



# Acknowledging caregivers' vulnerability in the management of challenging behaviours to reduce control measures in psychiatry

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## Abstract

**Background:** The management of challenging behaviours in inpatient with intellectual disability and/or autism spectrum disorders can lead to an escalation of control measures. In these complex situations where patients have an intellectual disability/autism spectrum disorder accompanied by a psychiatric comorbidity, the experiences of caregivers related to the crisis management have rarely been studied.

**Purpose:** This study examined the moral experiences of caregivers related to challenging behaviours' management and alternatives to control measures.

**Research design:** Using Charles Taylor's hermeneutic framework, a 2-month focused ethnography with a participatory approach was used.

**Participants and research context:** Sixteen caregivers were interviewed in a Canadian mental health setting for adults with intellectual disability/autism spectrum disorder and psychiatric comorbidity.

**Ethical considerations:** The research was conducted in compliance with the Declaration of Helsinki and local Research Ethics Board approval. Written informed consent was collected systematically from participants.

**Findings:** By accounting for caregivers' moral experiences, this study sheds light on a neglected dimension of the care relationship: the vulnerability of the caregiver. We highlight the main barriers and facilitators to alternatives to control measures. First, a caregiver's vulnerability was characterised by the overall impact of

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challenging behaviours and the moral distress associated with the use of control measures and exclusion mechanisms of intellectual disability/autism spectrum disorder patients. Second, a strong ambiguity between care and control measures and a lack of inclusive approaches were identified as the two main barriers to challenging behaviour management. Third, the involvement, both professional and personal, of caregivers was deemed necessary to implement alternatives to control measures.

**Discussion:** A conflict of values opposes two conceptions of autonomy: a rational autonomy, which is counterproductive to the reduction of control measures, versus a relational autonomy based on shared vulnerability.

**Conclusion:** The recognition of caregiver's vulnerability is a benchmark to create alternative approaches, which defuse the logic of control and promote an ethics of care within which caregivers' self-concern can be understood as fostering mutual respect.

### Keywords

Alternatives to restraint, autism spectrum disorder, caregivers' vulnerability, challenging behaviours, ethics of care/care ethics, intellectual disability, moral distress, psychiatric comorbidity, relational autonomy, seclusion room, theory/philosophical perspectives

## Introduction

Healthcare teams within psychiatric inpatient units work with patients with intellectual disabilities (IDs) and/or autism spectrum disorders (ASDs). When these patients are in crisis, they can exhibit challenging behaviours (CBs): self-harm, aggression, incoercible psychomotor agitation, pica, pervasive stereotypes, destruction of objects and endangerment.<sup>1–5</sup> In the particular context of hospitalisation, the goal is to assess and treat the psychiatric and/or somatic comorbidities that could be related to the persistence of CBs so that patients with ID/ASD can once again benefit from the community services that are usually recommended for them. These CBs can lead to physical injuries on patients, members of their families as well as on caregivers. The complications of CBs are numerous,<sup>6–9</sup> and the use of control measures (alternatives to CMs) is frequent, although it should be possible to limit them.<sup>10–13</sup>

In psychiatry, restraint has triggered a long-standing debate<sup>14</sup> that is still relevant today.<sup>15,16</sup> Its main controversies revolve around its 'therapeutic effect'<sup>17–19</sup> or its punitive excesses.<sup>20,21</sup> Psychiatry is more prone to exposure to violence than any other hospital department.<sup>22</sup> If CMs seem necessary in some situations, their use remains an ethical dilemma for the staff.<sup>23–26</sup> There are four types of CMs: physical interventions (e.g. manually immobilising a patient), seclusion (e.g. locking the patient in a room), sedation (e.g. administering oral 'PRN' or intramuscular chemical treatment)<sup>11,27</sup> and mechanical restraint (e.g. tying a patient to his or her bed with straps).<sup>28</sup> CMs should only be used as a last resort to ensure the safety of patients or of their surroundings when less restrictive measures have proven ineffective.<sup>29,30</sup> Today, numerous regulations govern restraint measures worldwide, but they are insufficient to limit their use in practice.<sup>31–33</sup>

## Background

The consequences of restraint on patients with ID/ASD can be severe both physically<sup>6,8,9</sup> and psychologically,<sup>34</sup> sometimes even lead to death.<sup>35–37</sup> Numerous qualitative studies report the traumatic experiences of restraint for both patients and caregivers.<sup>24,38–41</sup> In the field of ID/ASD care, health authorities require the use of alternative safety practices.<sup>30,42</sup> When patients with ID/ASD exhibit CBs, these guidelines are difficult to implement. Respect of the person's dignity must be maintained while making sure that his or

her safety is ensured. In this particular context, a daily issue for caregivers is how to contain CBs to preserve a reassuring environment for the patient, his family and the healthcare team, while ensuring maximum integrity of the person.<sup>43</sup>

Several studies report the existence of alternatives to control measures alternatives to CMs: mode of communication,<sup>34,44,45</sup> staff training,<sup>46,47</sup> behaviour modification programmes,<sup>10,48</sup> organisational approaches,<sup>49–51</sup> ‘response-blocking’,<sup>8,52</sup> and ‘restraint fading’ procedures<sup>53–55</sup> associated with the use of personal protective equipments.<sup>6,7,56</sup> Few of these studies focus specifically on the impact of CBs on the professionals providing care, personal accompaniment and safety for individuals with ID/ASD.<sup>57,58</sup>

## Purpose of the study

The objective of this focused ethnography study is to explore the ethical issues linked to situations of care and restraint by looking at the moral experiences of caregivers directly confronted with CBs. Through this approach, we seek to understand both the barriers and facilitators to the maintenance or development of alternatives to CMs in the context of ID/ASD with psychiatric comorbidities (e.g. major depressive episode, bipolar or schizo-affective disorders).

