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Perspectives of Support Workers on Supporting Persons with Intellectual Disability and Pica

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Abstract

The purpose of this paper was to determine the support needs of adults with intellectual disability (ID) and pica (the ingestion of inedibles). Through two focus groups, the perspectives of staff from institutional and community settings in Ontario were examined. Qualitative data revealed that three categories of intervention underpinned reduction in pica (i.e., preventative measures, formal supports, and familiarity with the individual), and that staff in both settings tended to be isolated in managing this complex behaviour. Further, inadequate resources, the lower functioning level of the individual, and lack of knowledge acted as barriers to implementing strategies to reduce the impact of pica on the person's life. This study provides important information on the barriers and successes experienced by support workers, and the service needs and recommendations for additional services for adults with ID and pica.

Individuals with an intellectual disability (ID) have a higher prevalence of comorbid psychiatric disorders and challenging behaviours compared to the general population (American Psychiatric Association, 2000; Borthwick-Duffy, 1994; Cooper, Smiley, Morrison, Williamson & Allan, 2007). Pica, the ingestion of inedible substances (e.g., paper, plastic, string, cigarette butts, hair, feces), is a behaviour that more commonly occurs among the ID population, affecting 0.2% to 25.8%; rates are higher in institutions (Ali, 2001; Ashworth, Martin & Hirdes, 2008; Danford & Huber, 1982; Swift, Paquette, Davison & Saeed, 1999; Tewari, Krishnan, Valsalan & Roy, 1995), and among those with more severe levels of ID (Ashworth et al., 2008; Danford, Smith & Huber, 1982; Lofts, Schroeder & Maier, 1990; Matson & Bamburg, 1999; McAlpine & Singh, 1986; Swift et al., 1999; Tewari et al., 1995; Witkowski, 1990).

Pica is considered a self-injurious behaviour because of its broad range of health consequences (e.g., malnutrition, anemia, parasitic infections, intestinal obstruction or perforation, death) (Danford et al., 1982; Decker, 1993; Lofts et al., 1990; Stiegler, 2005) and negative impact on quality of life (e.g., decreased engagement in recreational, productive, and social activities) (Ashworth, Hirdes & Martin, 2009; Bugle & Rubin, 1993; LeBlanc, Piazza & Krug, 1997). Research on functional analysis and intervention of pica have identified that pica appears to be maintained predominantly by physiological or sensory reasons, rather than social reasons (i.e., attention) (Applegate, Matson & Cherry, 1999; Matson & Bamburg, 1999; Matson, Mayville, Kuhn, Sturmey, Laud & Cooper, 2005; Wasano, Borrero & Kohn, 2009). That is, pica is considered self-stimulatory, as the individual takes pleasure in the sensory properties of the items they ingest, and the ingestion of those items automatically reinforces the pica (Piazza et al., 1998). However, some single-subject research indicates that pica can also be a function of social attention (Mace & Knight, 1986; Piazza et al., 1998). Taken together, pica behaviour can likely serve multiple functions for the individual, making it particularly difficult for caregivers and staff to isolate the variables maintaining it in order to design effective interventions.

Interventions for pica are predominantly behavioural approaches that range from the least (e.g., sensory interventions, non-contingent presentation of food/attention, discrimination training, differential reinforcement) to the most (response blocking, overcorrection, aversive substances, negative practices, self-protection devices, and physical restraint) intrusive methods (Burke & Smith, 1999; McAdam, Sherman, Sheldon & Napolitano, 2004), though psychotropic medication (Jawed, Krishnan, Prasher & Corbett,1993; Singh, Ellis, Crews & Singh, 1994) and nutritional supplements (Bugle & Rubin, 1993; Lofts et al.,1990; Pace & Toyer, 2000) are also used. Though these measures aim to ensure the safety of the person, they also jeopardize the person's quality of life (Burke & Smith, 1999; Stiegler, 2005) in that they reduce opportunities for social and recreational activities, and may serve to maintain pica over time as the individual is exposed to less stimulation.

