The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse

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Introduction

Medical procedures have often been used as analogues for childhood sexual abuse (CSA) and have been seen as opportunities to observe children's memories of these experiences in a naturalistic context (Money, 1987; Goodman, 1990; Shopper, 1995; Peterson Bell, in press). Medical traumas share many of the critical elements of childhood abuse, such as fear, pain, punishment, and loss of control, and often result in similar psychological sequelae (Nir, 1985; Kutz, 1988; Shalev, 1993; Shopper, 1995). It has been difficult, however, to find a naturally occurring trauma which incorporates aspects thought to be critical to the phenomenon of forgotten/recovered memories: namely, secrecy, misinformation, betrayal by a caregiver, and dissociative processes. There has been the added difficulty of finding medical events that directly involve genital contact and which accurately reflect the family dynamic in which abuse occurs.

The study which has come closest to identifying the factors likely to be involved in children's recall of CSA is a study by Goodman et al. (1990) involving children who experienced a Voiding Cystourethrogram (VCUG) test to identify bladder dysfunction. Goodman's study was unique in its inclusion of direct, painful, and embarrassing genital contact, involving the child's being genitally penetrated and voiding in the presence of the medical staff. Goodman found that several factors led to greater forgetting of the event: embarrassment, lack of discussion of the procedure with parents, and PTSD symptoms. These are precisely the dynamics likely to operate in a familial abuse situation.

The medical management of intersexuality (a term encompassing a broad range of conditions including ambiguous genitalia and sexual karyotypes) has not been explored as a proxy for CSA, but may provide additional insights into the issues which surround childhood memory encoding, processing, and retrieval for sexual trauma. Like victims of CSA, children with intersex conditions are subjected to repeated genital traumas which are kept secret both within the family and in the culture surrounding it (Money, 1986, 1987; Kessler, 1990). They are frightened, shamed, misinformed, and injured. These children experience their treatment as a form of sexual abuse (Triea, 1994; David, 1995-6; Batz, 1996; Fraker, 1996; Beck, 1997), and view their parents as having betrayed them by colluding with the medical professionals who injured them (Angier, 1996; Batz, 1996; Beck, 1997). As in CSA, the psychological sequelae of these treatments include depression (Hurtig, 1983; Sandberg, 1989; Triea, 1994; Walcutt, 1995-6; Reiner, 1996), suicidal attempts (Hurtig, 1983; Beck, 1997), failure to form intimate bonds (Hurtig, 1983; Sandberg, 1989; Holmes, 1994; Reiner, 1996), sexual dysfunction (Money, 1987; Kessler, 1990; Slipjer, 1992; Holmes, 1994), body image disturbance (Hurtig, 1983; Sandberg, 1989) and dissociative patterns (Batz, 1996; Fraker, 1996; Beck, 1997). Although many physicians and researchers recommend counseling for their intersexed patients (Money, 1987, 1989; Kessler, 1990; Slipjer, 1994; Sandberg, 1989, 1995-6), patients rarely receive psychological intervention and are usually reported as being "lost to follow-up." Fausto-Sterling (1995-6) notes that "in truth our medical system is not set up to deliver counseling in any consistent, long-term fashion" (p. 3). As a result, the intersexed child is often entirely alone in dealing with the trauma of extended medical treatment.

In cases where the intersexed child is identifiable at birth, s/he is subjected to extensive testing physically, genetically, and surgically, to determine the sex most appropriate for rearing. Kessler (1990) notes that "physicians… imply that it is not the gender of the child that is ambiguous, but the genitals… the message in these examples is that the trouble lies in the doctor's ability to determine the gender, not in the gender per se. The real gender will presumably be determined/proven by testing and the "bad" genitals (which are confusing the situation for everyone) will be 'repaired.'" (p. 16). Although the child is repeatedly examined through puberty, there is often no explanation given for

these frequent medical visits (Money, 1987, 1989; Triea, 1994; Sandberg, 1995-6; Walcutt, 1995-6; Angier, 1996; Beck, 1997). Because both parents and physicians view these treatments as necessary and beneficial to the child, the child's trauma in experiencing these procedures is often ignored. The underlying assumption is that children who do not remember their experiences are not negatively affected. However, medical procedures "may be experienced by a child or adolescent as a trauma, with the medical personnel considered as perpetrators in collusion with the parents… the long-range effects of these events may have serious and adverse effects on future development and psychopathology" (Shopper, 1995, p. 191).

