutionalized conditions, not being qualified to address additional needs of the person with LD, and lack of specialization in the external mental health care system. Ee et al. (2022) identified 14 qualitative studies that examined the experiences of mental health professionals providing services in this context and found that the main challenges mental health professionals faced were related to understanding people with LD, their interactions and relationships, and organizational factors.

Consistent with the challenging organizational factors for health care professionals working with adults with LD and mental health problems in the study by Ee et al. (2022), and specific to OCD, existing organizational frameworks are inappropriate in the context of OCD (e.g., multiple properties, structural conditions in large facilities, shift work, limited staff). Understanding and interacting with people with LD was identified as one of the main experiences of mental health professionals (Ee et al., 2022) and in this context can be classified as the pedagogical needs of people with LD. In other studies, other professionals involved (e.g., those in the mental health care system) also reported the lack of qualifications necessary to address the additional needs of people with LD and mental health problems, mainly in relation to the additional needs in the context of LD (e.g., understanding the person with LD, communication; Durbin et al., 2017; Ee et al., 2022; Schützwohl et al., 2016). In contrast, the challenge for caregivers in this study was understanding and categorizing the well-being and needs of people with LD through nonverbal signals, which can be characterized as the psychiatric or therapeutic needs of people with LD.

There are also significant challenges in diagnosing OCD in people with LD (Barnhill, 2011; Seidel, 2019). This well-known difficulty is also experienced by caregivers in recognizing and classifying ambiguous behaviors in the context of OCD because they typically lack training in the psychopathological behavioral

assessment of people with LD (Schützwahl & Sappok, 2020; Werner & Stawski, 2012).

This is where the specialization of the various professions involved and the natural boundaries of the disciplines concerned come into play (e.g., due to uncertainty; Grüter, 2023). Caregivers in this study are experiencing the challenge of not being qualified to address additional needs, primarily in relation to the additional mental health problem of the person with LD, so the management of OCD reaches the natural limits of pedagogical or nursing expertise (Grüter, 2023). However, for the pedagogical and/or nursing needs of the person with LD, the coexisting compulsive behavior creates an additional psychiatric and/or psychotherapeutic need. The caregivers in this study are not sufficiently or specifically qualified to meet these additional needs, and the psychiatric and/or psychotherapeutic support is not sufficiently integrated into the existing support.

Ee et al. (2021) identified 13 quantitative studies conducted to examine, among other things, the knowledge of health and social care professionals (e.g., nurses, doctors) about people with LD and additional mental health issues. They found that knowledge was limited, there was a lack of training in this area, and health and social care professionals with no experience of working with people with learning disabilities reported uncertainty (Ee et al., 2021). Other studies from Germany have confirmed the perceived challenge of the external psychosocial care system's lack of specialization and the underuse of care for people with LD and mental health problems in general, without referring specifically to OCD (Schützwahl & Sappok, 2020). Schützwahl and Sappok (2020) referred in this context to the increased need for care of people with LD, which becomes fundamentally more complex in the presence of additional mental disorders and is provided by various assistance systems under social law in Germany. In Germany, research in this context has shown that there is an unmet need for care in the area of behavioral and mental disorders in people with LD (Schützwahl et al., 2016; Schützwahl et al., 2018). This applies in particular to the need for psychiatric and psychotherapeutic care, which is not being met for people with LD in Germany (Schützwahl & Sappok, 2020). International assessments point in a similar direction, emphasizing that "there remain significant barriers to appropriate care and treatment for this underserved population" (Fletcher et al., 2018, p. 3). This is all the more serious because OCD is often undiagnosed (Wahl et al., 2010), the diagnosis of mental disorders in people with LD is generally difficult (Bertelli & Moss, 2022), and the complexity of diagnosing OCD in this population is even greater. This underscores the urgent need for caregiver-centered and disorder-specific guidelines for caregivers to help them identify and meet the additional psychiatric or therapeutic needs of people with LD in collaboration with the health care system.

