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Does Moral Case Deliberation Change Current Views on Restrictions?: Staff Perceptions on Restrictions

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Abstract

Background: In the care of people with intellectual disability, support staff apply restrictions to people with moderate intellectual disabilities (ID) in several domains of daily life, such as restrictions on bedtimes or on the amount of food intake. Support staff may experience moral dilemmas applying these restrictions. In this respect, moral case deliberation (MCD) is used as an instrument for support staff to jointly reflect on dilemmas in care and is considered a form of ethical support. MCD also seems to broaden the perspective of their participants.

Specific Aims: This study examined to what extent MCD led to changes in support staff’s perspectives with regard to daily life restrictions placed upon people with moderate ID. Consequently, this study examined to what extent support staff’s perspectives on these restrictions were broadened as a result of their participation in the study.

Method: Prior to and following a series of three MCD sessions on moral dilemmas commonly encountered in daily life care, interviews were held with 12 support staff across two teams. Participants were asked what they considered to be good care in the given dilemmas. To systematically compare all of the answers given in the interviews prior to and following the MCDs, the same interview-guide was used in both instances. Interviews were analyzed inductively.

Findings: Following the MCD sessions, the respondents tended to hold onto their perspective to restrict clients to provide them with structure, clarity and rest, as expressed prior to the MCD. However, some respondents adapted their perspective on restrictions and were willing to provide people with moderate ID more freedom after the MCD.

Discussion: This study contributed to the evidence underlying MCD in healthcare and in providing insights into MCD with regard to daily life restrictions in the care of people with moderate ID. Partly, MCD leads to a broadening of perspective on restrictions applied in the daily life of people with moderate ID.

Keywords: ethics, intellectual disability, practice, restrictions

Background

In the care of people with intellectual disabilities (ID), support staff apply restrictions to people with moderate ID in several domains of daily life, such as restrictions on bedtimes, on the amount of food intake or on the use of an iPad (Van der Meulen, Hermsen, & Embregts, 2018). In arriving at decisions concerning restrictions in the lives of people with ID, the perspectives of all stakeholders involved need to be taken into account (Heyvaert, Saenen, Maes, & Onghena, 2014) in order to reach a balanced judgment on whether or not to apply restrictions. In various studies, the perspectives of support staff and relatives on the restrictions applied to their clients and family members with ID are examined (e.g., Elford, Beail, & Clarke, 2010; Hertogh et al., 2015; Heyvaert et al., 2014). More specifically, in previous studies, support staff and relatives of people with a moderate ID endorsed daily life restrictions, indicating these restrictions contribute to the physical well-being, safety, structure, and “normal” appearance of their clients and family members (Van der Meulen, Hermsen, & Embregts, 2018; Van der Meulen, Taminiau, Hertogh, & Embregts, 2019). Moreover, relatives stressed the imperative role of support staff in the application and maintenance of these restrictions. In turn, support staff indicated that they indeed apply daily life restrictions in the interests of their clients, but that this causes moral distress to themselves at times (Van der Meulen, Hermsen, & Embregts, 2018). People with moderate ID (IQ 35/40–50/55), characterized by deficits in adaptive functioning, which can require ongoing assistance in self-care, conceptual tasks, and decision-making (American Psychiatric Association, 2013), affirmed the presence of restrictions in their daily lives and tend to consent to them, indicating these restrictions contributed to their own wellbeing or that of others. However, the view of their relatives was of great influence in their own positive evaluation of restrictions (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). This is in line with the tendency of people with ID to acquiesce with important others like
relatives or support staff (Heal & Sigelman, 1995). Signs of protest were apparent when people with moderate ID felt their dignity or privacy was affected (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). To show respect for a client’s dignity and privacy, it is thus important to acknowledge the possible resistance of clients and any potential subtle signs of protest against restrictions (Heyvaert et al., 2014; Solvoll, Hall, & Brinchmann, 2015). Moreover, care to which a person with ID shows protest or resistance, even when the signs are subtle, can be perceived as involuntary care according to Dutch law (Care and Coercion Act, 2018). In line with this law, applying daily life restrictions can be part of providing good care, but only insofar as these restrictions are in the best interests of people with ID and are decided upon in dialog with them (Abma et al., 2006).