Shame and Embarrassment

Goodman (1994) notes that sexuality is characterized in children's minds primarily in terms of embarrassment and fear. Children may thus respond to all situations that carry sexual connotation with embarrassment and shame. She suggests that "children come to react to situations that carry sexual connotation by becoming embarrassed— a shame that they are taught to feel, without necessarily understanding the reasons why. Perhaps one of the first things children are taught to be embarrassed about concerning sexuality is the exposure of their own bodies to others" (p. 253-254). Children who had experienced more that one VCUG were more likely to have expressed fear and embarrassment about the most recent test and to have cried about it since it occurred. A few even denied that they had had the VCUG.

Children experiencing other types of genital medical procedures also experience their medical procedures as shameful, embarrassing, and frightening. Medical photography of the genitals (Money, 1987), genital examination in cases of precocious puberty and intersex conditions (Money, 1987), colposcopy and examination in a girl exposed to DES (Shopper, 1995), cystoscopy and catheterization (Shopper, 1995) and hypospadias repair (ISNA, 1994) may lead to symptoms highly correlated with CSA: dissociation (Young, 1992; Freyd, 1996), negative body-image (Goodwin, 1985; Young, 1992), and PTSD symptomology (Goodwin, 1985). One of Money's patients reported "I would be laying there with just a sheet over me and in would come about 10 doctors, and the sheet would come off, and they would be feeling around and discussing how much I had progressed… I was very, very petrified. Then the sheet would go back to over me and in would come some other doctors and they would do the same thing… That was scary. I was petrified. I've had nightmares about this…" (Money, p. 717)

Similar scenarios have been reported by other intersexuals (Holmes, 1994; Sandberg, 1995-6; Batz, 1996; Beck, 1997). Like CSA, repeated medical examinations follow a pattern which Lenore Terr calls Type II traumas: those that follow long-standing and repeated events. "The first such event, of course, creates surprise. But the subsequent unfolding of horrors creates a sense of anticipation. Massive attempts to protect the psyche and to preserve the self are put into gear… Children who have been victims of extended periods of terror come to learn that the stressful events will be repeated." (cited in Freyd, 1996, p. 15-16). Freyd (1996) proposes that "psychological torment caused by emotionally sadistic and invasive treatment or gross emotional neglect may be as destructive as other forms of abuse" (p. 133). Schooler (in press) noted that his subjects experienced their abuse as shameful, and suggests that shame may be a key factor in forgetting sexual abuse. "The possible role of shame in causing disturbing memories to be reduced in accessibility… might well resemble those sometimes proposed to be involved in repression" (p. 284). David, an adult intersexual, states "We are sexually traumatized in dramatically painful and terrifying ways and kept silent about it by the shame and fear of our families and society" (David, 1995-6). Most intersexuals are prevented by shame and stigma from discussing their condition with anyone, even members of their own family (ISNA, 1995). This enforced silence is likely to be a factor in how their memories of these events are understood and encoded.

Secrecy and Silence

Several theorists have postulated that secrecy and silence lead to the child's inability to encode the abuse events. Freyd (1996) suggests that memory for never-discussed events may be qualitatively different from memory for those that are, and Fivush (in press) notes that "When there is no narrative framework… this may well change children's understanding and organization of the experience, and ultimately their ability to provide a detailed and coherent account" (p. 54). Silence may not impede the formation of the initial memory, but lack of discussion may lead to decay of the memory

or failure to incorporate the information into the individual's autobiographical knowledge of self (Nelson, 1993, cited in Freyd, 1996).