***Caregiver Strategies for Managing Compulsive Behavior in People with LD***

To date, we have no insight into the coping strategies that caregivers use in the daily support of people with LD and compulsive behaviors in institutionalized settings. In summary, we identified five key strategies, ranging from least to most intervening in managing the compulsive behaviors, caregivers use alone or in combination. These include tolerating and allowing, accepting and supporting, being involved, and limiting and stopping the compulsive act. The results show a spectrum of strategies caregivers use as well as ineffective strategies and even inappropriate strategies, which may result in the persistence of OCD.

The choice of strategy is related to the challenges identified, such as the experience that the strategies used have no effect on the compulsive behavior and the opinion that the person with LD needs the compulsive acts in some way. The caregivers' experience of uncertainty about how much the compulsive behavior distresses the person with LD and their fear of the reaction if the caregiver stops the compulsive act also influences the choice of strategy. The most common strategies caregivers use are intuitive or pedagogical strategies. More generally, disorder-specific or therapeutic strategies are used to some extent by caregivers as laypersons in this context, such as limiting and attempting to stop compulsive behaviors.

There are no official guidelines for caregivers on the specific issue of how to provide pedagogical daily living support to the person with LD in light of coexisting OCD. This may lead to the perceived challenge of caregivers having to develop their own (educational) strategies, which they therefore perceive as ineffective. Mental illness results in additional therapeutic and/or psychiatric needs that caregivers are not qualified to address (Schützwohl & Sappok, 2020). Seidel (2019) emphasized that OCD cannot be treated with pedagogical interventions and that pedagogical support can only supplement, not replace, therapeutic strategies based on therapeutic expertise. Seidel (2019) pointed out that professional psychotherapeutic and psychiatric treatment of people with LD and OCD should be characterized by the involvement of the immediate environment (e.g., caring relatives, a jointly supported "coherent, supportive approach"; p. 144).

Overall, there is a clear need for a comprehensive description of the roles and responsibilities of caregivers in institutionalized settings to deal with mental disorders in people with LD. In a scoping review on the management of mental disorders in people with LD in primary care settings, Pouls et al. (2022) examined caregivers' role expectations as one aspect of such care. They identified "recognizing symptoms of MHDs [mental health disorders] and seeking help; overcoming communication difficulties; providing additional information; co-decision making; implementing and monitoring the treatment plan; [and]

identifying adverse effects of psychotropic medications” (Pouls et al., 2022, p. 172). In the context of psychopharmacotherapy, attentive monitoring of medications’ side effects is one of the tasks of everyday support in the immediate environment that requires medical information (Seidel, 2019). It should also be considered that these caregiver roles and tasks need to be differentiated for different types of disorders, such as OCD. The role of caregivers in this context should be explicitly addressed through specific guidelines and training.

It is not surprising due to the care situation, but it is critical to note that none of the people with LD included in the case studies received psychotherapy. In all seven case studies, disorder-specific or symptomatic psychopharmacotherapy was administered on a daily or as-needed basis in addition to the strategies used, and psychiatric hospitalization was provided as needed.

Cognitive CBT with exposure and response management is considered the most effective treatment for OCD in the general population, according to the S3 guideline on OCD (Voderholzer, Rubart, et al., 2022). SSRIs are usually recommended for psychopharmacotherapy when exposure is not possible or not effective (Voderholzer, Rubart, et al., 2022). Regarding psychopharmacotherapy challenges for people with LD, the guideline by Schützwohl and Sappok (2020) may be additionally helpful as a support in OCD treatment. Koslowski et al. (2016) examined the evidence for interventions for mental health problems in adults with mild to moderate LD and concluded that no convincing evidence was found in the 12 included trials. However, Graser et al. (2022) reported a weak study base for the effectiveness of CBT for adults with LD and the effects of treatment with CBT; to date, the effects of CBT have only been demonstrated for depression, anxiety, and anger. Although the analysis revealed barriers to behavioral therapy for people with LD, it confirmed that behavioral therapy is feasible for people with mild to moderate LD (Gómez Albornoz, 2014). Few studies have specifically address the treatment of OCD in people with LD in small samples (Gómez Albornoz, 2014; Matson & Dempsey, 2009). As shown for Germany in particular, it must be taken into account that the psychotherapeutic care situation for people with LD is bleak (Schützwohl & Sappok, 2020).