To promote openness toward other people’s perspectives, which is considered a relevant moral competency, the existing literature shows that moral case deliberation (MCD) might be an appropriate method (Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2016; Spijkerboer, Van der Stel, Widdershoven, & Molewijk, 2017). MCD can be defined as a structured method for investigating a moral issue experienced by participants in practice. Instead of leaving the deliberation to a committee, the aim of MCD is to jointly explore the ethical question at hand and encourage critical reflection on the values associated with the case (Spronk, Widdershoven, & Alma, 2020; Van der Dam, Abma, Kardol, & Widdershoven, 2012). MCD can function as a model for sharing perspectives and deliberating over moral issues as well as enhancing the moral awareness and competencies of the participants as a result of moral reflection. Furthermore, MCD provides support staff with the ability to learn from each other (Rasoal, 2018). MCD, more specific the dilemma-method, manifests itself “by an emphasis on a concrete, practice-oriented case, which is experienced by the participating care professionals themselves, or is easy to envision for them” (Gerritsen, Widdershoven, Bossenbroek, & Voskes, 2020, p. 2). Furthermore, by examining what is morally right in a specific care situation, MCD contributes to the improvement of the ethical climate and the moral quality of the care process (Molewijk, Verkerk, Millius, & Widdershoven, 2008).

The contribution of MCD has been evaluated in mental health care organizations (Molewijk et al., 2008) with respect to moral dilemmas such as fixating or isolating clients. To the best of our knowledge, no evaluative research has been conducted on MCD (1) in the daily care of people with ID and (2) with regard to daily life restrictions in the care of people with moderate ID. In this exploratory study, we have therefore examined the extent to which MCD leads to changes in the perspectives of support staff with regard to daily life restrictions placed upon people with moderate ID. Since the study focused on changing perspectives of support staff no clients were involved. In the MCD sessions, fictional vignettes were discussed, originating from our previously conducted research among clients with moderate ID regarding restrictions applied to them (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). These vignettes were pilot-tested and confirmed as being well-known dilemmas by the support staff.

Methods

Participants and Setting

Two teams of support staff from one care organization supporting people with (moderate) ID in the eastern part of the Netherlands participated in this research. These two teams were selected out of 10 teams supporting people with moderate ID on the basis of their willingness to cooperate. Team A, which supports eight clients with moderate ID (aged between 32 and 42 years, mean age 35), consists of six support staff who all participated in this research; team B, which supports 11 clients with moderate ID (aged between 33 and 70 years, mean age 46), consists of eight support staff. Six of them participated in the research, the remaining two staff members refused since they felt unable to combine collaboration in this study with their working schedule. All participating support staff interviews were held before and after the MCD sessions. The clients supported by these support staff are people who are all identified in their clinical files as people with moderate ID. No challenging behavior or psychiatric disorders are reported in these clinical files (Table 1).

Intervention

We organized three sessions of MCD per team within a 6-week period. Each session had an average duration of 1 hour.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Demographics of participating support staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>40 years (range 25–58 years)</td>
</tr>
<tr>
<td>Work experience in the care of people with ID (mean)</td>
<td>22 years (range 5–41 years)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Secondary vocational education</td>
<td>4</td>
</tr>
<tr>
<td>Higher vocational education</td>
<td>2</td>
</tr>
<tr>
<td>Team A</td>
<td>5</td>
</tr>
<tr>
<td>Team B</td>
<td>1</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>47 years (range 24–58 years)</td>
</tr>
<tr>
<td>Work experience in the care of people with ID (mean)</td>
<td>29 years (range 7–40 years)</td>
</tr>
</tbody>
</table>
and was audio-taped. The MCD sessions took place at the care organization with the first author (AvdM acting as the facilitator. AvdM received formal training in MCD and has over seven years’ experience in conducting MCD. In each MCD session, one vignette was discussed (session 1, dilemma 1, etc.), originating from our previously conducted research regarding restrictions applied to clients (Van der Meulen, Taminiau, Hertogh, & Embregts, 2018). These vignettes were pilot-tested and confirmed as being well-known dilemmas by the support staff in both teams.