In addition to an overall lack of research on successful interventions for the treatment of pica, the nature of the support needs of adults with ID with pica is also unclear. There are no studies that have specifically investigated the perspectives of support staff in managing the behaviour, or the ways in which they support persons with pica on a day-to-day basis. Therefore, the literature is silent on some of the more "human" aspects of the challenges of working with this unique subpopulation. Understanding how pica is managed from the perspectives of support staff is an important, if not, crucial, aspect of identifying the factors that promote and hinder its management.

The main purpose of this qualitative study was to understand, from the support worker's perspective, the experiences of supporting persons with pica in the province of Ontario, with particular focus on what strategies they found successfully reduced the impact of pica behaviour on the lives of individuals and what barriers existed to implementing those strategies.

Given that this study is the first of its kind, we decided to exclusively focus on examining the experiences of support workers in the field who have the most adequate experience implementing strategies to manage the behaviour. Therefore, we sought the perspectives of staff from both institutional and local community settings in the province to compare and contrast their experiences and approaches. The inclusion of institutional staff was necessary given their greater exposure and expertise in managing pica in adults with ID (as pica is rarer in the community). In addition to providing information useful for developing guidelines and policies related to supporting persons with pica, this study will further elucidate what skills and knowledge will be needed by community staff and families to manage and improve the quality of life of individuals with pica in community settings, given the recent deinstitutionalization in the province of Ontario. Seeking the perspectives from family members and the individuals with ID and pica themselves is a future next step to this research.

Method

In this section, a description of the participants, sampling procedure, data collection and analysis are detailed.

Participants

The institutional focus group comprised four male staff from a single institution, all of who had worked there for an average of 24 years (range of 19 to 29 years). Six front-line staff (5 females, 1 male) from four community agencies in southwestern Ontario participated in the community focus group; all were full-time residential counsellors directly responsible for the day-to-day support of adults with ID and had been working in the field for about 5 years (range 3 to 8 years). Through previous research projects and initiatives, the researchers had previous work experience with two of the participating organizations, though not with the staff personally. The discrepancy of the number of years worked between institutional and community among staff participants is representative of the current personnel practices in each service setting in the province prior to the institutions closing. In fact, having 20 or more years of experience was not uncommon among institutional staff in the small communities in which the institutions were located; sometimes generations of family members worked at the institution, and many were considered 'family' to the residents of the institution themselves.

Due to difficulties recruiting staff with relevant experience in community settings, as well as logistical factors (i.e., time, geography), a sample size of ten was used. Given the nature of the study, a sample size of ten is deemed sufficient to learn about the main issues and perceptions important to managing pica (Kreuger, 1994).

Procedure

Although pica is a significant problem and is found with much greater frequency among persons with ID, it is still experienced by only a small minority of that population. Consequently, the number of developmental services staff with the relevant support experience is also quite small, particularly in the community where this type of behaviour is less frequent. This lower rate of occurrence in the community is due to the fact that, historically, most individuals with ID who exhibited severe and persistent pica behaviour into adulthood were institutionalized. Given the rarity of pica, we used purposive sampling to obtain participants from institutional and community settings who had the relevant experience and expertise with managing pica. As such, we acknowledge that our sample is not representative.

Information letters were first sent to each of the three remaining institutions in the province (prior to their closure), as well as to the nine largest community organizations in southwestern Ontario; these were later followed up with telephone calls. Managers from the community agencies and coordinators from each of the institutions were asked to approach their staff with the relevant experience with a brief description of the project and to provide information on how to contact the first author if they wished to participate or had any questions about participation. Among the nine community agencies contacted, two did not support clients with pica. Of the seven remaining eligible agencies, four agreed to participate (57%). Only one of the three institutions participated (33%); this institution supported a relatively large number of persons with pica. All participants provided informed consent.

Focus groups were chosen as the primary means to collect information about the perceptions of support workers for several reasons. They can provide rich data through direct interaction between the researcher and participants, and participants are able to build on one another's comments about an issue that little is known about. When contrasted with one-to-one interviews, the group dynamics in focus groups can actually enhance the type and range of ideas and feelings that individuals share about a certain topic through the social interaction of the group (Thomas, MacMillan, McColl, Hale & Bond, 1995). Due to time constraints and logistics, it was deemed more efficient to assemble staff into two homogeneous focus groups (i.e., community and institutional staff). While most experts suggest that one should run enough focus groups until a clear pattern emerges and subsequent groups produce only repetitive information (theoretical saturation) (Krueger, 1994), this study was limited to a single focus group for each of the two groups. Each focus group lasted approximately two and a half hours.