The cause of the behavior usually determines the possibility of an (appropriate) disciplinary response and the choice of intervention strategy. Given the challenges outlined in this study, especially the behavior’s multiple meanings, Došen’s (2018) suggestions may be helpful. Došen’s (2018) three types of compulsive behaviors in people with LD mentioned above may also be helpful in determining needs-based strategies (e.g., noninterventional, pedagogical, therapeutic, and/or psychiatric strategies).

Applying the existing knowledge about OCD to people with LD, the

behavioral characteristics of OCD identified in this study, and the identified challenges for caregivers in recognizing OCD regarding the well-known diagnostic issues in persons with LD (Bertelli & Moss, 2022), there is a particularly high risk of not recognizing OCD in people with LD. This can be explained by the fact that many of the possible indications of OCD at the behavioral level are rather nonspecific and that several factors known to influence the presentation of psychopathological symptoms in people with LD may coincide in the context of compulsive behaviors: masked or atypical presentation, diagnostic overshadowing, acquiescence, and cognitive distortion (Bertelli & Moss, 2022; Schmidt & Meir, 2014). This should be taken into account in the debate on this understudied topic to promote understanding of the specificity of this dual diagnosis (LD and OCD) and to formulate relevant guidelines.

### ***Strengths and Limitations***

The strength of this study is that it is the first of its kind to use a qualitative approach to explore caregivers' experiences of challenges and strategies as direct support workers and key informants in an institutionalized setting and from a disorder-specific perspective regarding OCD in people with LD. This empirical data on current support and needs may be important for further research (e.g., for the development of caregiver-centered guidelines and training to meet their needs). Concrete psychiatric steps and differentiated support needs of the person with LD and the environment of the person in the context of psychiatric care can also be derived (e.g., sensitization and education of the environment for disorder-specific handling).

The composition of the study participants must be considered restrictive because we did not contact all institutions in Germany. Rather, we recruited the sample from existing contacts throughout Germany. Only three of the participants with LD had an official diagnosis of OCD. Despite the precautions taken with the inclusion criteria and the close consultation with a psychotherapist in the selection of case studies, it cannot be ruled out that the findings on caregiver challenges and strategies are related to OCD and behaviors labeled as compulsive. Another limitation is that caregivers' disorder-specific experiences were collected in a small number of case studies (i.e., challenges and coping strategies of caregivers from seven institutions). Therefore, it cannot be ruled out that in addition to the individual experiences, the institutional setting of each institution may have had a positive or negative influence on the caregivers' reports. This limitation was addressed by the cross-case analysis of the empirical data but also needs to be verified in larger quantitative studies with a larger number of study participants (e.g., through an online survey) to minimize possible institution-related effects.

To investigate the research questions, the use of QDA software is

recommended to help structure the qualitative content analysis of guided interviews and group discussions. The exploratory approach we followed requires the ability to review and analyze not only deductive categories but also categorical compilations of coded text segments (text retrieval), which QDA software facilitates. The functions of the QDA software do not take over but support the differentiation of categories, the identification of inductive categories, the structuring of the coding process, and the analysis process for within-case and cross-case analysis (Kuckartz & Rädiker, 2022).

However, this was a qualitative study, which means that although there are differentiated findings regarding challenges and strategies for dealing with OCD in the context of LD, they are not representative and cannot be generalized due to the subjective interpretation of the empirical data: “The formation of categories—whether inductively from the material or deductively—is an act of construction, which is reported on the basis of prior knowledge, experience and, not least, the world view of the analyst” (Kuckartz & Rädiker, 2022, p. 139).

In this context, the fact that only one researcher conducted the coding could be seen as a limitation. Nevertheless, the qualitative data and categories were highly structured per the guideline used. Although the evaluation of one researcher’s coding passes in Case Study 1 revealed minor differences, the review did not lead to any additional or new categories. According to Kuckartz and Rädiker (2022), single-person coding is not a major problem when, as in this case, the interviews and discussions are highly structured by a guideline and the main categories are derived from the guideline used.

