

# DEMOGRAPHICS, LEARNING AND IMITATION, AND BODY SCHEMA IN BODY INTEGRITY IDENTITY DISORDER

Alicia J. Johnson, Sook-Lei Liew, and Lisa Aziz-Zadeh

*The Brain and Creativity Institute  
Division of Occupational Science and Occupational Therapy  
University of Southern California*

## ABSTRACT

Body Integrity Identity Disorder (BIID) is a condition in which people generally desire amputation of healthy limbs but can also desire paralysis, blindness, or other disabilities. The current study explored the demographics and experiences of individuals with this condition with specific attention to perceived physical differences of the affected limbs. Participants were recruited from three BIID-focused Internet forums to participate in two online surveys. There were 97 unique participants total, the largest sample size of individuals with BIID to date. It was found that individuals with BIID differ from the normal population in handedness and sexual orientation. Participants who reported differences in sensation in the affected limb(s) were also significantly more likely to report difficulty in learning/imitation, difference of feeling during use, and difference in performance of the affected limb(s). Furthermore it was found that individuals who achieved amputation almost always experienced phantom limbs and that many participants choose to use prosthetics post-amputation. These results shed light on the many facets of BIID and the perception of self and body schema. Future studies using neuroimaging may be able to better understand the neural bases of BIID.

## KEYWORDS

Body Integrity Identity Disorder, superior parietal lobule, forward model, inverse model, apotemnophilia

---

## INTRODUCTION

People with Body Integrity Identity Disorder (BIID) are characterized by a powerful desire to remove one or more healthy limbs. While they do not have co-morbid mental illnesses that may alter their perceptions and they understand that the limb(s) in question are healthy and function normally, they feel that the limbs are superfluous and unnecessary (First, 2005). Many fantasize about having the limbs removed, often going to great lengths to induce permanent damage to the limbs to necessitate amputations by medical professionals (Bayne & Levy, 2005; First, 2005). They believe that the amputations will give them a sense of being “whole,” restoring their “true identity” (First, 2005).

Many studies in the past have focused on the psychology of the disorder, often grouping together individuals with BIID and those with

apotemnophilia, or “amputee love,” in which people are sexually attracted to amputees or to the idea of being an amputee (Money, Jobaris, & Furth, 1977). While there often is a sexual aspect to the desire for amputations, the primary reason people with BIID report wanting amputations is to feel complete (First, 2005).

Recent studies have shown that there are biological differences between people with BIID and people who do not desire amputations. For instance, individuals with BIID have very specific, virtually unchanging lines where they would like the limb to be removed. One study has shown that above and below this line, there is a difference in skin conductance response (SCR), with the areas below the line of desired amputation having a significantly higher SCR than areas above the line or on the limbs that do not feel superfluous (Ramachandran & McGeoch, 2007). This means there is increased autonomic arousal in the affect-

ed limbs, indicating that there are unperceived physical differences between the affected and unaffected limbs. In one magnetoencephalography (MEG) study, there was an absence of activity in the right superior parietal lobule (SPL) when the affected limb was touched (McGeoch et al., 2009). Thus, one hypothesis behind BIID is that there is a mismatch between the genetically determined body map and the physical body, and this discrepancy is evident when examining SPL activation (Ramachandran & McGeoch, 2007).

The right SPL is active in proprioception as well as in tasks that require imitation or observation with the intent to perform an action (Buccino et al., 2004). Another study has shown that when a subject with congenital aplasia who has phantom sensations is asked to rotate the non-existent limbs, there is activation in the superior parietal cortex as well as the intraparietal sulcus and inferior parietal lobule (Brugger et al., 2000). People with congenital phantom limbs syndrome, to some degree, have the opposite issue as those with BIID – they have sensations from limbs that have never been part of their physical body while people with BIID, though they have the physical experience of having the present, functional limbs, do not feel that the limbs belong to the body. Thus, the SPL may be a key affected area common to both disorders, and it is possible that individuals with BIID have difficulty with learning and imitating movements with their affected limbs. Previous studies have not examined BIID's effect on learning and imitation, leading us to formulate our questions to learn more about these particular aspects.

As there are a limited number of studies regarding this population, the current study aimed to learn more about the demographics and experiences of individuals with BIID as well as perceived physical differences in imitation, execution, and sensation of the affected body parts.

