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Facilitating respite, communication, and care for children with intellectual and developmental disabilities: Preliminary evaluation of the Caregiver Pain Information Guide.

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Evaluation of the Caregiver Pain Information Guide

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Abstract

Background: Pain is common in children with intellectual and developmental disabilities (I/DD) and yet is an understudied issue. Respite workers commonly care for children with I/DD, but are lacking in resources to assist in pain assessment and management for this population. Without adequate knowledge in this domain, children with I/DD are at risk of their pain being under-recognized and under-managed. A resource for caregivers was developed to address this issue, facilitating communication between parents and respite workers, and better addressing the complex pain-related needs of children with I/DD. The objective of this study was to solicit initial feedback on the content, feasibility and usability of the resource. **Methods/Procedures:** Semi-structured individual interviews and questionnaires were completed with seven parents of children with I/DD and six respite workers. **Results:** All participants viewed the resource as important and potentially useful. Content analyses indicated that participants appreciated the comprehensiveness and format of the resource whereas the modifiability was identified as an area for improvement. Participants believed that the resource would be useful across settings with a variety of caregivers. Three categories of considerations were identified as potential facilitators and barriers for implementation: consideration of how the resource is being completed, who is completing it, and organization-based procedures. **Discussion/Conclusions:** Results from this study suggest that the Caregiver Pain Information Guide (C-PIG) is a

promising resource for helping respite workers better understand pain in children with I/DD. Future work is needed on implementation and impact of this resource in community settings.

Keywords: pain, assessment, management, children, developmental disability

Implications for Impact Statement: Children with intellectual and developmental disabilities experience pain frequently and are at risk of having their pain missed by caregivers. Parents would like to share pain-related knowledge and skills specific to their children with intellectual and developmental disabilities with those who support their child in other settings. The Caregiver Pain Information Guide was created to facilitate communication between parents and caregivers of these children. The current article discusses initial feedback from parents and respite workers regarding this new tool.

Available data suggest high rates of pain experiences among children with intellectual and developmental disabilities (I/DD) (Breau et al., 2003; Stallard, Williams, & Velleman, 2001; Stallard, Williams, Velleman, Lenton, & McGrath, 2002). For example, researchers in one study reported that over a two week period, approximately 75% of their sample of children with I/DD experienced pain, and this pain occurred on at least five days for 84% of the children (Stallard et al., 2001). In a different sample of children with severe I/DD, greater than one third experienced multiple hours of pain each week (Breau et al., 2003). Pain sources are diverse, with research suggesting that pain originating from illnesses, developmental comorbidities, or other non-injury causes (e.g., gastrointestinal, infection, musculoskeletal) may be the most common (Breau et al., 2003; Bottos & Chambers, 2006; Carter, McArthur, & Cunliffe, 2002). Pain from unintentional injuries (e.g., falling down), everyday pains (e.g., menstruation, earaches) and medical procedures (e.g., needles, surgery-related pain) also occurs (Bottos & Chambers, 2006; Breau et al., 2003). Children with specific disabilities may also be more likely to experience particular types of pain due to comorbidities. For example, common comorbid and painful conditions for those with Down syndrome include congenital health defects and oral health-related diseases (Bottos & Chambers, 2006).

Significant variability in these children's cognitive and physical abilities (e.g., some can communicate verbally while others cannot) has a marked impact on pain assessment and management (Breau, McGrath, & Zabalia, 2006). For example, these children may struggle to provide accurate and consistent self-reports or to use formal pain assessment tools (Chen-Lim, Zarnowsky, Green, Shaffer, Holtzer, & Ely, 2011; Dubois, Capdevila, Bringuier, & Pry, 2010; Fanurik, Koh, Schmitz, Harrison & Conrad, 1999). Further, children with I/DD may show different verbal and nonverbal expressions of pain than typically developing children (Dubois et

al., 2010) which can significantly complicate the process of behavioural observations for pain assessment by caregivers (de Knegt et al., 2013).

