

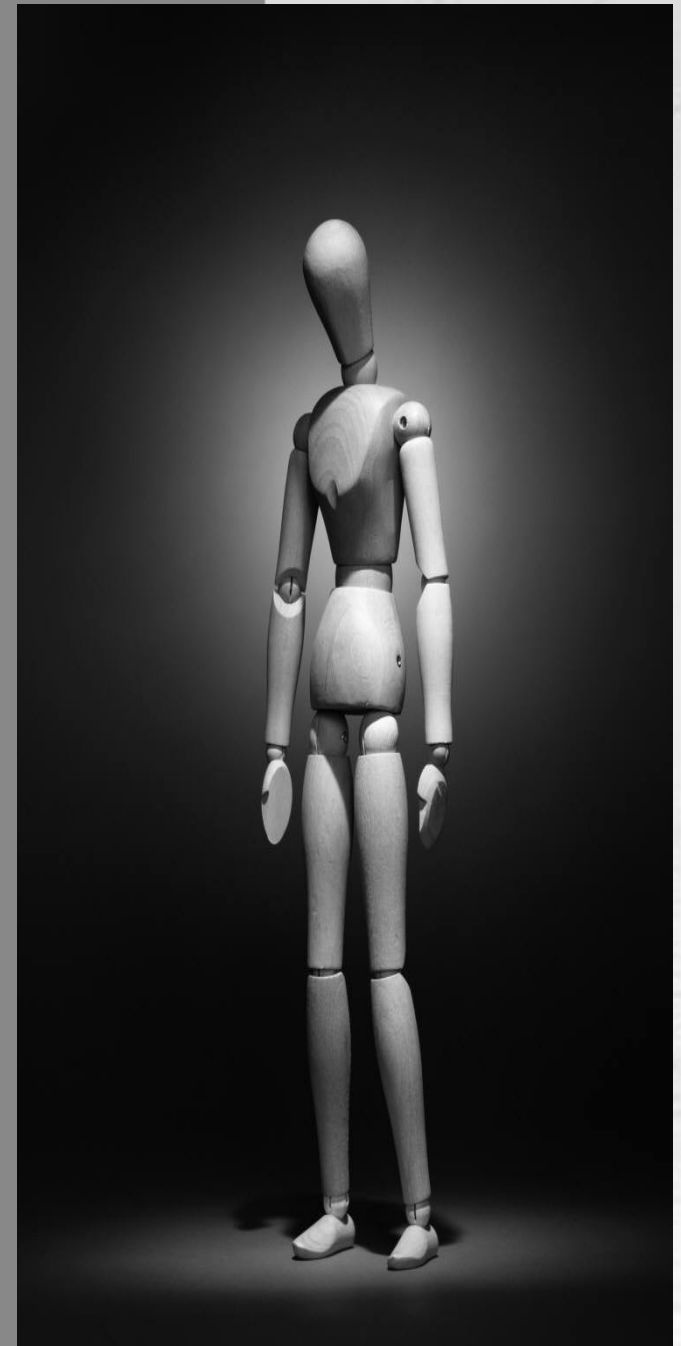


Body Integrity Identity Disorder: Selective Self- Amputation

Dr. Marian Swindell
Alabama/Mississippi Social Work
Education Conference
Thursday, October 19, 2006
Tuscaloosa Alabama

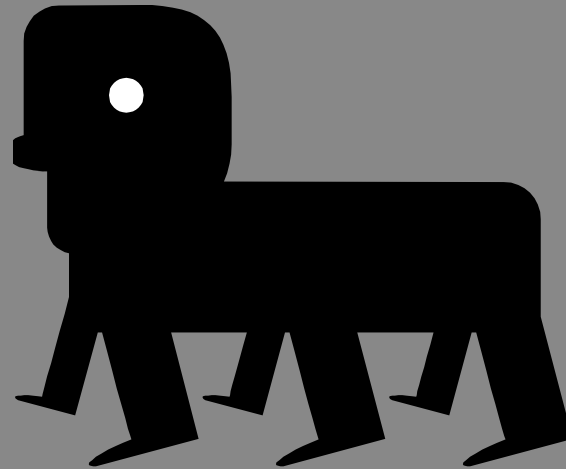
Body Integrity Identity Disorder (BIID)

Individuals with BIID struggle with the desire to amputate a perfectly healthy working digit or limb, such as a finger, arm, or leg.



Underlying Reasons

- “Limb feels unnatural”
- “Feels alien”
- “It just doesn’t belong”
- “It doesn’t belong to me”
- “I feel incomplete”



It's all in the way you look at things

- The survivors mentally see themselves one way and when looking into a mirror, they perceive themselves as abnormal or strange.
- They have a strong urge to make themselves “whole”, even if that means removing an entire limb from their body.
- “Less is More”



Factitious Disability Disorder

- In 1997, Dr. Richard Bruno of Englewood Hospital in New Jersey proposed this name, which he grouped into three types:
 - Devotees
 - Pretenders
 - Wannabes



Devotees

- Usually a non-disabled individual who has a special interest and/or is sexually attracted to people who are disabled.
- These attractions can range widely- from an amputation of a leg to hearing loss.
- The majority of devotees are men interested in women.
- There are women who are attracted to disabled men, and this occurs in all worlds-heterosexual, homosexual, and bisexual.
- A devotee could also be a wannabe.