## **METHODS**

### **Participants**

Ninety-seven participants completed online surveys that were posted on 3 BIID-focused Internet forums. Forty individuals responded to both of two surveys, while 25 responded only to the first (for a total of 65 responses to Survey 1), and 32 responded solely to the second (for a total of 72

responses to Survey 2). Written informed consent was obtained from all participants before inclusion in the study, and if consent was not given, the participants were asked to exit the survey. This study was approved by the University of Southern California Institutional Review Board and was performed in accordance with the 1964 Declaration of Helsinki.

### **Surveys**

**Survey 1.** The first survey was launched in November 2009 and closed in January 2010. Its first section inquired about the beginning of the desire (see Appendix 1 for a complete list of survey questions). The next section asked about the intensity of the desire and its fluctuation. Participants were then asked about sensation and use of the undesired limb(s). The final section asked about whether or not the participants had received treatment for BIID and if it had been successful, as well as about treatment of other psychological, neurological, or physical disorders or diseases. Subjects were also asked to submit any final comments as well as provide their email address if they were interested in being recruited for further studies. Out of 118 survey responses, 22 were unfinished, 6 were duplicates from participants who took the survey twice, and 25 were from one individual answering differently each time as determined by IP address tracking in the survey program. Removing those responses, we were left with 65 valid survey responses to analyze.

**Survey 2.** After reviewing the initial survey responses as well as the feedback from participants and forum posts, a second survey was created to follow-up with questions generated from responses to the first survey. The survey link was once again posted on the BIID-focused forums. The link was also sent to those participants who provided their email addresses in the first survey. The first section focused on demographics, including a question differentiating between BIID focused on amputation, paralysis, or the desire for other disorders. The following section inquired about whether or not individuals who desired amputations had obtained the amputations and their experiences thereafter. The next section asked the same of individuals who desired something other than amputation. An additional question asked whether or not there was a sexual

component to the participant's BIID experience. The responses to the second survey were then matched with the responses to the first survey. The second survey had 88 total responses, 11 of which were unfinished, two were from one individual with completely different answers, and three were duplicate responses, resulting in 72 valid responses. As mentioned previously, forty participants from the first survey also responded to the second, and their responses to questions asked on both surveys remained the same.

## RESULTS

### Demographics and BIID characteristics

The demographic questions were part of the second survey, thus for these questions, there were 72 respondents. The average age was 46 years ( $SD = \pm 16.11$  years). Thirteen were under 30 years old, twenty-nine were between 30 and 50, and thirty were 50 years of age or older. Ninety percent ( $n = 65$ ) of participants were Caucasian only, with 4 additional participants who identified themselves as Caucasian and another ethnicity (2 Native American, 1 Pacific Islander, and 1 Hispanic). There was also one Hispanic, one Native American, and one participant chose not to state ethnicity. Eighty-four percent ( $n = 61$ ) of respondents were male, 11% ( $n = 8$ ) were female, and 4% ( $n = 3$ ) listed themselves as other – intersex, transgendered (male to female), and “neutrois,” which the participant defined as “neither male nor female, as opposed to a mix of both.” Sixty percent ( $n = 43$ ) of participants were heterosexual, 25% homosexual ( $n = 18$ ), and 8% bisexual ( $n = 6$ ). Six percent ( $n = 4$ ) of participants listed themselves as “other” – two participants identified themselves “asexual,” one “autosexual,” and one participant responded that he was “too much into BIID etc.” One participant preferred not to state sexual orientation (see Table 1). Twenty-seven percent ( $n = 19$ ) of respondents were single, 28% ( $n = 20$ ) were in a long-term relationship, 32% ( $n = 23$ ) were married, 10% ( $n = 7$ ) were divorced, one was widowed, one was in the process of getting a divorce, and one was in a civil partnership.

**Table 1: Ethnicity, Gender, and Sexuality Results**

		#	%
<b>Ethnicity</b>	Caucasian	65	90%
	Caucasian and Native American	2	3%
	Caucasian and Pacific Islander	1	1%
	Caucasian and Hispanic	1	1%
	Hispanic	1	1%
	Native American	1	1%
	Chose not to state	1	1%
	<b>Gender</b>	Male	61
Female		8	11%
Other		3	4%
<b>Sexuality</b>	Heterosexual	43	60%
	Homosexual	18	25%
	Bisexual	6	8%
	Other	4	6%

Both surveys asked about handedness, resulting in 97 responses (40 respondents who answered both surveys, 25 who responded solely to Survey 1, and 32 who responded solely to Survey 2). Results were consistent between both surveys. Seventy-eight percent ( $n = 76$ ) were right-handed, 13% ( $n = 13$ ) were left-handed, and 8% ( $n = 8$ ) reported themselves as ambidextrous.