Most research to date in the pediatric I/DD literature has focused on improving pain assessment and management skills of primary caregivers and health care professionals. However, children with I/DD are cared for by many different people in their daily lives, and parents may not always be present to help interpret their child's pain. For example, respite workers are often prominent figures in the care for children with I/DD because they provide respite care, which is an external social support that provides a break or temporary relief from caregiving duties for families (Harper, Dyches, Harper, Roper, & South, 2013; Hoare, Harris, Jackson, & Kerley, 1998; Hodgetts, Zwaigenbaum, & Nicholas, 2014). The location of respite care (e.g., family home, in community, at an organization), type of programming (e.g., day camps, weekends away), level of support (e.g., 1:1, 2:3), and activities (e.g., community events, swimming) may all vary. To be optimally effective, respite workers must be able to successfully attend to the needs of the child in the parents' absence, including appropriate pain assessment and management. Results from our broad program of research have suggested that respite workers are frequently lacking specialized education and resources in this regard, and may hold inaccurate beliefs that can impact the care they provide to children with I/DD (Genik, McMurtry, & Breau, 2017; Genik, McMurtry, Breau, Lewis, & Freedman-Kalchman, 2018). For example, one study found that respite workers believed the ability to feel pain decreased as a child's I/DD severity increased (Genik et al., 2017). We have successfully developed, piloted, and systematically evaluated a specialized training program for children's respite workers (Genik et al., 2018; Genik et al., submitted); however, during the development phase of the training

caregivers also highlighted the need for specialized tools relevant to respite settings (Genik et al., 2018).

A number of observational pain assessment tools specific to pain in children with I/DD have been developed such as the Non-Communicating Children's Pain Checklist – Revised (Breau, McGrath, Camfield, & Finley, 2002) and the Pediatric Pain Profile (Hunt et al., 2004). Importantly, however, these tools have been used primarily in medical contexts and may not be suitable for respite. For example, it may not be possible for respite workers to observe and rate a child's behavior over an extended period of time on a detailed measure. Furthermore, research has highlighted the value of seeking parents' knowledge of their children to improve pain assessment and management skills of caregivers across environments (Carter et al., 2002; Quinn, Seibold, & Hayman, 2015; Voepel-Lewis, Malviya, & Tait, 2005). Empirically informed pain assessment and management resources to facilitate communication between primary caregivers and respite workers have not yet been developed.

The Caregiver Pain Information Guide[1] (C-PIG; to be available at: https://www.uoguelph.ca/pphc/resources/pediatric-communication-products), is an empirically-informed (e.g., Breau et al., 2003; Defrin, Lotan, & Pick, 2006; Dubois, Capdevila, Bringuier, & Pry, 2010) resource which was created to fill this identified gap. The C-PIG includes space for parents to record critical pain-related information about their child with I/DD such as common aches and pains, how the child expresses their pain, and effective pain management strategies. The approach taken within the resource is consistent with that suggested by Temple et al. (2012); namely, approaching pain assessment and management from multiple angles. For example, the

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[1] The Caregiver Pain Information Guide (C-PIG) was initially called the Caregiver Pain Resource (CPR) throughout the research study; however, given feedback from participants (see results section), the name of the resource has been changed to the C-PIG. It is referred to as the C-PIG throughout this manuscript for consistency purposes.

measure includes a number of different types of pain behaviours that have been highlighted within the literature and included in previously developed behavioral observation tools (e.g., Breau et al., 2002; Hunt et al., 2004). Pain management categories in the C-PIG also include pharmacological, physical, psychological and process strategies; approaches which have commonly been utilized and supported by children's pain research literature (e.g., pain management for vaccine injections: Taddio et al., 2015). The objectives of the current study were to introduce caregivers to the resource and gather qualitative stakeholder (parent and respite worker) feedback regarding the content, feasibility and usability of the C-PIG. These objectives were exploratory, and no a priori hypotheses were made. It was anticipated that this qualitative feedback could help to inform further development of the resource prior to implementation and quantitative feasibility and usability analyses.

