

Chapter 2

Epidemiology

This chapter reviews the epidemiology of pica. The first part briefly reviews the epidemiology of pica in individuals without developmental disabilities. The second part proceeds to review the epidemiology of pica in individuals with developmental disabilities including risk factors and their implications for treatment.

2.1 General Populations

There are several studies reviewed by Young (2011) on the prevalence of pica in the general population, including pregnant women and children. Pica is well known among pregnant women. Young (2012, Appendix B) reported some 47 such studies coming from many different parts of the world and published between 1950 and 2010. These studies reported estimates of the prevalences of pica that varied from 0.02 to 76.5 %. Studies that reported very high prevalences tended to have small samples—perhaps less than 100 participants and in some cases as low as only 40 participants. These studies also tended to study specific groups of pregnant women and to use personal interviews prospectively to collect data. In contrast, studies with low prevalences tended to have very large sample sizes—for example, in one study, there were 70,000 participants. They also tended to use retrospective, passive methods of data collection, such as reviews of clinical notes.

Similar trends can be found in Young's (2012, Appendix C) review of prevalence of pica among children which identified only 11 such studies published between 1942 and 2004. The reported prevalences varied from 1.7 to 74.4 %. The study that produced the lowest prevalence of 1.7 % was based on a representative sample of 659 children aged 1–10 years from two upstate New York counties, whereas studies which reported higher prevalences often used clinic samples of passive forms of data collection such mail surveys.

2.1.1 Clinical Populations

Among certain clinical groups such as individuals who are anemic (Beyan et al. 2009), including anemic pregnant women (Kettaneh et al. 2005) and individuals with sickle cell anemia (Ivascu et al. 2001), and children with lead poisoning (Riva et al. 2012; Ruddock 1924), rates of pica may be higher than other reference groups. For example, Young (2012, Appendix E) reviewed 28 studies on the prevalence of pica in populations with iron deficiency and/or anemia. These papers were published between 1962 and 2010 and reported prevalences of pica ranging as high as 76.5 % in a sample of 281 pregnant low-income women from Prairie View, TX. Figures varied considerably as some studies reported specific forms of pica, such as ice and starch, and very specific geographical/clinical populations, but many studies reported figures in the 20–40 % range.

2.1.2 Summary

Studies that have attempted to estimate the prevalence of pica have produced widely differing estimates, although certain subpopulations, such as pregnant women and people with anemia, do have higher rates of pica than other groups. These studies have produced a very wide range of figures reflecting problems in measuring pica, population definition and sampling, and other methodological problems. Consequently, no accurate answer can be given as to the question “What is the prevalence of pica?”.

2.2 Developmental Disabilities

Ali (2001) reviewed several studies of pica in individuals with ID/ASD in both institutional and community settings. Ali concluded that the prevalence in institutions ranged from 9 to 25 % and in community settings ranged from 0.3 to 14.4 %. Table 2.1 updates and extends Ali’s review and finds broadly similar findings. For the purpose of this chapter, these reviews were divided into the types of populations sampled, namely institutional populations, studies that sampled total population or specified geographical catchment areas and studies with ad hoc samples.

2.2.1 Institutional Settings

Several studies have reported the prevalence of pica in institutional settings. These studies tend to be published in the 1980s through the early 2000s reflecting the

Table 2.1 A summary of prevalence studies in developmental disabilities

Prevalence	Setting	Authors
1.9 %	Total	Jacobson (1982a)
16.7 %	Institution	Danford and Huber (1982)
13.7 %	Institution	Griffin et al. (1986)
9.2 %	Institution	McAlpine and Singh (1986)
10.1 %	Institution	Tewari et al. (1995)
0.0 % mild ID	Total	Smith et al. (1996)
0.4 % moderate ID		
0.1 % severe ID		
3.2 % profound ID		
5.9 % ^d	Community/clinic sample	Hardan and Sahl (1997)
6.0 %	Institution	Matson and Bamburg (1999)
22.1 %	Institution	Swift et al. (1999)
10.2 % (based on BPI)	Institution	Rojahn et al. (2001)
5.8 % (based on diagnoses in records)		
0.0–2.6 %	Total	Cooper et al. (2007)
0–5.2 % ^c	Community adults with ID and ASD	Melville et al. (2008)
5.0 %	Institution	Williams et al. (2009)
21.8 %	Institution	Ashworth et al. (2008, 2009)
2.9 %	Community	Hove and Bodfish (2004)
3.1 %	Community ad hoc	Zaja et al. (2011) ^c
18.6 %	Ad hoc ^a	Rojahn et al. (2012)
15.9 %	Ad hoc ^b	Mascitelli et al. (2015)