Both surveys asked about BIID characteristics, so all 97 participants responded, and results were again consistent across both surveys. Eighty-six percent ( $n = 83$ ) of the respondents desired amputation, 10% ( $n = 10$ ) desired paralysis, 2 individuals desired blindness, one person wanted a broken leg with a full leg cast, and another person wanted to be disabled, needing to wear a left brace. Of all participants who desired amputation, 42% ( $n = 35$ ) want left-sided amputations, 30% ( $n = 25$ ) want bilateral amputations, and 28% ( $n = 23$ ) want right-sided amputations. Eighty-one percent ( $n = 67$ ) desired the amputation of one or both legs, 10% ( $n = 8$ ) desired arm amputation, and 10% ( $n = 8$ ) wanted a combination of leg and arm amputations (see Table 2).

**Table 2: Desired Sites of Amputation**

	#	%
Left-sided	35	42%
Right-sided	23	28%
Bilateral	25	30%
Leg(s)	67	81%
Arm(s)	8	10%
Leg(s) and Arm(s)	8	10%

### Learning and Imitation

The questions regarding learning and imitation were on the first survey, which had 65 participants. Participants were asked if there is a difference in sensation between the undesired limb(s) and the unaffected limbs. Of the 65 individuals who responded to the first survey, 11% ( $n = 7$ ) reported more sensitivity to pain on the undesired limb(s), 15% ( $n = 10$ ) reported more sensitivity to touch, 14% ( $n = 9$ ) reported less sensitivity to touch, and 9% ( $n = 6$ ) reported more sensitivity to temperature. Eight subjects reported multiple differences in sensation. In total, 38% of the participants ( $n = 25$ ) reported some difference in sensation (see Table 3).

**Table 3: Reported Differences in Sensation Between Affected and Unaffected Limbs**

	#	%
More pain	7	11%
Less pain	2	3%
More sensitivity to touch	10	15%
Less sensitivity to touch	9	14%
More sensitivity to temperature	6	9%
Less sensitivity to temperature	2	3%
<b>Total participants reporting a difference in sensation</b>	<b>25</b>	<b>38%</b>

Fifteen percent ( $n = 10$ ) of respondents said that it is more difficult to learn new actions or imitate unfamiliar movements using the undesired limbs. Seventy-nine percent ( $n = 51$ ) of the participants said it was not more difficult, and 6% ( $n = 4$ ) chose not to respond to this question. While three respondents said that the limb was more awkward or clumsy, four individuals stated that it is not a physical difficulty but that they simply are not interested in using the limbs.

When asked if it felt different to use the undesired body part(s), 42% ( $n = 27$ ) of the 65 subjects reported that it does while 55% ( $n = 36$ ) said that it does not and 3% ( $n = 2$ ) chose not to respond to this question. In describing how it feels different, the answers generally referred to non-physical feelings – feelings of awkwardness, wrongness, distance, or unease. Two individuals mentioned that they could sense a stump when using or touching the limb. In general, the difference is in the feeling that the limb simply does not belong.

When asked if there is a difference in performance of the limbs, 19% of respondents ( $n = 12$ )

said yes, 72% ( $n = 47$ ) said no, and 9% ( $n = 6$ ) preferred not to answer. Participants who said yes said they were clumsier, had less control, or were not coordinated. One individual said that he did not want to use it properly.

Participants who reported a difference in sensation were significantly more likely to report difficulty in learning/imitation ( $\chi^2 = 14.06$ ;  $df = 2$ ;  $p < .001$ ), a difference in performance of the affected limb(s) ( $\chi^2 = 9.42$ ;  $df = 2$ ;  $p < .01$ ), and that it feels different to use the affected limb(s) ( $\chi^2 = 9.40$ ;  $df = 2$ ;  $p < .01$ ).

### BIID Post-Amputation

The second survey contained questions regarding phantom limb experiences and prosthetic use, and there were 72 respondents for these questions. Eleven of the 72 respondents have had amputations, obtaining them through self-amputation, by going to a foreign country, or by injuring the limb and necessitating amputation. Of these, 10 have experienced phantom limb sensations, including the 5 participants who have completely achieved their desired state. This is consistent with previous findings that 90-98% of people experience phantom sensations after the loss of a limb (Ramachandran & Hirstein, 1998). The one who has not experienced any at all had amputated three toes, not a limb.