## Method

### Design

This study is part of a multicenter ethnographic survey that took place in France, Canada and the United States. It created an inventory of alternative security devices to CMs used in the management of CBs for individuals with ID/ASD.<sup>6,7</sup> This article presents the Canadian part of the study, where the use of CMs was more significant. Ethnography is focused on a particular field within a specific context of care throughout a delimited period of time.<sup>59</sup> This methodological approach allows for important contextual data to be obtained to study the Canadian’s alternatives to CMs and its complexity. Our ethnographic approach builds on Taylor’s hermeneutic framework.<sup>60,61</sup> It puts forth the concepts of horizons of significance and social imaginaries, which promote the understanding of the institutional norms, structures and practices that shape the experience of a specific group.<sup>60,62</sup> In regard to defining ‘moral experience’, we will use the definition as proposed by Hunt and Carnevale:

Moral experience encompasses a person’s sense that values that he or she deems important are being realised or thwarted in everyday life. This includes a person’s interpretations of a lived encounter, or a set of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust.<sup>63</sup>

This conceptual framework, which implies a hermeneutic understanding of the values of care and support, enabled us to study the moral experiences of caregivers when faced with CBs’ management in inpatients with ID/ASD and psychiatric comorbidity.

The main investigator (J.L.-U.) is a nurse specialised in child psychiatry. He conducted the whole study, interviews, meetings and discussions as part of his doctoral research. Emphasis was placed on reflexivity by the main investigator because of his personal and professional experiences with patients with ID/ASD and his proximity to the object under study. He was asked by his supervisors (A.R., F.C.) to write down his hypotheses regarding the object of study and the results he would expect, before entering the study settings. A field notebook helped him report his personal observations and impressions of the research interviews.

To explore the moral dimension of extreme situations related to CBs, the research hypothesis of this focused ethnography was as follows: ‘Taking care during behavioural crisis management means protecting oneself and others from violence that jeopardises the bond necessary to accompaniment’. The Standards for

**Table 1.** Socio-demographic data of interview participants in 2017.

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Participants: n = 16
Age (years): 23–68, average: 46
Gender: 9 male/7 female
Professional experience (since graduation) (years): 1.5–40, average: 20-year experience
Job title: 8 nurses (including 2 Omega trainers), 2 orderlies, 1 manager, 1 administrative officer, 1 behaviour modification agent, 1 social worker, 1 specialised educator, 1 psychiatrist
Participants who have undergone Omega training: 7/16
Duration of interviews (min): 19–80, average duration: 45

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Reporting Qualitative Research (SRQR) checklist is used as a guideline to structure the different steps of our research process (e.g. data collection and analysis, report the study results).<sup>64</sup>

## Participant selection

The study was conducted between April and May 2017 on an inpatient unit dedicated to the assessment and treatment of psychiatric comorbidities with patients with ID/ASD (aged 18–65 years). The services surveyed had 16 hospital beds with four to seven health professionals. The average duration of the patients' stay was of 1 year. The ward was selected according to ID/ASD patients' severity of behaviours and to the high level of CM use. The managers placed posters around the unit to encourage professionals to take part in the study. Nurses, social workers, orderlies, psychiatrists and educators who expressed interest and met the research criteria were recruited.<sup>65</sup> Throughout the article, the term 'caregivers' refers to all healthcare workers included in the study and the term 'patients' refers to individuals with ID/ASD and psychiatric comorbidity. Inclusion criteria included current employment in the care of patients with CBs and active involvement in behavioural crisis prevention and management. Recruited participants presented diverse professional experiences regarding CBs' management (e.g. junior and senior professionals) (Table 1).

## Data collection

The main strategies for data collection include (1) participant observation, (2) semi-structured individual interviews of caregivers and (3) a review of the written documents.

1. *Participant observation* was the primary research strategy, as it is often the case in ethnographic studies.<sup>66,67</sup> We first developed a participant observation's grid to better target observation elements based on research objectives.<sup>68</sup> Fieldnotes were used to collect data related to participant observation, the content of informal interviews and the lead researcher's personal reflections (e.g. surprises or misunderstandings, personal feelings or reactions).<sup>69,70</sup> The lead researcher also took part in team meetings (twice a week) and nursing handover to observe team dynamics. In addition, he organised research progress meetings to enrich the iterative process of the study.
2. *Semi-structured individual interviews* were gradually set up after an initial information meeting to define the study's objectives. After 15 days, the team became more familiar and comfortable with the researcher's observations. Then, the first individual interviews were organised. Participants were selected on a voluntary basis.<sup>64</sup> Out of a total of 34 team members, 16 of those selected to participate met the inclusion criteria. Although the interviews were framed as general discussions on violence and crisis management, all participants spontaneously mentioned physical restraint.
3. *Review of written documents*: violence prevention protocols based on the 'Omega' pacification programme were reviewed, along with individualised intervention plans aimed at preventing and

monitoring CM use. This review enabled us to analyse the institutional norms, structures and practices, to understand whether the formalisation of written protocols on active prevention interventions helps avoid the escalation of aggressive behaviours.

Using a plurality of approaches favoured the triangulation of data<sup>59,71</sup> and enriched our understanding of caregivers' moral experience. Sampling was done along three major dimensions: time, people and context.<sup>72</sup>