When a child suffers a trauma, many parents attempt to prevent the child from focusing on it in hopes that this will minimize the impact of the event. Some children are actively told to forget the trauma; others are simply not given room to voice their experiences. This dynamic operates especially forcefully in the case of intersexed children (Malin, 1995-6). "Never mind, just don't think about it" was the advice of the few people to whom I spoke of it, including two female therapists," states Cheryl Chase. Her parents' only communication with her regarding her intersex status was to tell her that her clitoris had been enlarged, and so it had to be removed. "Now everything is fine. But don't ever tell this to anyone else," they said (Chase, 1997). Linda Hunt Anton (1995) notes that parents "cope by not talking about 'it', hoping to lessen the trauma for [the child]. Just the opposite happens. The girl may conclude from the adults' silence that the subject is taboo, too terrible to talk about, and so she refrains from sharing her feelings and concerns" (p. 2). Both Malmquist (1986) and Shopper have put similar views forth (1995), noting that a child may view the adults' silence as an explicit demand for his or her own silence. Slipjer (1994) noted that parents were reluctant to bring their intersexed children to outpatient check-ups because the hospital served as a reminder of the syndrome they were trying to forget (p. 15).

Money (1986) reports cases in which "the hermaphroditic child was treated differently than a sexually normal child, in such a way as to signify that she was special, different, or freakish—for example, by keeping the child at home and forbidding her to play with neighborhood children, placing a veto on communications about the hermaphroditic condition, and telling children in the family to lie or be evasive about the reasons for travelling long-distance for clinic visits" (p. 168). The Intersex Society of North America (ISNA), a peer support and advocacy group for intersexuals, notes that "This 'conspiracy of silence' … in fact exacerbates the predicament of the intersexual adolescent or young adult who knows that s/he is different, whose genitals have often been mutilated by 'reconstructive' surgery, whose sexual functioning has been severely impaired, and whose treatment history has made clear that acknowledgement or discussion of [his or her] intersexuality violates a cultural and a family taboo" (ISNA, 1995).

Benedek (1985) notes that even therapists may fail to ask about traumatic events. The victim of trauma may view this as a statement by the therapist that these issues are not safe topics for discussion or that the therapist does not want to hear about them. She suggests that retelling and replaying stories is one way for the victim to gain mastery over the experience and to incorporate it (p. 11). Given the infrequency of such discussions, it is not surprising that both CSA victims and intersexuals often experience negative psychological sequelae as a consequence of their experiences.

Misinformation

Alternatively, the abuser's reframing of reality ("this is just a game", "you really want this to happen", "I'm doing this to help you") may lead to the child's lack of comprehension and storage of the memory of the abuse. Like CSA victims, intersexual children are routinely misinformed about their experiences (Kessler, 1990; David, 1994, 1995-6; Holmes, 1994, 1996; Rye, 1996; Stuart, 1996). Parents may be encouraged to keep the child's condition from him or her, with the justification that "informing the child of the condition prior to puberty has an undermining effect on its self-esteem" (Slipjer, 1992, p. 15). Parents are often misinformed themselves regarding the procedures being enacted on their children as well as the possible outcomes for their child. One medical professional (Hill, 1977) recommends "Tell parents emphatically that their child will not grow up with abnormal sexual desires, for the layman gets hermaphroditism and homosexuality hopelessly confused" (p. 813). In contrast, ISNA's statistics suggest that "a large minority of intersexuals develop into gay, lesbian, or bisexual adults or choose to change sex—regardless of whether or not early surgical repair or reassignment was performed" (ISNA, 1995).

Angela Moreno was told at 12 that she had to have her ovaries removed for health reasons, although her parents had been given the information about her true condition. Angela has Androgen Insensitivity Syndrome (AIS), a condition in which an XY fetus fails to respond to androgens in utero and is born with normal appearing external female genitalia. At puberty, the undescended testes began to produce testosterone, resulting in the enlargement of her clitoris. "It was never addressed to me that they were going to

amputate my clitoris. I woke up in a haze of Demerol and felt the gauze, the dried blood. I just couldn't believe they would do this to me without telling me" (Batz, 1996).