Among the variety of methods to conduct MCD (Van Dartel & Molewijk, 2015), we used the dilemma-method, which is a structured and frequently used form of moral deliberating in healthcare (Stolper, Molewijk, & Widdershoven, 2016). In this method, participants discuss a concrete, experienced moral dilemma and are supported by an MCD-facilitator. The task of the MCD-facilitator is to structure and clarify the dialog, thereby supporting the participants in phrasing the moral dilemma. The facilitator invites the participants to discern what they perceive as two opposite sides of dealing with the given dilemma. Subsequently, the facilitator stimulates a joint dialog in which the motives underlying both opposites are explored. Finally, participants are requested to provide consensus (Rasoal, 2018) in how they would deal with the given dilemma. Unlike in the literature referred to, in this study three fictional cases are presented, which are formulated on former research. The cases are to be understood as hypothetical moral dilemmas. The three vignettes discussed in the MCDs were as follows.

1. An adult client with moderate ID likes to spend his time on his iPad. He is not controlled in the websites he likes to visit. He is allowed to do what he likes using his iPad: playing games, watching movies, etc. However, the client is restricted in his screen time. In the evening after 10:00 P.M., he has to switch off his iPad. The client is disappointed about this restriction applied by support staff and wants to decide for himself at what time he stops using his iPad.

2. A female adult with moderate ID has stayed at her parents’ home for the weekend. She returns to the care organization on Sunday evening. On Monday, she does not want to go to her work and tells support staff that she wants to stay at home. Support staff believe that the client has to go to work and force her to go by pulling her arms. The client shows resistance. Upon arriving at work, the client is still in a bad mood.

3. An adult client with moderate ID likes to phone his mother. During his calls, the client likes to tell her about all kinds of things that have happened in his life. His mother has difficulties with these telephone calls, since there seems to be no end to the stories told by her son. Therefore, the mother has decided that her son is only permitted to phone her for half an hour a week. The reason for this decision, according to the mother, is that the client cannot stop talking when he is on the phone, which is exhausting for others.

To explore a wide range of ethical dilemmas and variations in the character and perceived intensity of the dilemmas, the first dilemma described was chosen due to its educational character, the second due to its organizational character and the third because of its relational character. Moreover, in a pilot study, support staff (other than the participants of the study this manuscript reports) considered these themes to be exemplary dilemmas in the care of people with moderate ID.

The MCD sessions in our study were organized in line with the dilemma-method, a widely used form of MCD in healthcare organizations (Gerritsen et al., 2020). According to the dilemma-method (Gerritsen et al., 2020), the facilitator asks the participants to describe two opposite sides within the discussed dilemma and to summarize the corresponding values belonging to both sides. Subsequently, values are to be weighed against each other and participants discuss which values should prevail. This discussion ideally leads to a well-founded judgment in dealing with the dilemma. The role of the facilitator during the MCD is to structure and support the dialogue and stimulate the reflection process of the group.

Interviews

Permission to conduct this study was granted by the care organization in which the study took place, as well as by the Ethical Review Board of Tilburg University (EC-2018.78). In an information and consent letter, it was stated that all information provided by the support staff would be treated confidentially and that their input would not influence the evaluation of their work. The consent letter also stated that the data would be stored for 15 years, according to the guidelines of Tilburg University. During the interviews, support staff were given the opportunity to end their contribution to the study at any moment without providing a reason. All support staff of the two teams who participated in the research gave their written permission.

All participating support staff were interviewed individually in advance of the MCD sessions, as well as after the completion of the three MCD sessions. The interviews were semi-structured and lasted approximately half an hour. To systematically compare all of the answers given in the interviews prior to and following the MCDs, the same interview-guide was used in both instances. The interviewer (AvdM) described the aforementioned three vignettes at the start of the interview and consequently probed the interviewee by asking what he/she described as good care in the vignettes and to what extent the interviewee would meet the wishes of the client. In response to the answers of the interviewee, the interviewer asked for clarifications and explorations to deepen the content of the information provided.