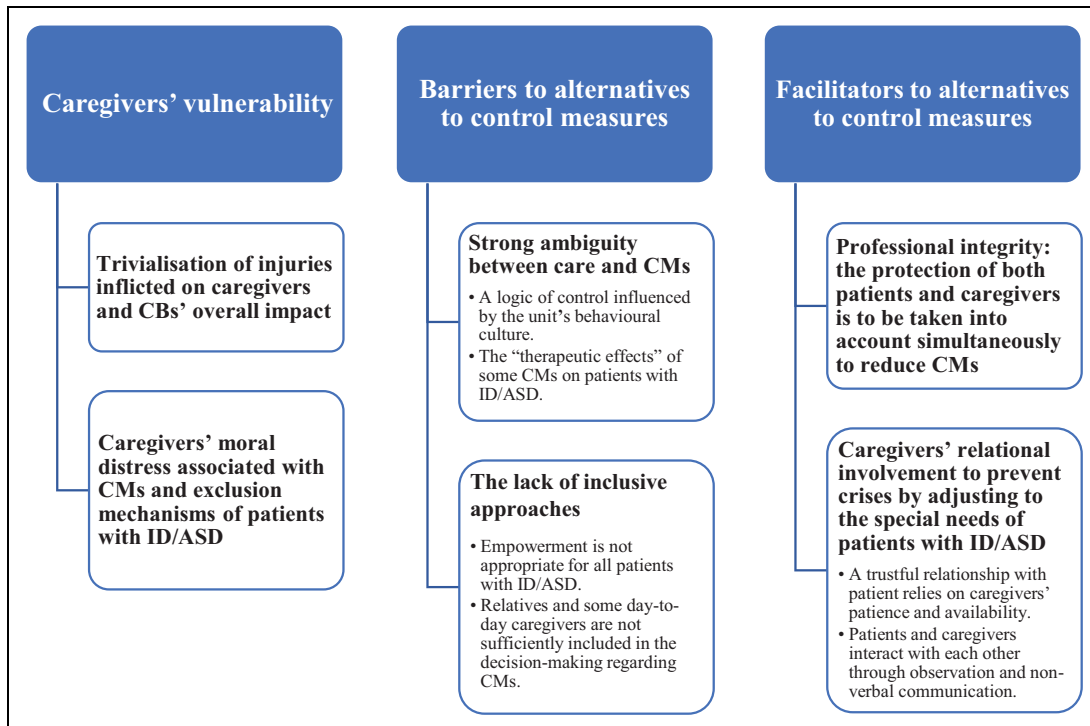
## Data analysis

Data analysis was guided by the interpretative frameworks of Benner<sup>73</sup> and Crist and Tanner.<sup>74</sup> Benner's framework, grounded in the discipline of nursing, is rooted in the tradition of Taylor's hermeneutics, focusing more on individual experiences and less on context. Crist and Tanner later built on Benner's work to develop more specific guidance for data analysis, which we combined with an analysis of the socio-historical-cultural context as described by Carnevale<sup>62</sup> and Montreuil and Carnevale.<sup>61</sup> The following interpretive steps occurred iteratively and non-linearly as well as during and after data collection:

1. Micro-analysis through open-ended interpretations of interview transcripts. Transcripts were equally distributed among the co-investigators (M.M., A.P., A.R.) for a global rereading of the lead researcher's initial comments. We were thus able to identify emerging similarities and differences within the interviews.
2. Production of an observation report integrating narrative summaries to clarify initial interpretations based on fieldnotes, interview transcripts and the review of written documents.<sup>68</sup> This report was provided to the local supervisor of the study (F.C.) once the immersion phase had been completed. Throughout this process, exemplars were identified to enhance understanding.<sup>73</sup>
3. Finally, four meetings took place between May 2017 and September 2020 to clarify interpretations and ensure the congruence of our results. At every meeting, many participants were present and expressly explained that all the results were representative of their experience within their unit. The participants also found the discussion part interesting, as it highlighted some of the limitations of their fields of intervention. This close collaboration with participants helped improve the analysis, leading to a richer and deeper understanding of the data.

## Ethical considerations

The research was conducted in compliance with the Declaration of Helsinki and local regulations. Data collection began after the research ethics board approval. Participants received an informative letter about the research. Written informed consent was collected from the 16 participants to the interviews (Table 1). The latter were conducted in a private room in the unit. All participants agreed to being recorded; interviews were transcribed and their verbatim saved for anonymised information. Recordings were kept safely in a dedicated archive in the lead investigator's research department. During the immersion time in the service, some of the patients were informed of the main researcher's role by their referred caregivers. Given that IDs range from moderate to profound, it was not possible for all individuals with ID/ASD to understand the main researcher's role in the setting. However, all the families were informed about the theme of the research (i.e. alternatives to CMs), which focused on caregivers, and about the main researcher's role in the service. Posters were also available in the unit and during the visits, and the surrogates could easily read them.



**Figure 1.** Summary of the moral experience of caregivers confronted with the management of CBs in inpatients with ID/ASD and psychiatric comorbidity.

ASD: autism spectrum disorder; CBs: challenging behaviours; CMs: control measures; ID: intellectual disability.

**Table 2.** Data on the use of control measures in the investigated unit from 2017 to 2019.

	2017	2018	2019
Total number of uses of control measures	794	621	766
Total number of uses of restraints	249	229	277
Total number of uses of seclusion room	545	392	489
Total number of patients with ID/ASD	20	27	31
Total number of patients with ID/ASD on restraints	10	14	16
Total number of patients with ID/ASD in seclusion room	18	17	18

ASD: autism spectrum disorder; ID: intellectual disability.

## Results

Participants' moral experience regarding CBs' management and care of patients with ID/ASD is structured around three metathemes (Figure 1). One deals with the vulnerability of caregivers and the other two present barriers and facilitators to maintaining or developing alternatives to CMs. To ensure the confidentiality of all study participants (Table 1), we anonymised the verbatim reporting without specifying the participants' professions. For example, 'P4V1' indicates the first verbatim of interview #4. Table 2 shows data regarding CMs on the unit from 2017 to 2019. Tables 3–7 in the Appendix help the reader refer to the verbatim relating to each theme. The number of

examples provided for each theme or category reflects its complexity. Most examples have been translated from French.

### Caregivers' vulnerability

Caregiver's vulnerability was characterised by two themes (Table 3): on one hand, the overall impact of CBs, and on the other hand, the moral distress associated with CMs and the exclusion mechanisms of patients with ID/ASD.

*Trivialisation of injuries inflicted on caregivers and CBs' overall impact.* Non-verbal patients were described as the most difficult to work with, in particular because their CBs were unpredictable (P3). Several caregivers sustained injuries in the course of their work with such patients, with many reporting having scars related to their work. Most participants reduced the moral and physical impact of these injuries or even compared them to a 'rite of passage' to work on the unit (P2V1, P14V1).

The frequency and intensity of CBs were also said to engender major dysfunctions that jeopardised the continuity of care and support (P6V1). Many caregivers were on sick leave, and the hardships associated with CBs' management led to chronic understaffing, high staff turnover (P1V1) and frequent use of float teams or interim staff. Participants described the negative repercussions of these disruptions on patients, many of whom are hypersensitive to staff changes and absenteeism of their primary caregivers, thereby causing more CBs.