Max Beck was carted to New York every year for medical treatment. "As I reached puberty, it was explained to me that I was a woman, but I was not yet finished… We'd head home again [after a treatment] and not talk about it for a year until we went again…. I knew this didn't happen to my friends" (Fraker, 1996, p.16). This lack of comprehension and explanation for the events happening to the child may result in their inability to make sense of their experiences and to encode them in a meaningful way. Parental and physician emphasis on the benefit of the medical procedures may also result in emotional dissonance which impedes the child's ability to process the experience; the child feels hurt, while being told that he or she is being helped.

Dissociation and Body Estrangement

Examining intersexed children's memories for their medical treatments may shed some light on the processes by which a child comes to understand traumatic events involving his/her body, and offers a unique opportunity to document what happens over time to the memory of these events. Because the child lacks the ability to comprehend the crossing of this body boundary as anything but destructive, regardless of the intents of parents and the medical community, genital procedures in childhood may have the same affective valence as CSA. As Leslie Young (1992) notes, the symptoms of sexual trauma are rooted in the issue of living comfortably (or not) in the body.

The boundary between "inside me" and "outside me" is not simply physically crossed against a person's will and best interests but "disappeared" … —not simply ignored but "made-never-to-have-existed." To physically challenge or compromise my boundaries threatens me, as a living organism, with annihilation; what is "outside me" has now, seemingly, entered me, occupied me, reshaped and redefined me, made me foreign to myself by conflating and confusing inside me with outside me. Of necessity this assault is experienced by me as hateful, malevolent, and entirely personal, regardless of the intentions of any human agents involved. (p. 91)

This confusion may be especially acute in intersexed children, whose bodies are quite literally reshaped and redefined through genital surgery and repeated medical treatments.

Among criteria listed as triggers for dissociative episodes during trauma, Kluft (1984) included "(a) the child fears for his or her own life… © the child's physical intactness and/or clarity of consciousness is breached or impaired, (d) the child is isolated with these fears, and (e) the child is systematically misinformed, or "brainwashed" about his or her situation." (cited in Goodwin, 1985, p. 160). Undoubtedly all of these factors come into play during the intersexed child's medical treatment; the child, having been told little or nothing regarding the rationale for the surgery and examinations, is fearful for his/her life, the child's genitals are surgically removed and/or altered, representing a clear breach of physical intactness, the child is isolated with fears and questions about what has happened to his or her body (and what will happen in the future), and the child is given information which does not reflect the true nature of the treatment or the details of the procedures.

Both Angela Moreno and Max Beck report extensive dissociative episodes. "I was a walking head for most of my adolescence" recalls Max (Fraker, 1996, p. 16). Moreno reports that "After years of therapy, she finally feels like she's in her body, filling out her skin and not just floating" (Batz, 1996). These statements are similar to those of CSA victims who report separating themselves emotionally from their bodies in order to withstand a physical violation. The woman subjected to repeated colposcopies reports that she "survived the vaginal examinations by completely dissociating herself from the lower half of her body—that is, becoming "numb" below the waist, without sensations or feelings" (Shopper, 1995, p. 201). Freyd (1996) calls dissociation "a reasonable response to an unreasonable situation" (p. 88). Layton (1995) notes that fragmentation is a likely outcome of experiences such as these: "… if the mirror of the world does not reflect your smile back to you, but rather shatters at the sight of you, you, too, will shatter" (p. 121). Dissociative response appears to operate as a defense and consequence in both CSA and medical procedures.

Betrayal Trauma

Jennifer Freyd (1996) has proposed that forgetting of the experience is more likely to occur when the child relies on and must maintain a close relationship with the perpetrator. Betrayal trauma posits that there are seven factors predicting amnesia:

1. abuse by caregiver
2. explicit threats demanding silence
3. alternative realities in environment (abuse context different from nonabuse context)
4. isolation during abuse
5. young at age of abuse
6. alternative reality-defining statements by caregiver
7. lack of discussion of abuse. (Freyd, p. 140)