Pretenders

- Pretenders are non-disabled people who live as if they have a disability.
- They use paraphernalia to make the experience realistic, such as having a wheelchair, leg braces, etc.
- Pretender paraplegics can confide themselves to their chairs full time and never walk.
- They report that they are very happy and sometimes blame not being able to walk on other excuses, such as diabetes.



Pretenders

- The pretender amputee has more difficulty trying to be an amputee and feels frustrated and dissatisfied.
- This frustration can often lead to a physical act of injury and personal violence.



Wannabes

- Wannabes are usually non-disabled individuals that want to become someone with a physical disability.
- See themselves in bodies that are not fully functioning.
- They are about finding identity.



So, are these people dangerous?

- Devotees may be so driven by their inner sexual impulse that their ethical and moral standards falter.
- Photographs of amputees are sometimes shared (especially on the internet)
- Some devotees though are kind and want to help the amputee.



BIID Population

- It consists of both men and women.
- These individuals are *not psychotic*.
- BIID survivors engage in help-seeking behavior, but many are unsuccessful.
- Many BIID survivors struggle in silence, suffering in agony and isolation.



Getting a Grasp on Matters

- To most social workers who have never come in contact with this population, we think it is just bizarre, strange, unimaginable, and incomprehensible.
- Clinicians have equated the psycho-emotional distress experienced by those with gender identity disorder or transgenderism.



What is “normal”?

- With this disorder, the prevalence of plastic surgery in today’s society can be compared to BIID.
 - Breast augmentation, electroshock therapy, Botox, Lip Injections, Calf Implants, the removal of ribs for a smaller looking waist, Gastric ByPass Surgery.
- The people feel uncomfortable in “their own skin”.
- People with BIID live everyday with thoughts about not feeling comfortable in their own skin.
- They experience anxiety, shame, guilt, and preoccupation.



Extreme Measures

- Because most surgeons refuse to amputate a healthy limb, some people with BIID go to extreme measures to get rid the limb.
 - Paying for surgery “under the table”
 - Abortion, At-Home Liposuction
 - Homemade devices
 - Using ice, train tracks, electric saws, etc.
 - At home “accidents”



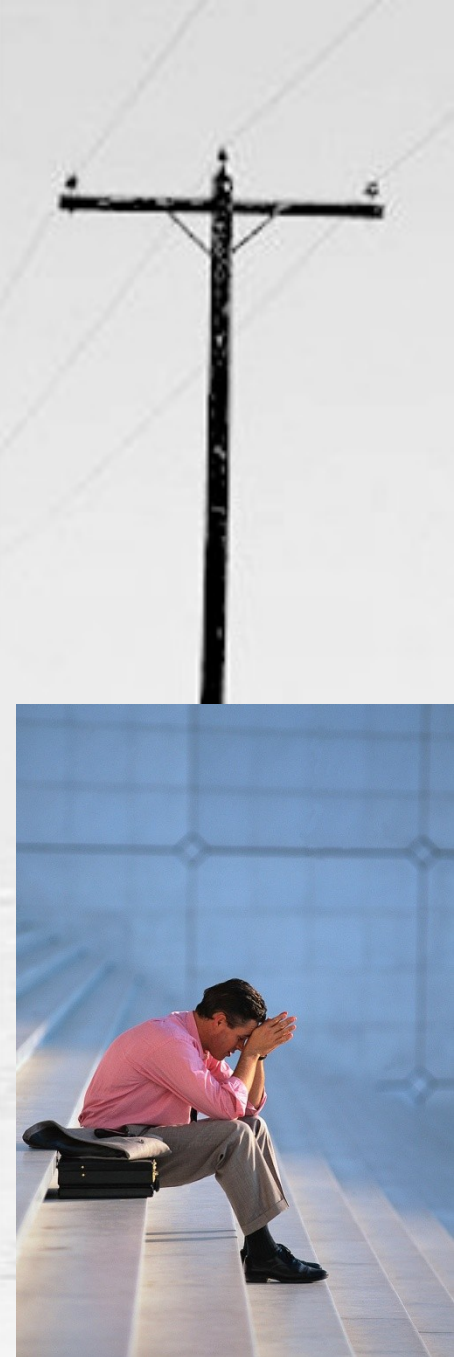
Documented Resources

- Research shows most of the BIID population had experienced a significant childhood event.
- Can show up as early as 4 or 5 years old.
- Typically no change in the desire for amputation.
- Participants who received amputation reported after amputation, they feel better than ever and lose the desire for further amputation.