Both focus groups were conducted by the first author. A semi-structured focus group interview guide was used to provide general direction for the focus group discussions (see Appendix). Although the questions were determined in advance, the researcher had the flexibility to question and probe ideas that arose, using a conversational style. Reflective notes were taken after each focus group session by the first author to record first impressions, thoughts, and feelings regarding the focus group. Participants in both the institutional and community focus groups were engaged and open about discussing their experiences. In fact, many were relieved to find out that other staff persons were experiencing similar challenges supporting persons with pica. They not only benefitted from feeling less alone but they also heard alternative ways to prevent and manage pica from other group members.

The focus groups were audio recorded by the first author (with participants' permission) and transcribed verbatim by a professional transcriptionist to ensure objectivity. Ethics approval was obtained from the University of Waterloo's Research Ethics Board.

Analysis

The focus group transcripts were analyzed by the first author and two undergraduate research assistants and coded to develop themes or categories. Two coding strategies were used: open and axial coding (Strauss, 1987). Coding ceased when no new themes emerged from the data. The constant comparative method was used to compare data on several different levels (e.g., comparison of categories and themes, responses between participants, and responses across settings). Final data analysis involved the interpretation of the patterns and themes. The credibility of the data was established by the inclusion of multiple data sources – i.e., the focus group data and descriptive, reflective, and analytic notes. Alternative explanations or categories were also followed up and considered. In addition, the first author also looked for, reported, and explained negative cases, or cases that did not fit with the established coding (Patton, 2002). To verify the coding scheme, random checks of the data were performed independently by the two undergraduate assistants. Participants were also asked to verify the accuracy of the findings and interpretations; the majority of the participants indicated that they agreed with the final themes (two did not respond).

Data were analyzed according to the constant comparative method (Strauss & Corbin, 1990). Although this method is commonly employed in grounded theory, the current study does not constitute a grounded theory study. Rather, it aimed to gather rich description from support staff on their experiences supporting persons with ID and pica.

Findings

Six themes emerged related to support staffs' experiences: three related to successful strategies (i.e., prevention, knowing the individual, and support networks), and three to barriers to supporting persons with pica (i.e., lack of knowledge, inadequate resources, and person's level of function). Excerpts from the focus groups are included to illustrate each of the themes, making use of the participants' own words.

Successful Support Strategies

Prevention

Prevention was the most consistently reported intervention used to manage pica behaviour in both settings and was felt to be the most effective. Prevention efforts discussed related to altering the environment and engaging individuals in other activities. Altering or "pica-proofing" the living environment (i.e., removing or locking up potential pica items, sweeping floors and cleaning up) was brought up by all staff as a way of creating a safe environment that also helped reduce the use of more intrusive strategies:

> "I'd say we've gotten rid of three quarters of the restraint use for pica just through prevention."

These pica-proofing routines appear to be internalized by both institutional and community staff to such an extent that they became automatic. Many staff reported that they worried about the safety of the person(s) they supported (that it was always in the back of their mind) and whether they had locked up everything and checked the environment while they were on shift and, often times, after their shift:

> "You worry. You constantly double guess, did I lock all the cupboards? Did I check, you know, under his bed? So your head's wondering, did you do everything you needed to do in order to try and keep him safe?"

Keeping individuals occupied and engaged in alternative activities is another tool that staff in both settings found helpful in preventing the occurrence of pica. The majority of staff spoke of providing safe sensory activities (e.g., oral-motor sensory items called chewlery or theratubes, fidget toys for their hands,) and recreation programs (e.g., provision of preferred activities or objects, outings) for the individuals to occupy themselves with.