^aIncluded 9 samples of children and adults in community and institutional settings ($N = 1122$)

^bIncluded 2 samples of adults in day and residential services ($N = 232$)

^cFigure varied according to the diagnostic criteria used

^dHardan and Sahl's (1997) sample of 233 individuals referred to a community clinic sample included 63 individuals with average intelligence and 36 individuals with "borderline" ID. The figure the authors reported was 4.3 % based on 10 cases of pica in the entire sample ($10/233 = 4.29\%$). If the figure is recalculated to include only individuals with borderline through profound ID, then the figure becomes $10/170 = 5.9\%$

^eSample was an ad hoc sample of adults attending a day habilitation program

growth of behavioral services in American institutions at that time during institutional reform, downsizing, and closure. For example, Danford and Huber (1982) found that the prevalence of pica was 25.8 % in a sample of 991 individuals. Griffin et al. (1982) surveyed all Texas institutions and found a prevalence of

13.7 %. Matson and Bamberg (1999) surveyed pica at a large residential facility in Louisiana and found a prevalence of 6 %. As shown in Table 2.1, surveys of pica in institutional settings have produced a wide range of figures which are consistently higher than surveys of entire community samples.

2.2.2 Total Population Samples

There have been fewer epidemiological studies which estimate the prevalence of pica in complete geographical samples of children and/or adults with ID/ASD. These studies typically analyze existing state registers of adult disability services that include surveys of challenging behavior completed at admission and/or annual staffing or sometimes use surveys that are designed specifically for the study and conducted prospectively. Such studies are important because they are not limited by sampling bias inherent in institutional studies where placement of individuals with the most severe challenging behavior and changing patterns of service provision over time may produce wildly varying prevalence figures. Here, we consider these papers.

Jacobson (1982a) published a notable early study based on the New York state register of individuals with developmental disabilities which included 30,578 children and adults with developmental disabilities. A standardized measure of challenging behavior was completed on each individual, which included an item related to pica. As noted in Table 2.1, the overall prevalence of pica was 1.9 %, but this varied substantially as function of degree of cognitive impairment, age, psychiatric disability, and setting. For example, in individuals aged under 22 years, the prevalence of pica was 0.2, 0.6, 2.4, and 3.4 %, respectively, in individuals with mild, moderate, severe, and profound ID, but among individuals aged over 22 years was 0.2, 0.2, 0.8, and 4.8 %, respectively, among individuals with mild, moderate, severe, and profound ID. Hence, there was a 5- to 24-fold increase in the prevalence if pica with increasing cognitive disability, but little systematic effect of age. Among individuals without psychiatric/behavioral disorders, the rates of pica were 1.9 % for children and adults, but for those with dual diagnosis, the rates were 3.0 and 2.1 % for children and adults, respectively. Finally, the prevalence of pica was substantially affected by the setting in which the person lived. Among children, the rates of pica were 0.0, 1.1, 1.0, 1.7, and 3.9 % among individuals living independently, with parents, in family care, in community residences, and developmental centers, respectively. Among adults, the corresponding rates were 0.0, 0.2, 0.2, 0.3, and 3.6 %, respectively. Hence, the rates of pica were substantially below or similar to the average of 1.9 % for all settings other than the developmental settings.