Certainly these factors operate in the medical management of intersexed children. Shopper (1995) suggests that medical procedures are "similar to those of child sexual abuse in the sense that within the family there is often a manifest denial of the child's traumatic reality. From the child's perspective, the family is seen as being in tacit collusion with the perpetrators (medical staff) of the traumatic procedures. This perception may lead to strong rage reactions against the parents, as well as affecting the sense of trust in the parents' ability to protect and buffer" (p. 203). Conversely, the child may stifle the recognition of this betrayal in order to keep the relationship with his or her parents intact. Freyd (1996) notes that "registration of external reality can be deeply affected by the need to preserve the love of others, especially if the others are parents or trusted caregivers" (p. 26). She also notes that the degree to which the child is dependent on the perpetrator, and the more power the caregiver has over the child, the more likely the trauma is to be a form of betrayal. "This betrayal by a trusted caregiver is the core factor in determining amnesia for a trauma" (p. 63).

In either case, the child's relationship with parents may be damaged. This may occur at the time of the trauma if the child holds the parent responsible for failing to protect him or her from the painful experiences, or later when the child recovers or reinterprets these early experiences. Freyd (1996) suggests that some people realize the full impact of the event when they realize the betrayal, either by forming a new understanding of the event or in recovering the event of the betrayal (p. 5). The way in which events are internally evaluated and labeled may be a key component of such recovery experiences (p. 47). Joy Diane Schaffer (1995-6) suggests that parents of intersexed children should be given full informed consent, including the fact that "there is no evidence whatsoever that intersexed children benefit from genital surgery…. Parents should also be routinely informed that many intersexed adults who received childhood genital surgery consider themselves to have been harmed by the procedure, and are frequently estranged from their parents as a result" (p. 2).

Directions for Future Research

Children treated for intersex conditions within the medical establishment experience many of the same types of trauma as children who are sexually abused. A study of intersexed children's experiences of their treatment and their memory for these events is likely to more closely approximate the experience of childhood sexual abuse than studies done to date for several reasons. The medical management of intersex conditions involves direct contact with the child's genitals by a person in power over the child, and with the cooperation of his/her parents. The procedures are painful, confusing, and repeated. The family dynamics of the child's situation also parallel those in familial abuse: children are routinely silenced or misinformed about what is happening to them and parents are held responsible for the harm that is done. Finally, the outcomes of these experiences result in remarkably similar negative psychological sequelae, including depression, body image disruption, dissociative patterns, sexual dysfunction, intimacy issues, suicide attempts, and PTSD.

Research design in a study of intersexual children's experiences of medical treatment would afford distinct advantages for the memory researcher over those done to date. A

fundamental criticism of past studies has been the difficulty in establishing "objective truth" regarding episodes of CAS. Because abuse is usually hidden, unless the child comes to the attention of the authorities, no documentation exists to show what events occurred. Critics of retrospective studies point out that it is therefore virtually impossible to compare the adult account with actual childhood events (the major exception to this rule being studies done by Williams, 1994a,b). In the case of intersex treatment, the researcher would have access to extensive medical documentation regarding the procedures and the child's responses while in the clinic or hospital. Intersex children could be interviewed at the time of procedures and followed longitudinally to see what happens to their memories of these events as they grow into adulthood. This would allow a more process-oriented approach to the problem of childhood memory of these traumatic experiences (How do children understand and encode trauma in the absence of external support or in the presence of misinformation? What is the effect of mood on memory processing? What is the role of parental interaction?) as well as adult recollection (How does the meaning of the trauma change over time? What is the long-term effect on the child's social and emotional development? What happens to the family dynamic when adults research their medical conditions and discover that they have been misinformed?). An observation of these children's emotional and cognitive strategies for dealing with their medical treatment may shed some light on how these processes operate for victims of child sexual abuse.

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Editor's note (1997): Tamara Alexander has been wedded in spirit to ISNA member Max Beck for almost four years. The couple make their home in Atlanta, Ga. When she is not writing papers and working on planning for a baby, Tamara is busy raising their four cats, a dog, and the consciousness of emory psychology undergraduates. Partners of intersexuals are welcome to contact her for mutual support.

Editor's note (2005): Max and Tamara now have two lovely children. Because Max has changed his legal sex to male, Max and Tamara's union is now legally recognized.