Knowing the Individual

Staff's familiarity with the individual(s) they support was another important factor to successfully supporting persons with pica. In particular, knowledge in three areas was highlighted: the person's preferred activities or items, the frequency and severity of the pica (both past and present), and the unique way each individual responds to different types of interventions. For example, all institutional staff and two community staff reported that although mechanical restraints are intrusive, they must be used in some instances:

> "With one specific individual that we support, it (pica) almost cost him his life. One more surgery, that's it for him. He's had three surgeries to remove objects and pieces of his colon were perforated. And so that's why a helmet with a face mask is a drastic measure but this is to save his life. So we can save lives."

Therefore, in this case, knowledge of the person's history in terms of severity and consequences of pica and their response to previous interventions helped staff make the best decision about the type of intervention to put in place to ensure the person's safety. By having good clinical knowledge about the person's pica, all staff said that they felt more able to prevent and manage the behaviour. For example, in the institutions, staff documented the preferred pica items for each of their residents, which in turn increased staff's awareness of what they needed to look for during pica sweeps. This in turn, reduced not only the frequency of pica but also the use of more reactive and intrusive approaches (such as using physical blocking procedures when an individual brings inedibles to their mouth), which can lead to negative and coercive interactions between staff and the individual.

Support Network

Another factor identified by staff to be helpful in managing pica was having a good support network. "Support network" refers to the group of family, staff, and other professionals who are invested in the person's well-being. Professional support was reported to be variable between settings and across community agencies: the institution had the most comprehensive team of professionals on-site (e.g., behavioural consultants, physicians, nurses, occupational therapists, dietician, and a speech-language pathologist), as well as specialized resources (e.g., for providing pica-friendly clothing and environments). Staff in both settings believed that it was their ability to meet and work together as a team that was the most beneficial in developing successful intervention strategies.

In contrast, the availability of health and clinical support varied across different community agencies; about half of community staff were not aware of specialized clinical services. When clinical services were available, half of the community staff reported experiencing difficulty dealing with physicians who often lacked the knowledge about the medical symptoms and complications of pica. On the other hand, those who reported positive relationships with the person's physician reported that referrals and medical services (e.g., regular ultrasound or X-ray examinations of the person's abdomen for foreign objects) had been facilitated. That said, in the community, family members and agency staff were reported to be the heart of the support network.

For this reason, staff consistency figured prominently in the staff's reflections on facilitating the management of pica in the community. It was reported that a consistent approach to managing pica was facilitated by having good staff relations among all staff (including management), open communication, and protocols in place – all of which are made easier through stability and consistency of staff. The value of consistency was emphasized by one staff in the institution who said:

> "Consistency is probably one of the most important parts. That's one of the main reasons we developed a protocol system, because if one staff had one feeling about something and I had another and another staff had another one, well depending on who's there, I may manage a behaviour in a different way. So we have found the need for consistency. So, especially for pica, this way it lets everybody off the hook. Like [another staff] and I don't have to get in to a disagreement about my approach versus his. It saves a lot of aggravation."

Consistency proved to be even more challenging when staffing arrangements were taken into account. Community staff commented on how conflict between full-time and part-time staff and staff turnover negatively impacted the ability to support the person, further showing how fragile the person's support network can be. Staff in the institution, too, expressed that maintaining good working relationships with co-workers and mangers was integral but they reported less work conflict compared to staff in the community.

Barriers to Implementing Successful Support Strategies

Lack of Knowledge

A common thread among the responses of both community and institutional staff was the lack of knowledge among staff, family, and the community at large regarding the causes of pica and its treatment. Lack of knowledge of this behaviour was felt to be due, in part, to the paucity of information available:

> "I've checked the internet quite often and there's not a lot really that helps aside from what we already do in the way of prevention."

Further, the majority of community staff had no knowledge of the services available to help them. Even when aware, there remained uncertainty about how to connect with specialized clinical services (e.g., behaviour therapists, psychologists). A number of community staff suggested that agencies could collaborate with one another and share expertise and experiences:

> "It would be helpful if we had more information about what pica is. What works for one individual might not work for another one. But if we had a hundred individual cases, from those hundred probably two or three would help my individual. So I would like more information, in the form of examples."