Symptoms

- Feeling of “incompleteness”
- A strong concept regarding the limb involved and the urge to amputate
- Intense jealousy at seeing an amputee
- Anxiety and feeling alone
- Repeated episodes of depression and sometimes suicidal thoughts
- Rehearsal activity, imitating an amputee
- Feelings of isolation



Surgical Intervention

- Controversial b/c of the Hippocratic Oath
- Cosmetic Surgery Mortality Rates
- Breast implant mortality rate study: Suicide risk up
<http://www.cosmeticsurgerytimes.com/cosmeticsurgerytimes/article/articleDetail.jsp?id=329880>



ONE BIID INDIVIDUAL EXPLAINS:

- “We need to expose the condition to medical science, and that in turn should lead to more understanding and maybe even an entry in the textbooks.
- The first major goal would be for surgery to be acceptable as a fully paid elective procedure”



Insight

- As to how I am doing, about 1/3 of the time I am severely depressed and the other 2/3 of the time I am optimistically looking forward to having my leg off, which seems to be an antidote to depression.
- Or maybe it is that when I fight down the BIID feeling it makes me depressed. Who knows.”



Insight

- If I could find a surgeon who would be willing to do the amputation(s), I would certainly have many questions as to why he/she would be willing.
 - “If someone is so indiscreet as to lead you to one, please do not pursue it. A surgeon will not risk his regular practice and any risk of publicity would end his willingness to help”



Implications for Social Work

- Advocacy for better treatment options
 - Medication that is effective!
 - Therapy that is effective!
 - Surgery
- Inclusion in the upcoming DSM as a disorder would assist with insurance reimbursed therapy but many of this population are willing to pay for an intervention that actually works
- Empirically driven research
- Understanding of the phenomenon and ethical intervention



Dixie

- I am 38 years old, female, never married--specifically because I could not risk sharing the most shameful part of my interior life with another without fear of abandonment.
- I am heterosexual, have never had any thoughts or feelings to the contrary, and have been engaged to three men in my life (all before 1996) and, with the exception of having been cheated on by one of them, my relationships were all generally healthy, supportive and unabusive.
- I have no children. I am a devout, practicing Christian.



Dixie

- Told the psychiatric resident I was assigned to the whole truth--that since I was a very little girl (approximately 2-3, to my knowledge), my limbs had felt foreign to me, physically and mentally, and that I wanted them gone--"cut off"--arms just below the elbows, legs off below the hips.
- I told him that since about the age of eleven I had dreamed (during sleep) consistently in the form and function of a quadruple amputee and that this, by itself, had caused me great anxiety and shame over the years because I knew that there was something disordered about my experience, even though I realized that my subconscious identified itself (and was more comfortable, happy and productive) this way.



Dixie

- I spent nearly six months in a state facility, as a result, and was punitively treated because I refused to submit to Haldol injections for my alleged "psychosis"--with no improvement of any of my symptoms.
- The second psychiatrist I consulted in 1993 had nearly the same reaction to my revelations; the third labeled me as Borderline, the fourth as Borderline and schizo-affective, the seventh as Borderline and OCPD.
- The Borderline diagnoses hinged on the idea that I was "self-mutilating" and distanced from my family--especially my long-time estrangement from my mother, which was her choice, not mine.



Dixie

- I have learned that this is the main problem for the majority people who suffer with BIID in consulting medical and mental health professionals:
 - those people with the credentials who are supposed to *help* us--without prejudice or harm--are incapable of doing so and unwilling to learn anything different.



Dixie

- Until physicians are willing and able to work with patients to discover what a person actually means when they say "...this _____ does not belong to me; I want it cut off; I want to live without it, it causes me anxiety to see/feel/know it is there; it makes me feel deformed/less than human/ashamed...", then we, as a minority health-care consumer population, are at risk of **dying** needlessly at our own hands



Dixie

- Many Drs. think we are uneducated, unrealistic and/or that we idealize the outcome of our actions.
- In my own case, I *know* that succeeding in acquiring the surgical interventions I need will very likely diminish my life expectancy, that I can have life-long complications that result in loss of mobility, loss of skin integrity, diabetes, organ failure, edema, etc..



Dixie

- But if I have to choose between *physical* health problems that result from appropriate, efficacious treatment for my disease and the life-long *physical, mental and emotional* torment I have had to contend with for lack of that treatment, I will gladly choose the former with all its risks.



Dixie

- For every freedom there is sacrifice and I would much prefer the disability incumbent of amputation to the much worse disability of a **broken life** that comes from a body that is not reconcilable to self.
- Used with written permission from “Dixie”



Implications for Social Work

This is an at-risk population who are not receiving adequate services.....what are your suggestions?



Conclusion

Questions, Comments, Feedback

Thank-you,

Marian L. Swindell

Mswindell@meridian.msstate.edu

601-484-0126