*Caregivers' moral distress associated with CMs and exclusion mechanisms of patients with ID/ASD.* Participants faced various fears in their practice: injuring patients and/or weakening the therapeutic alliance through traumatic recourse to CMs (P4V1) and fear of abandoning patients with ID/ASD. This led to an ethical dilemma (P8V1) with choices participants felt were limited: doing what should be avoided (e.g. tying a person to his or her bed) or not doing what should be done (e.g. holding off interventions with a person in need), both of which are ethically reprehensible. This led to moral distress for many of these caregivers. According to participants, three exclusion mechanisms characterise the use of CMs:

1. *Exclusion from community services.* Behavioural crises among patients with ID/ASD result from chaotic care pathways with numerous breaks in care and support. Incessant comings and goings of patients with ID/ASD between the hospital and the community services contribute to the persistence of CBs and further worsen patients' health through overexposure to CMs. Indeed, post-traumatic stress disorder (PTSD) is mentioned by some participants for patients who have been confined or tied up in hospital for too long because they cannot be accommodated and supported in community services adapted to their special needs.
2. *Exclusion within the hospital.* Patients with ID/ASD instil fear in, and rejection from other services. In the emergency unit, for example, these patients are more systematically overmedicated, tied up or put in seclusion, and even physically abused. The repercussions of CMs are all the more traumatic as they are used more frequently with these patients.
3. *Exclusion within the unit itself.* The more severely affected patients with ID/ASD are, the more left to themselves they are, which adds to their inability to adapt to the environment and the rhythm imposed by the unit. For some participants, the latest institutional restructuring (creation of the CIUSSS<sup>1</sup>) meant to optimise departmental resources by reducing the length of hospitalisation. According to some participants, this measure favoured the inclusion of patients with moderate ID to the detriment of the inclusion of severe cases (P6V2). This mechanism of 'internal exclusion' is a significant concern for patients with CBs, for whom recourse to CMs is often justified as being in the best interest of the unit (i.e. protection of all caregivers and other patients). This prioritisation of

group protection omits an individualised approach for patients with CBs, often leading to a stigmatisation followed by exclusion from within the unit. This exclusion mechanism of complex cases is often perceived as an unavoidable injustice by the staff (P16V1).

### *Barriers to alternatives to CMs*

The second metatheme (Figure 1) centres around two main barriers to implementing alternatives to CMs: the strong ambiguity between care and CMs and the lack of inclusive approaches.

*Strong ambiguity between care and CMs.* The strong ambiguity between care and CMs (Table 4) includes two categories: a logic of control influenced by the unit's behavioural culture and the 'therapeutic effects' of specific CMs on patients with ID/ASD.

- *A logic of control influenced by the unit's behavioural culture.* This aspect is directly related to the historical identity of the unit, once considered a pioneering 'Behaviours Modification Unit' in North America since the early 1980s. Today, during nursing care handovers (written and oral), the expression 'Good behaviour. Good day.' remains emblematic of this care culture mainly centred around patients' behaviours. Such behavioural culture still encourages the trivialisation of CMs, particularly in two ways:
  1. *A short-term consequentialist logic that fosters crises when caregivers overreact.* This logic in keeping with behavioural therapies comes from 'consequence management' as practised in the earlier years of the unit. This legacy is characterised by what participants called 'privilege removal' (P1V2). The effectiveness of this type of therapy is thought to rest on caregivers' ability to intervene quickly in response to CBs. At the time of the study, however, many caregivers considered that most crises are in fact caused by the hasty reactions of some of their colleagues (P8V2).
  2. *Socially inappropriate behaviours tend to be considered dangerous.* From a behavioural standpoint, the generalisation of 'socially acceptable' behaviour is of paramount value. When caregivers are unable to convince certain patients to adopt the behaviours they believe would optimise patients' social inclusion, an instrumentalisation of these patients ensues. Indeed, participants feel it necessary to immediately neutralise any mechanism that may lead to patients' exclusion from the community. In this behaviourist perspective, behavioural disorders are thus quickly judged to be 'socially inappropriate' or 'violent' if the team considers them to be a potential barrier to inclusion in the community (P2V2). For example, one caregiver stated it was his duty to maintain a certain frame in his daily practice so as not to trivialise a behaviour that would not be accepted in the community, even if it meant using CMs as a deterrent (P14V2). Participants reported that punitive strategies through CMs were sometimes used in situations that did not involve risks of immediate or imminent harm to the patient or to others. Other drifts related to the normalisation of behaviours and the use of force were also observed and criticised by some participants (P16V2). A split remains within the team, as some caregivers are in favour of 'old-fashioned' behavioural methods, while others support 'Omega approaches' (P13V1, P1V3). In the context of a crisis, Omega method is recommended by the whole hospital as a de-escalation strategy to limit physical interventions as much as possible to favour pacification through speech.
- *The 'therapeutic effects' of some CMs on patients with ID/ASD.* For many caregivers, setting 'acceptable' limits was difficult with patients with severe ID/ASD, who they believed were most often subjected to CMs (P4V2). The specificity of autistic functioning (e.g. sensory profile) appears to lead to more restrictive approaches for patients with CBs (P9V1). Participants reported that several non-verbal patients showed relief when placed in seclusion rooms or restrained in Argentino devices



**Figure 2.** Argentino mechanical restraints: jacket and suit.

(Figure 2). Some even spoke of ‘dependence’ on CMs to qualify these ‘therapeutic effect’ associated with some CMs (P10).

*The lack of inclusive approaches..* The second barrier to the implementation of alternatives to CMs is related to the lack of inclusive approaches (Table 5). This aspect is structured around the following two categories:

- *Empowerment is not appropriate for all patients with ID/ASD.* The Omega approach was generally well established within the unit and was described as useful in preventing most behavioural crisis. A weekly meeting including the main theoretical components of the Omega pacification programme (‘Grid of potential dangerousness’ and ‘Intervention pyramid’) aims to define patients’ dangerousness profile through a quantitative approach to prevent crisis. Nevertheless, some participants felt that this approach, which is based on a patient’s empowerment, does not sufficiently take into account the severity of certain impairments (cognitive and/or sensory) and the actual discerning or learning capacities of non-verbal patients (P4V3, P14V3). According to some of the participants, communication tools are not sufficiently adapted to patients’ special needs, especially with individuals with ID/ASD, who were described as functioning less on a rational level than on an emotional one (P8V3).
- *Relatives and some day-to-day caregivers are not sufficiently included in the decision-making regarding CMs.* According to some participants, CMs should only be used following consultations with families regarding their appropriateness (P9V2, P15V1). In this respect, the presence of parents in the ward is also a significant influencing factor to reassure patients with ID/ASD and prevent behavioural crises associated with the use of CMs in the daily life of the hospital. Indeed, as we saw during one of our observations, a patient’s father having cancelled his visit, the son suddenly spread his faeces all over his body and was then taken to a seclusion room by the caregivers. On another day, the same patient, often anxious while waiting for his father’s visits, was able to immediately calm down in his presence. Furthermore, some frontline caregivers were also poorly included in weekly clinical meetings and rarely participated in decision-making regarding CMs. Several frontline caregivers questioned the usefulness of individualised intervention plans, which they felt were too complex and not sufficiently focused on patients’ special needs. Many felt devalued in their role and complained of a lack of attention



**Figure 3.** An innovative security tool: The ITCA therapeutic ball.  
ITCA: Intervention Thérapeutique lors de Conduites Agressives [Therapeutic Intervention for Aggressive Behaviours].

from their colleagues (P8V4). One deplored being reduced to a ‘mere technician’ and denounced this lack of recognition of daily care (P16V3, P1V4). According to one of these two participants, the team’s hierarchy engenders dominance relationships between vulnerable patients and some day-to-day caregivers who are more authoritarian than others.