The community at large is also not educated on pica and its complications. The majority of community staff expressed feelings of embarrassment about their client's behaviour when in public. As a consequence, staff person were, at times, reluctant to take the individual out in the community:

> "It's not pleasant to have people staring at us because he's wearing a helmet. So find out why he's wearing a helmet. Don't just stare at him. Don't just point at him. Don't laugh at him. We've been really lucky when we take them to restaurants. But some restaurants, not the staff but the people eating, they look at us like were something out of this world. And that feeling, I don't like it. And I'm pretty sure that they (individuals she supports) don't like it either."

Therefore, staff tended to remain at the person's home, or go on "safe" outings (e.g., familiar restaurants or parks), in order to avoid embarrassment or negative reactions from the public. This further prevents the individual from engaging in the community and limits the community's exposure to pica, thus further contributing to their lack of knowledge.

Inadequate Resources

Inadequate staffing and costs were discussed by staff in relation to barriers to successfully supporting persons with pica. Inadequate staffing, though mentioned by staff in both community and institutional settings, really resonated with staff at the institution. In the institutional setting, the staff-to-client ratio was about 2:8, compared to 2:3 or 2:6 in the community. Due to the large numbers of individuals with pica in the institutional setting and the relatively fewer numbers of staff, a collective approach to managing pica was often used instead of individually-based solutions (e.g., pica wards and keeping the living environment pica friendly). A number of negative consequences of inadequate staff support were reported, including reduced opportunities for inclusion in recreational activities and community outings and the use of more intrusive measures, such as the use of mechanical restraints:

> "They just can't have fun in the yard because of the danger of grass and leaves and rock and twigs. So their ability to sort of become involved in things is absolutely one hundred percent dependent on the availability of staff to take them. So that whole ability to choose and be independent is gone."

As well, all staff noted that increased supervision is needed because of the often hidden nature of the behaviour and concurrent behaviours. For example, increased supervision is required for persons known to hide pica items for later consumption and for those who engage in self-injurious, destructive, or aggressive behaviour.

Staff in the institutional setting indicated that creating pica-friendly environments was expensive. Modifications range from the provision of specialized furnishings that are difficult to rip or tear apart, to putting metal around the edges of doors and windowsills, and coating the walls with cladding (a special surface coating that renders the dry wall inaccessible). Costs were also compounded by the fact that individuals with pica may engage in destructive behaviour (e.g., tearing furniture to consume the fabric). In contrast, community staff did not mention cost as a factor in maintaining a pica-friendly environment.

Functioning Level of the Individual

The focus groups revealed that many staff felt frustrated in supporting individuals with pica because of their lower functioning level (i.e., severe/profound cognitive impairment), which made it difficult for them to understand the dangers of pica or learn more adaptive behaviours. For example:

> "She doesn't have any verbal communication skills. So, I do tell her it's dangerous or I do try and tell her the reasons why but I'm not really sure if she understands."

All of the institutional staff and about half of the community staff also expressed frustration at the fact that the individuals they supported appeared to have very limited interests, making it difficult to engage them in alternative and safe activities. Limited communication skills also contributed to the difficulties associated with knowing whether the person was experiencing discomfort or more serious pain or medical symptoms from the ingestion of inedibles as persons are often not able to articulate how they are feeling physically, nor whether they have in fact ingested something:

> "But how do you know? Like we didn't know that the hairball was forming until she was very, very ill. So how do you know they're not getting obstructed bowels?

More than half of the staff in both settings perceived that, apart from environmental controls, there really were few alternatives for managing pica because of the person's lower functioning level.

Discussion

This study was conducted to understand the perspectives of staff supporting persons with ID and pica. It also sought to better understand what strategies were found to be useful in reducing the impact of pica behaviour on individuals, and what barriers existed to implementing those strategies. The results provide important information for both those planning clinical services for this unique population and for those facing the significant challenge of helping individuals with pica on a day-to-day basis.