Analysis

The MCDs were all audio-recorded and transcribed verbatim. Two researchers (AvdM, ET) checked whether all phases distinguished in the dilemma method were processed systematically in the MCDs. Next, all 24 interviews were recorded and transcribed, that is, 12 interviews in advance of the MCD and 12 interviews afterwards. Subsequently, the transcripts were inductively coded using Atlas-ti software (Muhr, 2005). Using an inductive approach, codes were compiled on the basis of the data itself. From the 24 interviews, six transcripts (25%) were also systematically coded by a second researcher (ET) in line...
TABLE 2
Values underlying sticking to the rules or providing freedom to the client

<table>
<thead>
<tr>
<th></th>
<th>iPad</th>
<th>Day centre</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>A</td>
</tr>
<tr>
<td>Values underlying sticking to the rules</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical wellbeing</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Relatedness to family</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clarity and structure</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Broaden the world of the client</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normalization</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional responsibility</td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Values underlying freedom to the client</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respect and self-respect of the client</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Self-determination of the client</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Empathy</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relation between the client and support staff</td>
<td>x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

with the standards for qualitative research (Kratochwill et al., 2010). In cases of differences in coding, a consensus was negotiated. Since the same interview guide was used in the first and second interviews, we could compare the answers provided prior to and following the MCD sessions. More specifically, to explore whether the respondents displayed any changes in their perspectives toward applying restrictions and to assess why this may have been the case, we analyzed whether the respondents were more or less inclined to grant space to the wishes and demands of clients. Next, the reasons cited for providing their clients with more or less space were analyzed. This analysis was conducted by two researchers (AvdM, ET). In the event that the researchers found differences of opinion regarding fulfilling clients’ wishes both prior to and following the MCDs, then this was deemed to constitute a change in the respondents’ perspectives. The analysis for each of the respondents was discussed by the entire project team (AvdM, ET, CH, PE).

Results

In exploring the extent to which MCD leads to changes in perspectives among support staff with regard to the application of restrictions to clients, we identified that respondents tend to evaluate the vignettes in the same way prior to and following MCD. However, some respondents changed their perspective from a focus on sticking to the restrictions to a focus on adapting the restrictions to provide more freedom to the client. In order to clarify this, first, the underlying values for restricting or providing freedom outlined during the MCDs are presented (see Table 2). Second, we describe whether and in what ways the respondents changed their perspective on restrictions following the MCDs (see Table 3).

Values

In their joint dialogue during the MCDs, the respondents reported that the following values underpinned their choice for sticking to the rules, namely clients’ physical wellbeing, relatedness to family, clarity and structure, broadening of their clients’ worlds, normalization, and professional responsibility (Table 2). The respondents in groups A and B all named physical wellbeing, specifically physical health, sleep deprivation and addiction, as the value that underlay their decision to stick to the rules. Next, relatedness to the family was reported as an underlying value. This comprises respecting the wishes of clients’ families, protecting the mother-client relationship, and preventing from becoming frustrated. For example, in response to the vignette about establishing phone rules, one staff worker stated:

“In the event that you stimulate the client to phone his mother, and the mother does not like this at all, then the client has a problem. The client will probably receive a negative response from his mother…” (Staff worker, group B).

TABLE 3
Evaluation of vignettes by support staff prior to and following the moral case deliberation

<table>
<thead>
<tr>
<th></th>
<th>iPad vignette</th>
<th>Day centre vignette</th>
<th>Phone-rule vignette</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to the MCD</td>
<td>Respondents: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12</td>
<td>Respondents: 1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12</td>
<td>Respondents: 1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12</td>
</tr>
<tr>
<td>Following the MCD</td>
<td>Respondents: 4, 5, 6, 11, 12</td>
<td>Respondents: 2, 3, 7, 8, 9, 10, 11, 12</td>
<td>Respondents: 1, 4, 5, 6</td>
</tr>
</tbody>
</table>

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Furthermore, apropos the vignettes about the iPad and day care center, both groups named clarity and structure as underlying values for restricting their clients and providing them with clear boundaries. As one staff worker reported:

“It is in the interest of the client to maintain the daily structure and to go to bed on time” (Staff worker, group A).