Method

Participant Recruitment and Participants

This study received ethics clearance by the university's Research Ethics Board and the informed consent of participants included permission to utilize direct quotes to illustrate research results. Eligibile participants were over the age of 18, and proficient in English. Inclusion criteria were that participants had to be either (a) parents or long-term primary caregivers of a child with I/DD (0-18 years) receiving or having received respite care within the past year or (b) respite workers providing care to children with I/DD. To be considered a respite worker, participants needed to be connected to a formal respite care organization and providing respite care to children with I/DD in any context. Participants were recruited by phone or email through children's respite organizations in Southwestern Ontario within a 1.5 hour radius of Guelph, Ontario, as well as the researchers' database of participants interested in future contact. Data

were collected until data saturation was achieved. Participants included seven biological parents (M_{age}: 41.33, range$_{age}$: 31-57, 7 female), and six respite workers (M_{age}: 40.67, range$_{age}$: 23-65, 6 female). Twelve of the 13 participants (92.3%) identified as White/European. Parents' children with I/DD ranged from 5-17 years (M_{age}: 10.29) in age and held a variety of diagnoses (e.g., autism spectrum disorder, cerebral palsy, developmental delay). Respite workers had two or more years (M_{years}: 9.08; range$_{years}$: 2-24) of experience working with children with I/DD. Although it is possible that some participants may have heard about this resource from prior participation in pain-related training programs and research studies, no participants had actually used the resource in practice prior to participating in the qualitative interviews.

Procedures

Following informed consent, each participant completed a demographics questionnaire. They were then given a copy of the C-PIG and were told to review the resource for as long as necessary. On average, participants took approximately five minutes to review the resource, and then completed a semi-structured interview and an additional feedback questionnaire about the C-PIG. Participants were provided with a copy of the C-PIG and a link where they will be able to freely access the resource once finalized. Participants could also enter a $15 gift card draw.

Materials

Demographics Questionnaire. Separate demographics questionnaires were developed for parents and respite workers. The demographics questionnaire for parents included questions concerning their age, their child's age, identified disabilities and past use of respite care. The demographics questionnaire for respite workers included questions concerning their age and their past respite work experience.

Semi-Structured Interviews. Interviews were conducted in person and lasted approximately thirty minutes in length with a facilitator and note-taker present. All interviews were conducted by one of the two primary investigators: a PhD candidate (L.G.) and an undergraduate honours thesis student (G.M.). Facilitators and note-takers received training from a primary researcher who was a PhD Candidate (L.G.) with experience conducting interviews and focus groups informed by a qualitative research methods resource (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). The research advisor on the team (C.M.M) who has experience in conducting focus groups and interviews also provided additional guidance and instruction regarding interview procedures and approaches. Parallel interview question guides were based on key questions identified in prior usability studies (see supplemental Table 1; e.g., Stinson et al., 2006). Interviews were audio-recorded and later transcribed for content analyses (see below).

Additional Feedback Questionnaire. The first part of the additional feedback questionnaire was made up of six 0-10 Likert ratings about the importance of the resource and its usability; see Table 1 for these questions. There was also one question asking participants to rate their format preferences (e.g., hard copy, online download) and four questions soliciting any additional comments about information covered in the C-PIG related to: pain assessment, pain management, resource format, or any other aspects not solicited within the feedback. This questionnaire was intended to complement the interview methodology.

Analyses

Demographic data and rating responses were analyzed using descriptive statistics such as means, medians and ranges. Interview data and responses to the 4 open-ended questions from the C-PIG additional feedback questionnaire were collapsed and analyzed together using an

inductive and deductive content analysis approach as per guidelines by Elo and Kyngas (2008; i.e., preparation, organization, reporting). More specifically, generated categories were based on how frequently a topic was addressed and knowledge from literature on pain assessment and management of children with I/DD (e.g., Defrin et al. 2006; Carter et al., 2002; Dubois et al., 2010). During this process, care was taken to follow recommended reliability procedures for qualitative analyses including (a) maintaining an audit trail, (b) reviewing and cross checking interview data, field notes, and expanded field notes, and (c) discussing the content analysis process and data interpretations with a supervising researcher during category development (Barbour, 2001; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Results

Participants' Ratings of and Initial Reactions to the C-PIG

Participants' mean Likert scale ratings were above a 9 indicating that the C-PIG was viewed as important (see Table 1); these ratings also echoed participants' initial reactions to the resource during the interviews. For example, as explained by one parent participant "If you've given somebody this much information about potential pain, then you're going to worry a lot less. 'Cause that's always my concern, especially if it is a new caregiver." Another parent participant expressed that this could help parents feel less "on call" during respite care, as they felt that "respite stops being respite if [the parent is] the only one who can interpret [the] child's pain."