Some 14 years later, Cooper et al. (2007) assessed 1023 individuals living in Glasgow aged 16 years and older, using a standard battery of screening questions, psychometric instruments, and semi-structured psychiatric interviews. As noted in Chap. 1, they found an overall prevalence of 0.0–2.0 %, depending upon the diagnostic criteria used. The prevalence was correlated with gender and degree of

cognitive disability. The prevalences were 2.5 and 1.3 % for men and women, respectively. Among individuals with mild ID, the prevalences were 0.0 and 0.5 % among men and women, and among individuals with moderate through profound ID, the prevalences were 3.9 and 1.9 %, respectively. (This study did not report data broken down by setting.)

A third such population study comes from Hove and Bodfish (2004). They identified 311 adults with ID living in 20 counties of the west coast of Norway of whom approximately 40 % were identified as having mild ID, approximately 43 % moderate ID and 17 % severe/profound ID. There were 2.9 % who were identified with pica. There was an increasing trend such that those with more severe ID were more likely to show pica. Thus, 0.8, 3.8, and 5.9 %, respectively, of individuals with mild, moderate, and severe/profound ID showed pica but this difference was not statistically significant. Finally, individuals with ASD were more likely to show pica than those without pica ($p = 0.0002$). The prevalence of pica was notably lower than that reported in almost all other studies. Presumably, this was in part because it included both community and institutionalized participants, but perhaps also due to underreporting when collected data using interview and psychometric measures.

Finally, Smith et al. (1996) prospectively surveyed 2202 adults with ID in a total population sample using trained interviewers and a standardized psychometric measure of challenging behavior. They found that the prevalence of pica was 0.0, 0.4, 0.1, and 3.2 % of individuals with mild, moderate, severe, and profound ID, respectively. (They did not report an overall prevalence in this paper.)

These total population studies consistently report that pica is a relatively low-frequency problem which occurs in 1–4 % of individuals with ID. Very few individuals with mild, moderate, and severe ID show pica and around 3–5 % of individuals with profound ID show pica.

2.2.3 Risk Factors

As noted earlier gender, the variable that has the strongest correlation to risk of pica is degree of disability; that is, most individual with ID and pica have profound and some have severe ID, but few have borderline through moderate ID. Despite this relatively strong association, it is unclear why it exists and why some individuals with profound ID show pica and some do not. Some studies have found additional correlations between lack of sociability and social skills, but again how these two risk factors result in the development and maintenance of pica is unclear. Some, but not all, studies have found a somewhat higher prevalence of pica among males than females. Again, why this is so is unclear.

Settings also have large influences on the rate of pica. Namely, there are consistent findings that pica is more common in institutional than other settings. The differences between institutional and other settings are quite large (see Table 2.1). Again, the reasons for this difference are unclear, as it may reflect some causative

factor related to institutional environments or selection factors in terms of patterns of admission and discharge.

Other risk factors that have been evaluated include autism and certain genetic syndromes such as tuberous sclerosis and phenylketonuria (PKU). The section below will review these studies.

2.2.3.1 Autism Spectrum Disorders

Individuals with ADS sometimes also show pica (see Johnson and Hassenfledt 2013; Stiegler 2005 for reviews) which may be of sufficient intensity to warrant behavioral interventions (Donnelly and Olczak 1990; Falcomata et al. 2007; Fisher et al. 1994a, b; Foxx and Martin 1975; Myles and Hirsch 1996; Piazza et al. 1996; Rojahn et al. 1987; Smith, 1987). Some studies have reported relatively high rates of pica among individuals with ASD. For example, LoVullo and Matson (2009), in a sample of adults in an institutional setting, found that approximately 36 % of those with ID and ASD showed pica, but this study did not report direct comparisons of the rates of pica among those with and without ASD. Clark et al. (2010) found that 48 % of 48 children with ASD in a community sample in Alberta, Canada, with ASD showed pica. This figure is high compared to other community samples (see Table 2.1), but may reflect the fact that this was a community only sample.