According to the respondents, sticking to the rules in these vignettes also served to broaden clients’ worlds. For example, they indicated that there was more than only an iPad, or in response to the vignette on the day care center, they noted that there was a need to meet other people. Next, normalization was described by both groups in response to the dilemma on the day care center, due to the fact that the respondents believed that going to work forms a key part of living a normal life and “you cannot just decide not to go.” Overall, the respondents in both groups preferred to stick to the rules in relation to the dilemmas, indicating that, as professionals, they know what is ultimately best for their clients. Moreover, they saw it as part of their professional responsibility as direct support staff to provide good care to clients. As one staff worker stated:

“It is our job to help clients in their daily activities. As support staff we are expected to assist them to arrive at decisions that are in their own interest” (Staff worker, group B).

With respect to providing more freedom to their clients, the respondents named the following underlying values, namely respect for and self-respect of the client, self-determination, empathy, and the maintenance of a good relationship between clients and support staff (see Table 2). Respondents were willing to afford their clients freedom, because then they showed that they respect the client, while, simultaneously, stimulating the self-respect of the client. According to the respondents, this also increases clients’ self-determination.

“It is a good thing that a client may decide for himself whether to use the iPad or not. Then he feels he is taken seriously by us as support staff” (Staff worker, group A).

Furthermore, group A named empathy toward the client as an underlying value for providing freedom to the client in response to the dilemmas about the day care center and facilitating telephone contact with clients’ mothers. In the described vignettes, respondents showed their understanding of the disappointment and frustration felt by clients when their wishes were not fulfilled. As noted by a staff worker from group A reflecting on the vignette of the day care center:

“Feeling empathy with the client is an important value. It is a hard thing that the client has to go to a place where she does not want to go. In a certain way, I feel sorry for her” (Staff worker, group A).

In relation to the vignette on the iPad, the maintenance of a good relation between the client and direct support staff was cited as an underlying value for providing freedom to their client.

**Perspectives**

Since the vignettes differ in their character and perceived intensity (vignette 1 educational, vignette 2 organizational, vignette 3 relational), findings with regard to perspectives of respondents prior and following the MCDs will be described per vignette.

**iPad vignette.** In the vignette with the iPad, a male adult has to stop using his iPad at 10:00 pm. Prior to the MCD, all respondents indicate that sticking to this restriction is providing good care because a client needs guidance from support staff to receive enough rest. Following the MCD, respondents tended to hold onto this view, stating that there are justified reasons to restrict a client in the use of the iPad just before bedtime, that is, maintaining a clear day-and-night structure for the client in order to protect his physical and mental well-being. In cases in which the client receives enough time to spend with the iPad in the day, these respondents have no difficulties in restricting the client during the night. In this sense, restricting is seen as a form of providing good care. The following example provides an illustration of this view:

“During the day a client has to feel healthy. Therefore it is good care to provide a client a good night’s sleep. After using an iPad late at night your sleep will worsen. I would say, let this client use his iPad another moment during the day and not late at night” (Respondent 1—second interview).

Some other respondents who first focused on sticking to the restriction were willing to adapt the restriction and provide the client with more freedom following the MCD. They stressed the importance of trust in a client with respect to developing his self-learning capacity. In their view, a client is allowed to make mistakes, that is, “dignity of risk” (Nay, 2002). They indicated that in case the client is really fatigued the next day after using his iPad late at night, client guidance is needed by imposing restrictions in his use of the iPad, but not beforehand. The space provided to clients to experiment is seen as good care.

For example, a respondent who wanted to restrict the client prior to the MCD is willing to adapt the restriction and to meet the wish of the client under certain terms following the MCD:

Prior to the MCD:

“Good care is to draw a line as a team. Ten o’clock is the rule. As a support worker you have to stick to this rule and communicate the rule with the client. The client just needs his sleep” (Respondent 5).

Following the MCD:

“I am willing to give the client space to use his iPad after 10:00 pm. The MCD taught me that it can be a learning moment for him. Who knows, he may switch off the iPad
Day care centre vignette. In the second vignette, a female adult is forced by her support staff to go to the day care centre on Monday morning, although the client shows resistance. Prior to the MCD, respondents stipulate the necessity to stick to the restriction and maintain the day structure of the client. Additionally, they stress practical organizational issues such as limitations in their working-time as justifications for maintaining the restriction. Following the MCD, respondents are inclined to hold on to this view. The same justifications as prior to the MCD were mentioned, as well as the fear of recurrence of conduct of the client. In case support staff give in to the wish of the client according to this view, the client will possibly misuse her freedom to stay home more often. The consequence for support staff is that they have to work longer to which they are not inclined, since normally their shift is over when clients go to their work. In the following example, we provide an illustration of this practical-organizational justification for sticking to the restriction:

“The problem is that in case the client stays at home instead of going to her work, no support worker will be present at home anymore. As support staff, we leave after our shift and just close the door. So, even though it is against her will, the client has to go to the day centre... If we do not act like this, the next time we will have the same problem” (Respondent 7—second interview).