### *Facilitators to alternatives to CMs*

The last metatheme concerns the involvement, both professional (Table 6) and personal (Table 7), of caregivers in the development of alternatives to CMs (Figure 3).

*Professional integrity: the protection of both patients and caregivers is to be taken into account simultaneously to reduce CMs.* Given the hardships and impacts of CBs on caregivers, the Omega approach prioritises staff safety. In this perspective of pacification, caregivers have the duty to protect themselves and their colleagues to intervene in a safe and non-abusive manner with patients (P8V5, P4V4). Some participants described self-protection as their professional responsibility and duty since caregivers’ sense of safety determines the likelihood that CMs will be used or avoided (P13V2). In other words, by ensuring their own sense of safety, caregivers ensure that CMs will not be used excessively. Tying the protection of patients and that of caregivers together could thus effectively limit the use of CMs. One participant argued that individual precaution could even

promote global prevention, reassuring all caregivers and enabling a collective dynamic conducive to de-escalation approaches (P9V3). Still, in a crisis context, caregivers found it difficult to protect themselves (P9V4) and tended to neglect themselves, prioritising others' safety instead of their own. For example, one participant noted that when confronted with violent behaviours, self-control and good knowledge of colleagues' strengths and weaknesses facilitate the promotion of mutual aid within the team. One caregiver, aware of his eagerness and impatience due to his impending holiday, signalled to his colleague his need to stay back to avoid overreacting and resorting to CMs (P8V6). Caregivers' humility (P16V4) is thus essential to protect patients in a way that is not at the expense of caregivers' safety.

*Caregivers' relational involvement to prevent crises by adjusting to the special needs of patients with ID/ASD.* This theme comprises two categories:

- *A trustful relationship with patients relies on caregivers' patience and availability.* From the perspective of caregivers, establishing a relationship with patients with ID/ASD requires learning how to adjust to their level of impairment to gradually open up to their personal experience (P16V5). Given some patients' inability to postpone their requests, participants emphasised the importance of making themselves quickly available. CBs were often linked to a frustration born from the need of immutability in patients' daily routines. When caregivers are unable to interrupt their work, this generates anxiety and misunderstanding, which can turn a feeling of anger into rage. Thus, to respond to his patients' requests or make them understand an instruction, a participant in an interview told about the importance for his colleagues and himself being loyal to their commitments and remaining as consistent as possible in their interventions (P4V5). When caregivers invested in their relationships with patients in this way, they succeeded in defusing and effectively preventing most crisis situations in the long term (P13V3).
- *Patients and caregivers interact with each other through observation and non-verbal communication.* Close observation and precise knowledge of patients' specific rituals were described as crucial to understanding behavioural aetiologies and preventing outbursts. The slightest change in a patient's habits was deemed an early warning sign of a crisis (P9V5). Participants indicated that body language is often the only way for patients with ID/ASD to express their special needs (P7). Non-verbal communication was described by caregivers as follows:
  1. *Socio-affective cues, eye contact and gestures.* Several caregivers interacted in a playful and humorous manner to prevent emotional tension and strengthen the therapeutic alliance with patients (P14V4). A former caregiver now part of the institution's crisis intervention team explained that when he arrives in the unit, he is usually able to quickly defuse crises only because the patient already knows and recognises him (P9V6). Another participant, referring to two concepts of Watson's theory of human caring (phenomenal field and transpersonal relationship), explained how it is possible to achieve a level of 'advanced empathy' by adhering to patients' specific routines and mirroring stereotyped behaviours (P15V2).
  2. *Sensory cues, touch and body language.* Some participants contended that sensoriality should be favoured to reassure patients and create human connection. For example, body mediation is essential for patients who need bodily contact or proximity to meet their needs for attention and reassurance (P5). Through reciprocity fostered by such body language, the adherence of patients who are usually non-cooperating could be promoted (P16V6).

Some interviewees deplored the fact that the nursing profession is becoming increasingly bureaucratic, thereby relegating patients' relational needs to the background. In this respect, many participants emphasised the importance of enjoying working with patients with ID/ASD as a precondition to implementing alternatives to CMs. Indeed, the pervasive behaviour of these patients is very difficult to cope with on a daily basis.

## Discussion

Accounting for caregivers' moral experiences strengthens our understanding of the different factors influencing the use of CMs with complex patients with ID/ASD. Indeed, a neglected dimension of the care relationship emerges, which is the caregivers' vulnerability. Having based on our conceptual framework related to Taylor's hermeneutics, we have highlighted the main barriers and facilitators in the development of alternatives to CMs. A conflict of values opposes two conceptions of autonomy: a rational autonomy based on empowerment<sup>75</sup> versus a relational autonomy<sup>76–78</sup> based on shared vulnerability. This ethical dilemma will be discussed through 'local imaginary', that is, what is morally meaningful to the caregivers, in addition to institutional norms, structures and practices in this particular context.<sup>61,62</sup>

### *The ideal of inclusion: from empowerment to an imperative of adaptation*

In the second metatheme of our results, we identified two contextual factors that influenced caregivers' perception of patients' autonomy as a rational capacity to be accounted responsible: behavioural culture and 'Omega pacification'. These two influencing factors have enabled us to qualify 'empowerment' as what Taylor described as 'hyper-good', dominating the unit's local imaginary. Empowerment through accountability is thus a value shared by the team, which the latter applies equally to itself.