Only one study has directly addressed the question of the prevalence of pica among individuals with ASD and whether they are at special risk for pica. Kinnell (1985) compared the prevalence of pica among 70 adults with ASD and 70 with Down syndrome (DS). Kinnell found that 60 % of those with ASD but only 4 % of those with DS showed pica. Those with Down syndrome that showed pica were described as having autistic features in two cases and schizophrenia in another. Thus, this study showed that individuals with ASD are much more likely to show pica than individuals with DS.

2.2.3.2 Tuberous Sclerosis

Tuberous sclerosis is a rare autosomal dominant gene genetic disorder associated with ID and multiple biomedical problems such as seizure disorders. Morrison et al. (2015) reported the point prevalence of pica among a sample of 100 individuals with Tuberous sclerosis from a case register. They found only 4 % of the sample, all with severe and profound ID, showed pica. These figures are similar to other figures from community samples shown in Table 2.1 and substantially lower than those reported in individuals with ASD above.

2.2.3.3 Crit du Chat Syndrome

Ross, Collins, and Cornish reported a survey of challenging behavior among a sample of 66 individuals aged 6–37 years with Crit du Chat syndrome, a rare genetic form of ID resulting from partial deletion of the short arm of chromosome 5. Family members completed the BPI. Some 27 % of the sample showed pica. Although this study did not include any comparison group, these figures are rather higher than most of the data reported in Table 2.1 and much higher than studies from studies of community samples and total samples. Thus, individuals with Crit du Chat syndrome appear to be at greater risk of pica than individuals with ID/ASD generally. It is unclear, however, if this is due simply to their severe/profound ID, or whether it is due to some specific factor relating to Crit du Chat syndrome.

2.2.3.4 Phenylketonuria

Baieli et al. (2003) reported the clinical features of a series of 500 individuals with PKU, a rare recessive genetic disorder. Untreated PKU results in severe/profound ID and biomedical problems. ID associated with PKU can be detected at birth and treated successfully by dietary modification. Baieli sample included only 35 individuals with ID who had been diagnosed late. Of the total sample, only 1.6 % had pica. Thus, treated PKU with average IQ is not a risk factor for pica.

2.2.3.5 Down Syndrome

As noted above, Kinnell (1985) found low prevalences of pica among individuals with DS and those that did show pica had additional diagnoses of ASD or schizophrenia. Thus, individuals with DS without additional psychiatric diagnoses are a very low risk of pica. This is consonant with a broader literature that shows that individuals with DS have lower rates of severe challenging behavior, such as aggression, than many other individuals with ID, although they are at higher risk of other psychiatric disorders, such as Alzheimer's Disease (Dykens 2007).

2.2.4 Discussion

Some findings on the epidemiology of pica are relatively robust: Individuals with profound ID who are relatively asocial and in institutional settings are at greater risk of pica. These data, especially those relating to institutional populations, are suspect as deinstitutionalization has continued rapidly since the publication of many of these studies. Thus, these figures may be inaccurate today.

An important consideration when interpreting these survey data is whether the data refer to formal diagnoses of pica, typically based on reviews of medical

records, or whether they refer to the presence of pica behavior, often assessed prospectively through psychometric measures. Data from Rojahn et al. (2001) sample of 432 individuals in an institutional setting illustrate this point nicely. Their table reported that 12 (2.8 %) had a primary diagnosis of pica, 13 (3.0 %) had a secondary diagnosis of pica, and none had a tertiary diagnosis of pica; that is, 25/432 (5.78 %) had a psychiatric diagnosis of pica. When the authors reported frequency of individual symptoms from the BPI, they found that raters endorsed the pica item in 10.2 % of the sample. The meaning of such a twofold difference is unclear. Perhaps, pica did not rise to the level of clinical significance in half of the individuals who had the pica item endorsed on their BPI. Alternatively, perhaps, clinicians were unaware of the problem or the records systematically underreported the diagnosis of pica.

Pica is underreported as there is no universal methodology for determining whether pica is diagnosed based on medical records, direct observation, and product measurement (e.g., stool checks or spitting up foreign objects). In fact, to date, no one has suggested how this diagnosis would be determined by a psychologist or behavior analyst. One sure method is documentation of surgery to remove foreign objects. We believe all of these methods should be employed, and none should be skipped if a thorough behavioral evaluation is to be done.