However, some respondents changed their opinion due to the dialogue within the MCD. These respondents told us that they now realize that physically forcing a client to go to her work has a great impact on them. We will clarify this in the following example.

Prior to the MCD, the respondent provides the same justification as mentioned above:

“I cannot see it as a restriction. The client has to go to work, although it is unpleasant for her. As a support worker, I have to finish my work in the morning and cannot support this client anymore. It is time for me to go home” (Respondent 12).

Following the MCD, this same respondent mentions:

“After discussion during the moral case deliberation, I think I am more aware of the resistance this client shows... Two support staff grab her by the arm, that is really heavy. That is something different than just using words to guide the client in the desired direction... Yes, in the case of grabbing the client by the arm, you can speak of a serious restriction” (Respondent 12).

Thus, for some respondents it has become clearer due to the MCD that coercing a client to go to work is not desirable. The MCD has clarified for them that physically forcing a client to go to the day care centre is more threatening than verbally persuading a client to go to work. These respondents mention that for one time an exception in a client’s obligation to go to the day centre should be made. They are willing to give the client a day-off. Furthermore, these respondents propose contacting the family of the client and inquiring whether “things went wrong over the weekend,” indicating this information might be helpful in case the client refuses to go to work again.

Phone-rule vignette. The third vignette describes a restriction in phoning initiated by the mother of the client. The male adult in this vignette is only allowed to phone her for half-an-hour a week. After initial protests, the client resigns to this restriction. Prior to as well as following the MCD, respondents tended to stick to the restriction in phone calls in order to sustain the relation between the mother and the client. They indicated they would not be inclined to challenge the relationship between the mother and the client as there is a risk that the relationship between mother, client, and support staff deteriorates. They stress that contact between the mother and her son needs the willingness of both sides. Furthermore, support staff consider the mother to be responsible for the restriction in phoning. They indicate that they as support staff are not restricting, but the mother herself is.

The following example provides an example of this view:

“It is the mother, not the support staff, who has made the decision. The mother sets the boundaries. We have to respect that. It is not a form of good care to do something which the mother does not want. As support staff, it is better not to intervene between the mother and the client” (Respondent 3—second interview).

Next to this dominant view prior to and following the MCD, some respondents altered their view due to the MCD. Instead of maintaining the situation of weekly half-an-hour contact, their intention is to sustain the client in his wish to phone his family more often following the MCD. Support staff now state that it is their task to promote the interest of the client. It is seen as a form of good care that support staff contact the mother of the client or other family members to look for alternatives in order to promote more contact between the client and their family. This change in perspective is visible in the words of the following respondent. Prior to the MCD, the respondent mentions:

“It is a pity that the family of the client acts in this way. But the mother has made this decision. In case the client would want to make more phone-calls with the mother, the contact between them would worsen. I think it is best to follow the will of the mother” (Respondent 4).

Following the MCD, the same respondent states:

“Deep inside the client wants to have more contact with his mother, that is what I have learned from our group meeting (‘Moral Case Deliberation’ - AvdM). This is what he really wants. I would try to arrange something with the mother of the client. Possibly, the client can phone more often than he does right now. Maybe three times ten
minutes a week instead of half-an-hour a week” (Respondent 4).

In summary, we have found that respondents following the MCD tend to hold on to their expressed view prior to the MCD. The ethical deliberations about the vignettes sustained their opinion that it is necessary to keep to the restrictions and provide the client with physical and mental rest (vignette 1), day structure (vignette 2), and an enduring relationship with family (vignette 3). On the other hand, some respondents were inclined to adapt the restrictions and to provide the client with more freedom after the MCD. Due to the dialogue in the MCD, these respondents mentioned that they are more aware of the impact of a restriction for the client and are willing to take their wishes and needs seriously. This, in their eyes, is seen as good care.