Prevention, knowing the individual, and support networks emerged as helpful strategies. Prevention, in the form of environmental controls and staff monitoring, was the most common strategy used, though provision of alternative stimulation was also employed. Knowing the person's preferences and history of pica behaviour was also essential to developing individualized strategies that are appropriate to the person. A strong support network was also identified as a key factor in facilitating both access to and sharing of information and professional support, as well as in providing consistency to the individual being supported. There were also a number of specific challenges to supporting persons with pica reported by staff. The staff often spoke of frustration related to inadequate staff support, the impact of lower functioning levels, and general lack of knowledge about pica. Inadequate staff support was a concern in both settings. In the institution, it often led to the use of more intrusive interventions and reduced social and recreational opportunities for individuals with pica. The lack of understanding about pica, its causes and consequences, hindered staff in accessing information and trying new approaches. Staff also reported that the general lack of understanding of this behaviour by the general public sometimes caused feelings of embarrassment for staff and individuals with pica while in the community. The lower functioning level of the persons with pica contributed to difficulty in finding activities and interests among individuals with more severely impaired cognitive and communicative abilities; it also prevented staff from trying new strategies for managing pica (that may have required more active participation than the person was capable of).

The themes that emerged from this study provide insight into the support needs of individuals with pica, as well as demonstrate the complexities and barriers associated with their support. Moreover, the findings contribute to an understanding of the nature of pica behaviour. It is clear from the staff's perspective that, overall, there is little known about how best to support persons with pica. However, a new understanding of the facilitators and barriers may inform what adjustments might be made to the service system to enhance supports for adults with pica.

Again, prevention was the predominant approach to managing pica in both settings, where modifications to the living environment were costly. While pica is more frequent among persons in institutional settings, deinstitutionalization is underway or completed in many jurisdictions in Canada and around the world. Because of the costs and levels of supervision associated with creating pica-friendly environments, there is danger that efforts will concentrate on creating homes specifically for persons with pica; therefore creating a situation in which the presence of this behaviour overshadows the person's preferences and needs when planning living arrangements.

Adequate staffing levels are key, not only to ensuring the person's safety, but also to ensuring that they have the opportunity to engage in community-based social, recreational, and productive activities of interest. Further, staff have found that recreational activities and engagement reduces pica. Staff's frustration in finding alternative activities for individuals with pica also highlights the need for training related to identifying the preferences of person's with more severe levels of cognitive impairment. This training is especially important because such individuals are often dependent on others to participate in activities (Jones et al., 1999). Persons with ID who engage in pica also tend to engage in other forms of challenging behaviours (Emerson et al., 2001; Sigafoos, Arthur & O'Reilly, 2003), which again leads to the need for intensive supervision and individualized interventions. This is consistent with the current thinking on treating behavioural problems (Rush & Allen, 2000). Researchers and practitioners need to investigate the function of the behaviour, try different approaches, and consult with people that know the individual best, such as staff and family. By having an adequate support network in place, staff persons have the time to get to know the individual and use that knowledge to prevent and manage the individual's pica.

At present there appears to be little interagency communication and collaboration in dealing with individuals with ID with multiple, complex needs in the community. Consequently, there are missed opportunities for sharing expertise, experiences, and successes that further perpetuates the lack of knowledge among staff and consequent opportunities for persons with pica. Interagency collaboration would not only help to bring together the skills and experience of staff, it might also help to reduce the feelings of isolation and frustration expressed by staff. While barriers still exist in terms of interagency collaboration, important strides in this area have been made. For example, networks of specialized support and video-conferencing have been created to enhance community agency access to professionals (MCSS, 2006). However, this network will only be effective if all parties involved (including the executive directors, board of directors, managers, and staff of each developmental service organization) know that the service exists, and how to access it.

This study had several limitations which should be taken into consideration when interpreting the findings. To begin with, only ten staff participated in the focus groups; a larger sample might have enabled the researcher to further develop the themes. Although the transcripts were extensively reviewed until it was determined that no new information could be gleaned, it is likely that with a much larger and diverse sample from different regions of the province it would have potentially revealed additional themes. Similarities and differences in support needs and practices across the province could be better articulated. As such, an important next step in this program of research will be to replicate the study with a greater diversity of staff in other community agencies in Ontario as well as other jurisdictions (both rural and urban areas). However, it is important to note that the number of front-line staff with experience supporting persons with pica continues to be small, as pica is a low incidence behaviour and very complex to support. Second, the study was limited to the perspectives of support staff supporting adults with ID and pica. In the future, similar studies should seek input from adults with pica themselves and their family members, as well as from administrators of community agencies and policy makers in developmental services. Future studies should also conduct focus groups with children or adolescents with ID and pica and their family members, so that their perspectives can be understood and taken into consideration to assist with a lifespan approach to planning supports and practice guidelines for persons with ID and pica.