On the unit, this hyper-good constitutes a hindrance to alternatives to CMs for several reasons. The consequentialist logic discussed earlier (i.e. all patients are considered responsible for the consequences of their actions) can reinforce caregivers' overreaction, making the use of CMs more likely (Table 4). Moreover, by making caregivers accountable through the Omega quantification of risk in potential crisis situations (e.g. during weekly staff meetings), a culture of mistrust towards patients with ID/ASD insidiously sets in. Indeed, patients' alleged capacity for discernment may amplify the judgement of some caregivers who perceive patients as 'insolent' and some of their behaviours as 'unhealthy'.

This conception of individualistic autonomy based on rationality and a person's capacity for self-determination reflects the prevailing ideal of 'inclusion in the community' endorsed by the unit's care programme. More generally, this ideal is part of a broader horizon of significance<sup>62,63,79</sup> that corresponds to the paradigm of community health, which has been dominant in Canada's healthcare system since the 1960s.<sup>80,81</sup> Indeed, most caregivers have expressed pride about the successful inclusion of patients with ID/ASD in the community, even before they evoked their unit's primary mandate focused on assessing and treating psychiatric comorbidities. While recovery and psychosocial rehabilitation may be effective for patients with less severe ID, such rational conception of autonomy is counterproductive for patients with CBs. The logic of empowerment, which values a person through his or her cognitive abilities, disadvantages patients with severe ID/ASD. Besides, by setting an imperative of adaptation as a precondition for inclusion, it can also foster and normalise the use of CMs and reinforce the stigmatisation of patients with CBs. The utilitarian drift and ensuing 'exclusion from within' mechanism, deplored by some participants, reflects the excesses of this logic of accountability, which can be used to justify the use of CMs in the name of 'inclusion'. For patients with severe ID/ASD, this conception of rational autonomy based on accountability tends to prioritise group security at the expense of individualised security. In this utilitarian perspective, the patients with CBs can be held responsible for the consequences of their actions and it reveals one of the limits of the paradigm of community health when the most serious cases are also the most excluded.

### *When relational autonomy is revealed through caregivers' vulnerability*

The above conception of autonomy coexists with another that helps shape the local imaginary of the unit. This conception based on the care relationship is made obvious by the caregivers' vulnerability. Indeed, as

our results show, it is not possible to contrast patients' extreme dependence with caregivers' alleged 'invulnerability'. Far from being all-powerful and independent figures, caregivers embody vulnerability. This is one of the most important results of this study: there is a shared vulnerability between, on one hand, patients with ID/ASD, who are both exposed to greater use of CMs and victims of exclusion, and on the other hand, caregivers, who can often face persistent crises and see their physical, psychological, professional and moral integrity severely affected by violent CBs (Table 3).

The interdependence between caregivers' sense of security and recourse to CMs (Table 6) is related to a conception of relational autonomy focused more on emotions (e.g. when a healthcare worker overreacts out of fear of getting injured)<sup>76</sup> and less on patients' behaviour. However, such relational autonomy can also value patients' socio-affective dimension mainly characterised by emotional intelligence and sensory-motor skills to promote non-verbal communication in extreme cases (Table 7). According to our results, to reduce CMs, caregivers must simultaneously consider their protection along with that of the patient (Table 6). Besides, many caregivers report difficulty in protecting themselves as well as patients. In a crisis context, an ethical challenge emerges whereby caregivers must learn to better protect themselves by maintaining a safe physical distance, while also maintaining a sufficient bodily proximity to preserve the link required to defuse a crisis. Thus, we can draw a first conclusion concerning the numerous physical injuries sustained by caregivers:<sup>8,82</sup> they may reflect their difficulty in balancing the need for both safe distance and therapeutic proximity<sup>83</sup> which means adjusting to the specific functioning of patients with ID/ASD (e.g. spatiality, theory of mind deficit).

### *Impact of the participatory dimension of the study on the development of alternatives to CMs*

The main researcher conducted four feedback sessions and discussions with the team. They revealed the caregivers' vulnerability, which was then taken into account by the managers to a greater extent, to support their relational capacities in the long term.<sup>84</sup> In this perspective, since the beginning of the study, the use of CMs decreased by 40% between 2017 and 2019 (Table 2) and several measures have been implemented to develop alternatives to CMs in the unit:

1. *About the organisation of the programme.*<sup>50-52</sup> A systematic debriefing session<sup>34,40,85</sup> is held between the managers and the day-to-day caregivers when CMs are used, to ensure that the staff's safety and moral distress<sup>86</sup> are not neglected. If caregivers are physically injured, managers recommend specific personal protective equipment (e.g. wearing long-sleeved jackets to prevent scratches or bites).<sup>7,56,87,88</sup>

Moreover, the team has also developed a more interdisciplinary and participatory approaches to consider all frontline caregivers as moral agents<sup>86</sup> and to strengthen collaboration with families in decision-making processes related to CMs. According to the team, these more inclusive approaches have resulted in a more diverse set of perspectives, which facilitate the development of alternatives to CMs and the patients' reintegration into the community. This sentence has been moved to the previous paragraph.

2. *About training staff and a new setting adapted to both caregivers and patients.*<sup>46,47</sup> In 2019, Omega training was provided to all members of the team (which was not the case in 2017, see Table 1). For non-verbal patients with ID/ASD for whom the use of CMs remains problematic, the team is considering a complementary training to promote alternatives to CMs by the use of the 'ITCA therapeutic ball' (Figure 3). In community services adapted to individuals with severe ID/ASD, this safety tool limits the risk of injury to professionals and individuals with ID/ASD and preserves the relationship integrity through visual contact and non-verbal communication.<sup>7,89</sup> Indeed, the purpose of using the ITCA therapeutic ball is the prevention of behavioural (pre)crisis and it also enables to take action during a crisis management context. Usually this ball is strategically located to anticipate

crises and easily redirect a patient with CBs to a specific location by avoiding physical interventions. In everyday life, individuals with ID/ASD can play with that ball, which allows them to see it positively. It must remain in the common areas at all times to be quickly accessible, if necessary, for the professional. The implementation of this innovative security tool is part of the improvement of care facilities, namely a support relationship based on mutual trust. The unit's environment has also been redesigned with the implementation of a calming room to prevent crises by promoting relaxation through sensory approaches, which obviously improves communication.<sup>34,44,45</sup> This involves the use of other occupational therapy tools (e.g. bean bags, mattresses, cushions and hand massagers) that have been shown in the literature to facilitate de-escalation and foster creativity to develop alternatives to CMs within a safer place to work.<sup>8,90</sup>