2.3 Other Clinical Populations

Some studies have systematically evaluated the prevalence of pica in other clinical populations. At risk, groups include people with medical problems such as sickle cell anemia and individuals with lead poisoning.

2.3.1 *Sickle Cell Anemia*

Sickle cell anemia is a genetic condition due to a single recessive gene. It results in malformed red blood cells and multiple biomedical problems including problems with oxygen transport and anemia. People with sickle cell anemia are at increased risk of pica.

In addition to the individuals' case studies of the complications of pica among individuals with sickle cell disease (Al Achkar et al. 2012; Altepeter et al. 2011; O'Callahan and Gold 2012; Roberts-Harewood and Davies 2001), there have been a number of surveys of reporting relatively high prevalences of pica individuals with sickle cell disease. For example, Aloni et al. (2013) reported that 56 % of 55 children with sickle cell disease exhibited pica. Ivascu et al. (2001) found that 33.9 % of 395 children with sickle cell disease showed pica, predominantly for paper and fabric. Finally, Lemanek et al. (2002) reported that 62.2 % of 146

children and adolescents with sickle cell disease reported pica; 57.8 % had mild or moderate; and 4.4 % had severe pica.

Thus, rates of pica are quite high among children and adolescents with sickle cell disease. Interestingly, the most common pica items are rather different from those typically reported in studies of individuals with ID or ASD, suggesting perhaps that pica among this population may be somewhat different than pica in pregnant women and individuals with profound ID.

2.3.2 Children with Lead Poisoning

Pica is common in children with lead poisoning and is sometimes reported in adults with pica for lead. It is often implicated as a cause of lead poisoning due to the ingestion of lead in paint and plaster in older housing (De la Burde and Reames 1973; De la Burde and Shapiro 1975), contaminated soil (Calabrese et al. 1993), cosmetics containing lead (Gogte et al. 1991), and other lead-containing pica items such as toys and inhalation of lead vapor from burning car batteries. This has long been recognized (Berg and Zapella 1964; Bicknell 1967, 1975; Boris et al. 1996; Greenberg et al. 1958; Lourie and Wehrle 1971; Millican et al. 1956; Oliver and O’Gorman 1966; Ruddock 1924; Smith et al. 1963), and the seriousness of this problem is attested to by several reports of behavioral treatment of pica in children with lead poisoning (Finney et al. 1982; Madden et al. 1981) and environmental modifications to reduce exposure to lead.

Christian et al. (1964) study illustrates the specific association between lead poisoning and pica. They reported the prevalence of accidental lead poisoning over a three-year period in 9853 cases in Chicago. Pica was strongly associated with lead poisoning. Of those with a history of lead ingestion, 59.7 % reported pica, whereas among those with no history of lead ingestion, only 2.6 % reported pica. Lead poisoning and death from lead poisoning were common among children aged 12–36 months. Low-income African Americans were at greater risk of lead poisoning than White Americans. Many of the studies of lead poisoning are older, and the picture of environmental exposure to lead is continually changing as risk factors change substantially over time and from location to location.

2.4 Summary

Pica is a relatively uncommon problem across the entire population, but the overall low prevalence of pica hides the relatively high rates of pica among certain populations including pregnant women, certain cultural groups, individuals with sickle cell anemia, lead poisoning, and other medical conditions, and individuals with severe and profound ID, especially those in institutional settings. Among individuals with

ID/developmental disabilities, those with autism and certain genetic syndromes may be at higher risk than others.

Among individuals with ID, those with weak social and communication skills and who are more socially withdrawn than others are especially at risk of pica. These risk factors perhaps have treatment and prevention implications. For example, establishing social interaction as a secondary reinforcer early on in life, and teaching social and communication skills may be helpful in prevention. Perhaps, other prevention strategies not implied by these data might also include establishing typical eating behavior and discouraging consumption of unusual items early on might also be important.

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