Content and Acceptability

Two main categories best reflected what participants liked about the content; the first was the C-PIG's comprehensiveness. One respite worker participant reported liking "how detailed it is, because when you ask parents 'what is your child like when they're in pain?' it's very vague.

So this [resource] really makes them focus." Parents and respite workers commented that the resource "just helps you not to forget something", and goes from "start to end which is good." The second category was related to the resource's layout. Specifically, both parents and respite workers appreciated its logical format and pleasing appearance. For example, parents and respite workers stated: "the order [of the questions] is definitely something I really, really, like", "I like the way it's laid out so you can circle it [the options]", and "I like that it's separated like that, 'how to tell my child is in pain', 'How to make my child feel better', that's really cool."

One category related to improvement of the resource's content was also identified: the need for modifiability. Many parents and respite worker participants commented on this, stating: "I wonder if there needs to be a little more flexibility in terms of the tool so that parents can do some of the modifying"; "imagine if it was online, you could individualize it, and that would be really cool." In addition to these comments, both parents and respite workers expressed a belief that increased modifiability could help ensure the resource is not overwhelming or cluttered. Indeed, some parents expressed concern about not having enough room to write all of the essential information about their child's pain experience. One parent expressed that they were "worried [be]cause [I] want to be actually able to write down what it is. [Be]cause some kids are very specific." Subcategories related to modifiability included: options to add more descriptive information and examples alongside existing information (e.g., how the child self-soothes, eye-gazing behavior, better defining aggression and what it looks like), being able to modify what information is included or excluded on the resource specific to their child (e.g., "I am going to take the general organization of this and create something that works for [my child].""), and having both online and hard copy options. For example, a parent indicated "you may find that

it's help[ful] to have a paper and pencil version, but it may be helpful to have a software version that could be modified by parents. I would use the latter."

Feasibility and Usability

Parents and respite workers perceived the C-PIG as a resource that could be useful across settings with a number of different users. For example, one respite worker stated: "I feel like the schools and group homes would really benefit [from the resource]. Anywhere, really." Another respite worker reported seeing the C-PIG as "a base" for paperwork in respite agencies because it is "such a good summary that encapsulates everything." A parent also spoke about using the C-PIG at home: "I think I will actually do this at home. Just put it on the fridge." Thus, two broad categories of potential use were identified: (a) in the home with parents, other family members, caregivers and babysitters, and (b) outside of the home in external respite settings, at school, in medical settings, and in the community.

When thinking about use of the C-PIG in practice, parents and respite workers identified three categories which should be considered and may play a role in facilitating or limiting the uptake and use of the resource. Firstly, participants spoke about the need to consider how the C-PIG would be completed including the benefits of having it completed by parents in advance and updated regularly. In discussing their thoughts about the resource, one parent stated: "it'd be a prevention thing, and a tool that can evolve too as [child's name] is growing and changing - so it would be important to update it too."

Secondly, participants thought it was worthwhile to consider which caregivers are completing the C-PIG. The importance of knowing the child well when completing the resource was evident. For example, one parent described the resource as an opportunity to share 'red flags' with workers who support the child. Participants believed that in some cases it may make

sense for multiple caregivers to complete the resource. For example, a respite worker indicated: "so say they go to mom's one weekend and dad's another…make sure you get [feedback from] both…and have them fill them out separately, not together." Respite workers also supported the design of the resource in arguing that primary caregivers should be available to complete and discuss the resource with relevant caregivers. A respite worker noted that the resource "should probably be filled out at [the] initial meeting with the parents before [the worker] even see[s] the child."

Thirdly, participants spoke about the need to consider organization-related procedures and how this could impact the uptake of the resource. For example, there would be a need to understand how the C-PIG aligns with current intake and documentation procedures, and ensuring that staff are allotted sufficient time to review and understand the information in the resource. One parent spoke about this in the context of the other non-pain related documentation required from agencies: "I find a very concrete difficulty that most parents have is that there are lots of resource[s] out there here, but they're very spread out so each agency is designing their own tool, has its own intake form and so on. But it is also very repetitive, very scattered out." All suggestions related to further improving the feasibility and usability of the C-PIG were related to the modifiability of the resource as discussed above.