### ***Implications for Research***

The study’s exploratory design provides a basis for further substantive research on the challenges and strategies of professional support in each of the professions involved due to the dual diagnosis of LD and OCD. We identified the specific challenges of caregivers as (new) demands on them, which should be explored in more detail. Caregiver support should be based on empirically supported and continuously evaluated evidence that takes into account the realities of people with LD and their caregivers in institutionalized settings. In this context, future research should be more participatory and examine not only the general experiences of people with LD and mental disorders with services provided by the mental health care system but also their individual or disorder-specific needs in institutionalized settings. The challenges and strategies we identified highlight the need to support caregivers in their professional roles. These exploratory findings may generate empirical evidence for the content of and need for caregiver-centered guidelines on psychiatry-related topics to help caregivers recognize and support people with LD and OCD. There is now a sufficient body of research on possible atypical symptoms of mental disorders in people with LD. Further research should determine whether the behavioral



features of OCD identified in this study actually yield diagnostic clues, including follow-up studies of behavioral clues for various disorders in people with LD (e.g., to help caregivers identify mental health problems).

### ***Implications for Practice***

Understudied in theory and present in practice, the additional compulsive behaviors of people with LD pose challenges regarding the need for caregivers to find ways to deal with them. This study provides the first in-depth insight into these specific needs, support realities, and strategies of caregivers in institutionalized settings in the support of the daily lives of people with LD and OCD. We now know that the additional compulsive behaviors of a person with LD can affect everyday support for which caregivers are not sufficiently qualified and therefore need targeted support.

From the results, concrete psychiatric steps and differentiated support needs of the person with LD and the person's environment can be derived in the context of psychiatric care (e.g., sensitization and education of the environment for disorder-specific handling). The empirically identified challenges and strategies can be the starting point for a demand-oriented professionalization. For practical implementation, this means that there are no disorder-specific guidelines for caregivers in dealing with people with LD and OCD or that the current official guidelines are primarily geared to the needs of psychosocial professionals in diagnosis and differential diagnosis and in therapeutic and psychiatric support. In this study, the nonspecific behavior of the person with LD proved to be very challenging for caregivers. To meet the challenge of recognizing and classifying behaviors due to behavioral ambiguity, disorder-specific guidelines should inform caregivers about (atypical) OCD symptoms by describing symptoms at the behavioral level<sup>1</sup> and at the behavioral level by distinguishing them from behaviors related to LD, stereotyped behaviors, autism spectrum disorder, and daily habits and rituals. The guide should also allow caregivers to observe and describe compulsive or compulsive-labeled behaviors not in isolation but embedded in situations.

Regarding the management of OCD, information on the role of caregivers and their needs concerning OCD should be formulated in concrete terms and for an institutionalized setting, and it should refer to holistic support with examples of possible support scenarios.

Roundtables should be established to bring together interdisciplinary professionals and family members involved in providing support. Their central aim should be the holistic planning, implementation, and further development

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1 Grüter, L., & Grünke, M. (2023). *Understanding Behavioral Manifestations of Obsessive-Compulsive Disorder in People with Intellectual Disabilities – A Qualitative Study*. [Manuscript submitted for publication]. Department of Rehabilitation and Special Education, University of Cologne.

of support, whereby the transfer of knowledge in the disciplines can be supported by the exchange of expertise and experience.

### CONCLUSION

People with LD and mental disorders are an important target group for psychiatric care. To provide practical mental health care for people with LD and OCD living in institutionalized settings, close collaboration between psychiatric and therapeutic care and caregivers as a central part of the person's immediate environment is needed for early identification of OCD and appropriate support. OCD in people with LD results in additional psychiatric and/or therapeutic needs for which caregivers in institutionalized settings are not and cannot be adequately qualified. Classifying OCD in people with LD and finding strategies is a major challenge for the caregivers, who urgently need theory-based, disorder-specific guidelines to identify and support people with LD and OCD appropriately.

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