## Strength and limits

We believe the emic perspective of the main researcher and the participatory nature of the study have given it its real strength. First, the main investigator's clinical experience with individuals with ID/ASD and CBs, coupled with their disciplines (i.e. nursing ethics and moral philosophy), both contributed to finding the right balance between theory (i.e. the section on the ethics dilemma) and practice (i.e. the section on the impact of the participatory dimension). The emic orientation facilitates an authentic dialogue with the participants and thus contributed to a rich discussion regarding alternatives to CMs and the values of ID/ASD care. Second, the immersion of the main researcher (J.L.-U) and continued collaboration with participants over 3 years has led to the collection of rich data, both experiential and contextual. These feedback sessions have also helped ensure the congruence of our analysis; they have also deepened our understanding of the local imaginary specific to the unit and enriched our discussion with a vision which has helped the team improve their practices regarding the implementation of alternatives to CMs.<sup>6,7</sup> The interpretation process was highly iterative and also strengthened by the use of our participatory research framework. However, the participatory dimension could have been developed earlier by including participants in the elaboration of the research objectives to better integrate the needs of the unit. Although the sample is representative of the interdisciplinary nature of the team, results might have been further enriched through the inclusion of users<sup>34,44</sup> and their families.<sup>91</sup> We are aware that certain meanings and cultural associations are difficult to convey; for the purpose of the present publication, key quotes have been translated by a native English speaker aiming to render the meaning, tone and idioms of participants' accounts as faithfully as possible. Similarly to any other research in a specific context, the data are not intended to represent all mental health contexts of individuals with ID/ASD. Nevertheless, this research provides an in-depth analysis of this particular setting, which can inform practices in other settings with similar patient populations, programmes and therapeutic culture. Due to abundance of the contextual data, the potential readers of this study can realise the way its results can be applied to their specific environments and also be able to open up to ethical reflection (e.g. concerning the socio-historical, political and cultural factors of their care context). Moreover, the ethicists or philosopher reader will be able to open up to the relational dimension of everyday ID/ASD care and support practices.

## Conclusion: from self-care to mutual respect

The notion of shared vulnerability<sup>1,6,7</sup> makes it possible to conceptualise and interpret behavioural violence degrees by linking them more closely to patients with ID/ASD to express their special needs.<sup>8</sup> In crisis contexts, the recognition of caregivers' vulnerability is a benchmark to find a more balanced approach between their omnipotence (i.e. total power over others) and their impotence (i.e. impossibility of acting). Thus, by protecting themselves to protect others, caregivers can circumvent the two pitfalls of rejection and

intrusion, towards the creation of alternative approaches based on relational autonomy.<sup>76,77,92</sup> This seems to be congruent with relational ethics, which considers vulnerability as a virtue.<sup>93–96</sup> By taking greater account of caregivers' vulnerability, today, the team is mainly focused on active prevention (e.g. recognising the warning signs of anxiety that contribute to triggering the crisis) and is defusing the logic of control which was notably influenced by the historical behavioural culture of the unit. This has renewed the unit's local imaginary through the tradition of care ethics<sup>84,97–100</sup> within which caregivers' self-concern can be understood as a step towards mutual respect.<sup>101,102</sup>


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### Note

- i. CIUSSS (Centre intégré universitaire de santé et de services sociaux, or Integrated university health and social services centre) is a highly centralised structure resulting from the grouping in 2015 of hospital centers, local community health centers, rehabilitation centers for intellectual disability and pervasive developmental disorders and other services in Quebec.

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## Appendix

**Table 3.** Caregivers' vulnerability (verbatim).

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- *Trivialisation of injuries inflicted on caregivers and CB's overall impact:* 'I've had two fingers broken, I've been bitten, I've still got the mark. I've been spat on, etc. Here, you got scratched, you got beaten, you got kicked in the stomach! Injuries have become so normal, it's like a joke: "Oh congratulations, welcome to the unit!"' (P2V1); 'I've been punched before, but the most brutal was when I got a metal thermos flask thrown at my face'. (P14V1); 'Patients who are non-verbal can hit hard, you have to be very, very careful. For example, if he hits, it really hurts or when she grabs your hair, some stays in her hands'. (P3); 'We are so used to violence, we are subjected to it, we don't pay attention to it anymore, and because of our working on unity we end up living in frustration because others trivialise it. I once had a patient who, because he broke down, sent four out of six people to the CSST [occupational health and safety committee] at night when he was sick. They got beaten up. Another nurse we had, she was caught by the throat and was traumatised by it. Since then, she hasn't been able to work here again'. (P6V1); 'I've got a ton of injuries, and I've got colleagues who've gave up work because of this'. (P1V1)
  - *Caregivers' moral distress associated with CMs and exclusion mechanisms of patients with ID/ASD:* 'When you have to apply restraints or use the seclusion room to constrain the person, it becomes more difficult to maintain the bond. One patient broke her wrist struggling in an Argentino jumpsuit. She was covered in bruises'. (P4V1); 'It's so hard to do this, to go against your own values, but that's what happens'. (P8V1); 'Those that are non-verbal, they are forgotten or put aside so that others can get out faster. It's a vicious circle that's problematic. Serious cases are more difficult and the system does not encourage their discharge . . . At hospital, other departments do not welcome ID and in the community the waiting lists are huge'. (P6V2); 'This is a "Great departure" for a "Great return"'. (P16V1)
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ASD: autism spectrum disorder; CB: challenging behaviour; CM: control measure; ID: intellectual disability.