Discussion

Pain is common for children with I/DD, and accurate interpretation of their pain can be difficult (Breau, Camfield, McGrath, Rosmus, & Finley, 2001; Breau et al., 2003). Despite a need for more effective pain assessment and management of children with I/DD, there is an apparent lack of standardized communication tools to meet this need in non-healthcare community settings. The C-PIG was therefore developed to facilitate communication between

parents and respite workers, and better address pain assessment and management needs of children with I/DD. The current study was conducted to gather initial stakeholder feedback regarding the content, feasibility and usability of the C-PIG. Overall, participants responded very positively to the resource and believed it would be an important resource to implement.

Content and Acceptability. Consistent with the literature highlighting the complexity of pain in children with I/DD (Beacroft & Dodd, 2009; Carter et al., 2002; Chen-Lim et al., 2012; Quinn et al., 2015), participants appreciated the comprehensiveness of the C-PIG. Parents and respite workers reported that the prompts in the C-PIG to gather pain information were extensive and detailed. Although content is certainly critical, the layout and appearance of a resource, as aspects of acceptability, are also important. This is consistent with other usability work related to pediatric pain which has also found benefit to exploring and addressing these aspects (e.g., Stinson et al., 2015).

Modifiability. Despite the many benefits and important features of the C-PIG as outlined by participants, limitations of the resource were also highlighted. In particular, a need for increased modifiability was identified. As Defrin et al. (2006) demonstrated, level of I/DD affects a child's behavior. Thus, it makes logical sense that children with varying degrees of I/DD may require different formats of the C-PIG in order for it to effectively address their needs. For example, brief as well as more in depth versions of the resource could be relevant depending on individual child needs and caregiver preferences. Alternatively, using electronic technologies such as an app could be an important next step in the implementation of the C-PIG in order to facilitate further individualization. Indeed, a systematic review of pain apps found that many had 'very good' or 'excellent' potential for function and clinical utility (Smith et al., 2015).

Feasibility and Usability

Children with I/DD are supported in many environments where they may experience pain without their parents present to assist with pain assessment and management. Examples of these include respite settings, camps, schools, and hospitals. Participant reports during our study suggest that the C-PIG could be useful across a wide range of contexts, implying that it may be more versatile in some ways than other previously developed measures which tend to focus solely on assessment and often in the context of a particular medical procedure (e.g., *Non Communicating Children's Pain Checklist – Post-Operative Version* [Breau, Finley, McGrath, & Camfield, 2002]; *revised Face, Leg, Activity, Cry and Consolability Scale* [Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006]). Parents and respite workers also reported that the C-PIG appeared easy to use and understand, and was laid out clearly. Judging from this feedback, the user may not need extensive training in order to use the C-PIG effectively which increases feasibility and access.

A number of factors were highlighted which would impact implementation. For example, many respite worker participants spoke about the need to consider organizational factors such as intake procedures and staff time to review the resource. The C-PIG could be incorporated into pre-existing organization practices in at least two ways: 1) as part of an intake package to be completed if pain is a known issue, and 2) as a readily available resource that travels with the child so that care staff can easily access relevant pain-related information. Both of these approaches could also enable further conversations with parents about a child's pain cues and preferred pain management approaches. Implementation considerations could be gleaned from partaking in the 'adapting knowledge to the local context' and 'assessing barriers to knowledge use' phases in the knowledge-to-action cycle (Graham et al., 2006). Ensuring that information and resources are appropriate for the setting and that barriers to knowledge use have been

explored and addressed could facilitate early adoption of this tool such as during intake. For example, it would be important to consider whether paper-based or electronic formats would be most feasible for a given context, and the best approach to gathering the appropriate information (e.g., completing resource with a staff member present versus having parents complete and return in advance of first appointment). Without these considerations, it is possible that the tool may not be used to its full potential or gather the information of which it is intended. Appropriate and effective use of the tool early on would provide caregivers with the needed information and opportunity for discussion *prior* to the experience of pain during respite care; in turn, this could decrease reliance on the trial and error often needed to support the child in a new setting.