Discussion

Our research focused on the question of to what extent MCD leads to changes in the perspectives of support staff with regard to daily life restrictions applied upon people with moderate ID. Our findings are twofold. First, we found that respondents tend to hold onto their previous view with respect to sticking to the restrictions in all the three vignettes and as a consequence maintained their earlier expressed perspective. Both prior to and following the MCD, the view to restrict clients to provide them with structure, clarity, and rest stayed dominant. In all three vignettes, this justification is pivotal; this is particularly the case in vignette 3 in which support staff seek ways to not disturb the existing relationship between the client, staff member, and the mother. The applied restrictions are seen as best interest care, according to these respondents. They consider it necessary to care for the client’s physical and mental condition (vignette 1), a structured day-rhythm (vignette 2), or an enduring relationship between the client and their family (vignette 3). This result is in line with our earlier research with regard to restrictions in the daily lives of people with moderate ID (Van der Meulen, Hermsen, & Embregts, 2018; Van der Meulen, Taminiau, Hertog, & Embregts, 2018; Van der Meulen, Taminiau, Hertog, & Embregts, 2019). In these studies, support staff as well as relatives of clients emphasize the necessity of applying daily life restrictions to provide clarity, structure, rest, and safety.

Our second finding is that for some respondents, MCD engendered a new perspective on how restrictions could be adapted in such a way that the client is afforded greater freedom to fulfill his or her own wishes, even if, as was the case in the phone-rule vignette, these wishes are not explicitly expressed by clients. We observed respondents changing their perspective from sticking to the restrictions for his or her own well-being to a perspective in which there existed more room for the wishes of the clients.

We would like to make some remarks regarding these outcomes. First, restricting a client does not automatically mean that support staff show a lack of sensitivity for the client. Holding onto the perspective of restricting might be a justified choice and as such a form of good care in cases in which it promotes the well-being of the client and is applied in dialogue with the client (Van der Meulen, Taminiau, Hertog, & Embregts, 2018). For instance, the arguments mentioned by respondents in the vignette surrounding restricting the client in the use of the iPad seem reasonable in case a client gets exhausted as a result of the use of the iPad. It is a form of sensitivity to focus on the physical and mental health of the client in case the client’s health deteriorates. In the second vignette in which the client is forced to go to her work, the application of the restriction seems less defensible. In cases in which a client is physically forced to go to her work, there have to be urgent reasons to justify this coercion. More sensitivity for and openness to the wish of the client is desirable here. In the third vignette concerning the client who is restricted in phoning his mother, respondents tend to sustain the position of the mother of the client. The reasoning of the support staff, namely that they do not want to disrupt the relation between the mother and her child, is understandable, but can also be used as an excuse to avoid a conflict with the mother of the client. It seems desirable that support staff also feel free to act as advocates of their client (Van der Meulen, Taminiau, Hertog, & Embregts, 2018) without losing respect for the wishes expressed by the family of client. In this case, support staff may start a dialogue with the mother of the client to look for alternative solutions. Second, besides the dominant tendency that MCD did not lead to new perspectives for these respondents, there were cases in which the opposite was true. Following MCD, these respondents stipulate that they are more aware of the impact restrictions may have on a client, especially in case physical force is applied as in vignette 2. It is interesting to notice that respondents from group A with a younger mean age, less work experience and with younger clients to care for, were inclined to provide more freedom for their clients than respondents from group B. In all, MCD can be regarded as a key for promoting greater attentiveness toward the viewpoint of the other (Jellema, Kremer, Mackor, & Molewijk, 2017; Molewijk et al., 2008; Spijkerboer et al., 2016, 2017). Consequently, one interesting avenue for future research would be to investigate support staff’s perspective on the usefulness of MCD.