**Table 4.** A strong ambiguity between care and control measures (verbatim).

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- *A logic of control influenced by the unit's behavioural culture:*
    - (1) *A short-term consequentialist logic that fosters crises when caregivers overreact:* 'First, you negotiate the person's behaviour, if the person doesn't want to, then you offer a PRN [medication], and if it gets out of hand or if the person refuses, it's a physical intervention and the injection if the person doesn't want to take it orally. Some people go as far as restraints. But before that, you start cutting privileges. Example, cut off their cigarettes. You cut off what they like to try to play with. And you can do the same thing with outside visits'. (P1V2); 'Most situations of aggression arise from the behaviour of staff in response to the patient's behaviour'. (P8V2)
    - (2) *Socially inappropriate behaviours tend to be considered dangerous:* 'Here, we don't want to be "too positive," to encourage people to look outside of the unit'. (P2V2); 'If I see that the person is not controllable enough or dangerous to themselves or others, I can put them in the seclusion room, and the same goes for behaviour when patients get undressed, you can initiate an Argentino jacket [Figure 2]'. (P14V2); 'Here, it's not the meek who are being assaulted. Force should be used if necessary but not necessarily. The problem with violence is: if you're brutal with a patient, you're teaching them brutality [ . . . ] They're not animals! And if we do that, we're dehumanising ourselves'. (P16V2); 'Omega, it always bends towards the patient's will, while at some point you also have to show who the boss is'. (P13V1); 'Abusive is: you don't have the right to hit the person. That's just controlling the person. It's non-abusive self-defense'. (P1V3)
  - *The 'therapeutic effects' of some CMs on patients with ID/ASD:* 'Sometimes it can be problematic with patients when they're non-verbal. Here, it's a very constraining environment. Sometimes it's taken negatively by patients, sometimes it's reassuring. Some patients like it. It makes them feel good to be in a controlled environment. For some, if it's too open, it's scary'. (P4V2); 'A measure of control is an extreme care, but it remains a care. It has an effect. For a fairly severe autistic person, having a restraint makes them feel secure. Some of them even come back to ask for the restraint and I will accept it, but I will be very restrictive about the duration'. (P9V1); 'Sometimes we're gonna have patients punching because they like to be squeezed'. (P10)
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ASD: autism spectrum disorder; CM: control measure; ID: intellectual disability.

**Table 5.** The lack of inclusive approaches (verbatim).

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- *Empowerment is not appropriate for all patients with ID/ASD:* ‘Omega, I think it is a strategy that’s very respectful of the autonomy of the person. It avoids physical intervention, it’s pacification through speech, but for patients with severe ID and CB it’s more complicated to implement!’ (P4V3); ‘The aim is to make the patient more responsible, even if this is a bit utopic with the type of clientele we have’. (P14V3); ‘For some individuals with autism, self-mutilation brings something, some relief. There’s no interpretation, no guilt. Some patients only learn to react to stimuli, and if it is a positive, a “wrapping stimulus,” they will react with that. We should forget our intellect to understand them more instinctively. I think that would help’. (P8V3)
  - *Relatives and some day-to-day caregivers are not sufficiently included in the decision-making regarding CMs:* ‘In ID, for restraint, I think you have to work with the family to find out how far you go after this or that stage, before the Argentino [Figure 2]’. (P9V2); ‘We need the judgment of families to respect the autonomy of non-verbal patients and give them more choice’. (P15V1); ‘As a caregiver, we often see ourselves in a controlling role, we say to ourselves, I must achieve my goal, but the patient’s goal is not taken into consideration’. (P8V4); ‘We don’t want caregivers to think. All directives always start from above, not from here’. (P16V3); ‘Me, I’m nothing’. (P1V4)
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ASD: autism spectrum disorder; CB: challenging behaviour; CM: control measure; ID: intellectual disability.

**Table 6.** Professional integrity: the protection of both patients and caregivers is to be taken into account simultaneously to reduce CMs (verbatim).

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‘If we take care of our safety, we will also be more respectful and professional with the person’. (P8V5); ‘When action occurs, the important thing is to secure the environment, secure the patient and secure yourself’. (P4V4); ‘The use of CM depends on the staff: if they have little confidence they are more likely to use restraints’. (P13V2); ‘A team working with a sense of security changes its way to harbour profound intellectual disability or autism’. (P9V3); ‘With people with ID, we tell ourselves that they don’t understand anything and that without acting, “nothing will ever be done for them.” Often workers will forget themselves because they feel they have to intervene with the client, because they don’t want him to get hurt or hurt someone else, and by intervening too quickly without thinking, they put their safety at risk’. (P9V4); ‘I trust my colleague completely because he can tell me if he is not capable. At least he is professional enough to recognise when he is not in top shape’. (P8V6); ‘I have my weaknesses which are complemented by others’. (P16V4)

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CM: control measure; ID: intellectual disability.

**Table 7.** Caregivers’ relational involvement prevents crises by adjusting to the special needs of patients with ID/ASD (verbatim).

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- *A trustful relationship with the patient relies on caregivers’ patience and availability:* ‘It’s long, it takes years. But when trust is established between you and the patient everything changes, and the patient is much less apprehensive and you can make him or her wait quietly. Deficient patients think, but at their own level. They see the world according to their own world. It’s difficult to really interact unless you can get into their game. I enter their world at their level and become a child’. (P16V5); ‘With patients, what makes the difference is the link, the relationship, it’s the idea of preserving that integrity, because without a therapeutic bond nothing happens. In the long term, it pays off, since the investment in the relationship reduces the occurrence of crisis episodes and gives your intervention more weight [ . . . ]. Show respect in your approach, have consideration, if for example a patient asks you something, do not say “wait.” If I give a deadline, I respect the deadline. If I commit to do something, I respect it’. (P4V5); ‘Here, the difference is at a relational level, you bring your personality, your way of getting in touch with the patient. By being there in their everyday life you avoid a lot of problems. A presence is worth a lot of PRN and a lot of restraints, especially in this context with the profound non-verbal deficient patients who have severe behavioural problems’. (P13V3)
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(continued)

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- *Patients and caregivers interact with each other through observation and non-verbal communication:* 'The importance of observation in ID is in the details, it requires to be receptive to the slightest sign and to be attentive to their often very specific routine'. (P9V5); 'They are going to tell us, but in a non-verbal way, by relaxing their muscles, facial expressions'. (P7); 'I take my time to go and talk to them, I'm often joking and laughing with them and I notice that it works very well'. (P14V4); 'What helps a lot is that people recognise us. When I intervene in crisis situations, most of them, as soon as they see me, switch and calm down'. (P9V6); 'This patient's PRN [medication], it's his daily dose of affection. The restlessness you see it in the eyes. I summon their attention, I go looking for them, for sometimes they are avoidant, their contact is fleeting. There is one, he swirls a lot, he even goes as far as coprophagy, trichotillomania, and when he swirls I do a little "swirling" to go and look for his gaze'. (P15V2); 'I caress his back a little. People are afraid of him. But me, I come close and I'm even glued to his face. He likes it when I'm close by'. (P5); 'I had in the past a profound intellectually deficient patient, nobody succeeded in making her eat. I used to blow in her hair. She liked it. It made her smile'. (P16V6)
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ASD: autism spectrum disorder; ID: intellectual disability.