Conclusion

To the best of our knowledge, this is the first study to examine the perspectives of front-line staff persons who support adults with ID and pica. The findings validate the notion that persons with ID and pica have distinct support needs, and that better services are needed (especially clinical services) to improve the lives of individuals. This information is very important in the context of the closure of institutions in Ontario, Canada, and abroad. Full inclusion of persons with ID in the community will require that all community-based professional services (e.g., physicians, psychologists, behavioural therapists, occupational therapists, etc.) understand the full range of needs of this population – including those related to everyday living, health, mental health, and behaviour.

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Key Messages from This Article

People with disabilities: People who have pica sometimes eat things that they are not supposed to, like paper, string, or hair, and this can make the person very sick. There are a lot of ways that staff can help people with pica, but there are also a lot of things standing in their way. It is important to help staff so that they can improve the quality of life of persons with pica.

Professionals: Helpful strategies for managing pica involve prevention in the form of supervision and environmental controls, knowing the individual, and having good support networks. As well, interagency collaboration is necessary not only to help bring the skills and experiences of staff together but also to reduce feelings of isolation and frustration staff often report.

Policy makers: Individuals with intellectual disability and pica have distinct and intensive supports needs. Policies that promote better clinical services are required to help improve their lives.

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Appendix: Interview Guide

General Attitudes

1 a) Now, I'd like to ask each person about their experiences of caring for an individual(s) with pica?

Probes

- What happens in a good day?
- What happens in a bad day?
- Ask for examples

Time

2 a) How much time do you spend in daily activities together?

b) What kinds of activities does the person or individuals enjoy?

c) How much time do you spend in a day managing the person's pica behaviour?

Probes

- How often does that happen?
- What is the staff to client ratio?

Approaches for Managing Pica

3 a) What approaches do you use to deal with the person's pica?

Probes

- Managing the environment – the removal or locking up objects
- Provision of safe "mouthing toys"
- Provision of food/drinks
- Not leaving them alone or unoccupied
- Blocking by use of verbal prompts ("stop") or physically preventing them from ingesting items
- Redirection to other activities, or to food
- Providing choices or rewards when pica does not occur – toys, food, access to things the person enjoys
- Teaching them what is and isn't edible
- Punishment – oral hygiene routines etc. contingent on pica
- Self-protective devices
- Brief physical restraint (e.g., holding the person's arms at the side of their body for a few seconds)
- Medications

continued on following page

Appendix: Interview Guide (continued)

b) What strategies work well for the person?

Probes

- Ask for examples
- Why is that?

c) What strategies do not work well for the person?

Probes

- Ask for examples
- Why is that?

Resources

4 a) What resources do you use right now to help you deal with pica?

Probes

- Personal support worker
- Respite care (for families)
- Behavioural support plan
- Professional help (e.g., behavioural therapist)
- Informal supports (family, friends)

b) What other approaches are available that you know about or you can access?

c) Are there additional supports you desire or need that would help in managing pica?

Challenges

5 a) What challenges or barriers make it difficult to reduce pica?

Probes

- Financial
- Not enough staffing
- Friends, other people in his/her life

b) What challenges or barriers make it difficult to achieve better quality of life for persons with pica?

c) What problems have arisen because of pica?

Probes

- Physical (medical problems)
- Social consequences (isolation, less likely to engage in meaningful activities)
- Strained relationships
- Feeling overwhelmed

d) Do you have difficulty accessing medical or other supports, as needed? Please expand.

Caregiver Workload

6 a) Overall, how does pica affect you as a caregiver? Also, how does it affect other caregivers or family members?

Probes

- Ask for examples
- Both positive and negative experiences

Wrap-Up

7 a) Is there anything else you would like to tell me about your experiences of caring for someone with pica?