The findings of our study indicate that MCD does indeed engender a change in perspective, as a consequence of increasing support staff’s openness to other people’s viewpoints. In the present study, this openness manifested itself in terms of clients being provided with greater freedom to make their own decisions. As a result, some of the respondents broadened their perspective as a direct consequence of participating in the MCDs. They widened their viewpoint and were willing to adapt their formerly expressed opinion. While broadening the mindset of the support staff can perhaps be regarded as a minor result when it comes to conducting MCD, in relation to such a delicate subject as applying restrictions on clients’ everyday lives, extending support staff’s view on restrictions is an important step. The restrictions discussed in the three vignettes can indeed all be considered as restrictions on clients’ daily lives, which in many instances are implemented as house rules (Dörenberg, Embregts, Van Nieuwenhuijzen, & Frederiks, 2013). As a consequence of this, support staff can often consider these rules as being “normal, everyday, rules.” MCD has made it clear to some support staff that these rules can instead be seen as restrictions, which, in turn, have a serious impact on clients. This can help to enhance awareness of and sensitivity toward what clients are
going through. In terms of avenues for future research, it would thus be interesting to investigate how MCD could help to stimulate increased sensitivity toward clients. However, it is important to stress here that broadening support staff’s perspectives does not automatically mean that those support staff whose perspectives are less broadened are less sensitive toward their clients. Indeed, the choice to restrict a client to protect them from danger or to avoid physical exhaustion can also be driven by profound sensitivity.

Consequently, it seems to be advisable for care organizations to invest in this moral dialogue, potentially through MCD on a regular basis, but also through a multidisciplinary discussion among support staff and other professionals about the necessity of restrictions (Schippers, Frederiks, Van Nieuwenhuijzen, & Schuengel, 2018).

Finally, several limitations are to be mentioned. The first limitation concerns the validation of this study and refers to the dilemmas discussed. These dilemmas did not originate from the teams of respondents themselves but were derived from earlier studies (Van der Meulen, Hermen, & Embregts, 2018; Van der Meulen, Tamimiau, Hertogh, & Embregts, 2018). Although these dilemmas were tested in a try-out and were considered as well-known dilemmas by support staff in both teams, they were hypothetical and not compiled on experiences with their own clients. As a consequence, the study focused solely on the opinions and perspectives of support staff and not on changes in their actual conduct. However, support staff were stimulated to reflect upon these well-known dilemmas, which may lead to greater awareness about other people’s perspectives (Spijkerboer et al., 2016) and possibly engender a change in attitude toward how they care for their own clients. A second limitation is that the interviewer of the support staff was the same person as the MCD-facilitator (AvdM). Due to this dual role, respondents possibly provided socially desirable answers in the interviews in which the significance of MCD is stipulated. Therefore, separating these two research roles could have potentially diminished the risk of socially desirable answers. An additional limitation is the use of one specific version of the dilemma-method. Since there are different versions of the dilemma-method available, each of which has differences in terms of both their structure and emphasis, any comparison with other versions of the dilemma-method may be limited. In this study, the dilemma-method is used to discuss exemplary moral cases. Support staff recognized the cases as well-known dilemmas. However, MCD’s with a focus on generally formulated cases may be difficult to compare with MCDs in which concrete, actual experienced moral practices are discussed (Jellema et al., 2017; Molewijk et al., 2008; Spijkerboer et al., 2016, 2017). In MCDs with a focus on exemplary cases, support staff are discussing what they should be inclined to do given the situation. Here, in a broader sense, systematic moral reflection regarding dilemmas is supported. In MCDs with a focus on concrete cases, support staff are more personally involved which may lead to other outcomes.

The strength of this study is that its outcomes did not stem from questionnaires in which respondents have to evaluate MCD by self-descriptions, as is common practice in evaluating MCD (De Snoo-Trimp, Widdershoven, Svantesson, De Vet, & Molewijk, 2017; Spijkerboer et al., 2016, 2017). Self-descriptions in questionnaires may lead to socially desirable answers. Although this risk is also present in our study, it is minimized by our qualitative approach in which we have accurately analyzed the interviews of all participating support staff prior to and following the MCDs. In this way, this study contributed to an evidence-based underlying MCD. Moreover, this study provides insight into how MCD functions with regard to the theme restrictions in a care-setting for people with ID, whereas the evaluation of MCD is mostly conducted in mental-health settings. Conducting and evaluating MCD in the care of people with ID may increase the sensitivity and awareness of support staff for the perspective of the client.

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Conflict of Interest

The authors declare no potential conflict of interest.

References