Strengths, Limitations and Future Directions

This study addressed a gap in the literature about a vulnerable and under-researched population – children with I/DD. Inclusion of two important stakeholders, parents and respite workers, garnered perspectives of those who would be completing the resource as well as those who would be using it in practice. Stakeholder involvement is an important component of feasibility studies (Bowen et al., 2009), and an approach that has been used in the past in the development of other pain measurement tools for children with I/DD in medical settings (e.g., Voepel-Lewis et al., 2005). In gathering qualitative data from participants, recommended procedures for increasing rigor in qualitative research methods such as the use of an audit trail and meeting data saturation were employed.

It is also important to discuss some limitations. First, although interviews are a strong qualitative method, focus groups could have provided an added layer of depth as they reveal differing opinions and interactions between participants (Turner, 2010; Rabiee, 2004). The use of focus groups was initially the preferred approach by researchers, but was not feasible given

participant schedules. The difficulty in scheduling may speak to the significant time demands of parents raising children with I/DD, as well as the varied and shifting schedules held by respite workers. Second, this study included only a small sample of participants, with 12 of 13 participants identifying as White/European. Further, parents who participated had children who ranged from age five to 17. While appropriate in scope for a pilot/initial exploratory study, results may be limited in scope, meaning that our results are not fully representative of the larger population intended to use this tool. Future work on this tool should make explicit efforts to gain a more diverse sample of participants in terms of ethnicity, as well as children's age ranges and diagnoses to further determine the usability and scope of the resource. Third, this study did not explore views of respite organizations or management with regard to the feasibility of using this resource within their settings. It is possible that managment may hold different views than front line respite staff, and these opinions should also be sought. Finally, this study also did not explore the use of the C-PIG in practice, which is an important aspect of feasibility. In terms of next steps, we first intend to revise the C-PIG and incorporate participants' feedback about the modifiability of the resource. For example, a modifiable online document that could be downloaded by parents, respite workers and other knowledge users may be one way to address participant feedback. Important components of this modifiable download would be the ability to choose which information and what level of detail is included. Another option is to develop a C-PIG smartphone application. Developing an app may be particularly beneficial, as it could be updated regularly by multiple stakeholders, would be portable, and would able to house more information. A C-PIG app could also include programmed notifications for caregivers to update information, for example after pre-determined periods of time, after certain milestones, or when registering with a new respite setting. Next, we intend to explore the implementation and use of

the C-PIG in respite settings.The use of the C-PIG by various other caregivers such as grandparents, teachers, educational assistants, and babysitters should also be assessed. Where possible, it will likely be beneficial to use this resource in a more comprehensive treatment plan intended to span across care contexts and care. For example, if this resource were adapted to an app-based platform, all relevant care providers could have access to the child's pain-related information, and parents could provide more regular and immediate changes to this resource as relevant.

Pediatric psychologists could play a key role in helping to ensure parents have adequate knowledge about pain, how to use the C-PIG, and with whom to share the information. Research has demonstrated that parents would like more support from professionals in developing pain-related knowledge and skills (Carter et al., 2017), and these types of discussions and resources may help address parents' needs. This resource could be used by parents to communicate about their child's pain with individual pediatric psychologists as well as with professionals in other disciplines who may be within or outside of an interdisciplinary team. For example, it could be used during initial intake appointments to help parents communicate about their child's pain behaviours and what parents have tried/what has been effective when managing their child's pain. Further, it may also be used to support the identification of pain behaviours and track interventions over time, supporting consistent information sharing and treatment planning.

Conclusion

The C-PIG was perceived by parents and respite workers as a potentially effective way to communicate with each other about pain in children with I/DD including assessment and management. Future research should be conducted to assess the usability and feasibility of the C-PIG when implemented in respite settings. If implemented in a respite setting, it will be

important to evaluate the impact through the perspectives of all users including parents, respite workers, and organizations. Following this, more broad-based implementation and use of the resource with other support providers such as teaching assistants and medical professionals should also be explored. It is hoped that this resource will: improve the pain assessment and management skills of respite workers and other caregivers of children with I/DD, reduce parents' concern that their child's pain is not being addressed effectively, and ultimately improve the quality of life of children with I/DD.

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