When asked what devices they use post-amputation, 4 of the 11 said that they do not use anything. Notably, all four of these individuals amputated fingers or toes only (two of those participants amputated fingers, and two amputated toes). All of the participants who had limb amputations use various devices. When asked to list what they use, all 7 listed prosthetics. In addition, four of them listed some form of crutches, and two of them use a wheelchair. When the participants who have not had their desired amputations were asked what devices they would use, prosthetics were listed 31 times, crutches 24 times, wheelchairs 18 times, canes 2 times, and a skateboard once (see Table 4).

**Table 4: Devices Respondents Currently Use or Would Use Post-Amputation**

Devices participants use/would use	# of people	%
Prosthetics	38	66%
Crutches	28	48%
Wheelchair	20	34%
Cane	2	3%
Skateboard	1	2%
<b>Total participants that use or would use a device</b>	<b>51</b>	<b>88%</b>

The individuals who had only achieved part of the amputations they desired were satisfied with the results so far, but still felt a strong urge to obtain the full amputations, with one participant saying, "It is a part of the complete picture...a work in progress." Participants who had achieved the full amputations they desired were all content with the results of the amputations, and no new desires arose after the amputations. When asked to describe how their perception of themselves had changed post-amputation, they responded with statements such as, "I am confident in myself," "I feel much more comfortable with my body," and "I feel whole, like I am finally in the body that I should have been born in."

## **DISCUSSION**

### **Demographics and BIID characteristics**

A prior interview study with a smaller sample size ( $N = 52$ ; First, 2005) found a high proportion of males and homosexuals in their BIID group, leading us to ask the same questions to see if we obtained similar results. Ninety percent of our participants were Caucasian, with 96% being fully or partially Caucasian, similar to First's study in which all but two participants (96%) were Caucasian. Eighty-five percent of our participants were male, again comparable to the First study (2005). Out of our participants, 25% were homosexual (28% of males and 13% of females) and 8% bisexual (7% of males and 67% of people who reported "other" as their gender). The latter percentages are in contrast to the general population, where it is estimated that 2.8% of males and 1.4% of females identify themselves as homosexual or bisexual (Laumann, Gagnon, Michael, & Michaels, 1994). They are, however, similar to the results of First's study (2005).

The age of the participants was also similar – 46 years in our study, and 48.6 years in the earlier study (First, 2005). This is particularly interesting considering the desire generally starts during childhood. One might expect young people to be more proficient with technology and thus more likely to seek out or create forums like these and consequently be part of our subject pool. It is unclear whether these demographics, with a high percentage of males and homosexual participants with an average age in their 40s, reflect the characteristics of individuals with BIID or if it is simply a reflection of the people who use these online forums. Further research should be done to determine the reasons for these differences.

Eighty-one percent of participants wanted only leg amputations, 10% wanted only arm amputations, and 10% wanted a combination of arm and leg amputations, results once again comparable to those of First's study (2005). We also found similar results regarding laterality, with 42% of our participants desiring a left side amputation, 28% a right side amputation, and 30% bilateral amputations. The current study also found that 22% of our participants were left-handed, which is more than double the average observed in the general population (10%; McManus, 2009). Previous work suggests there are differences in the right side of the brain among people with BIID, and these results add to that conclusion (McGeoch, 2009).

Fourteen percent of respondents listed things other than amputation as their primary desire. In individuals who desire amputation, 8 desired paralysis as well, and there were several desires mentioned by individuals: baldness, a left leg brace, a short leg, and polio. These non-amputation forms of BIID have not been studied using any physiological or neuroimaging measures. Further studies investigating this might be able to determine similarities to and differences from amputation-focused BIID, clarifying whether or not these desires should be classified as BIID or as a separate disorder or facet of BIID.

While our results confirmed previous findings regarding demographics and characteristics of BIID, the current study goes beyond First (2005) by recruiting a much larger subject pool and looking into participants' use of the limb in learning and imitation as well as body perception.

### Physical Learning and Imitation

Only 15% of individuals noted a difference in learning or imitation using the affected limbs. This could be due in part to the nature of the question itself, “Is it more difficult to learn new actions or imitate new movements using your undesired limb(s) than your unaffected limbs? (For instance, would it be harder to learn to play guitar using an undesired hand?)” Since most respondents were right-handed (including all of the participants who affirmed a difference in learning or imitation) and many wanted a left limb removed, difficulty in learning could be attributed to the fact that it is difficult to learn to do tasks with the non-dominant limb in general (for example, left-handed people would likely use a left-handed guitar). Participants also said that they avoid using the affected limbs, so it could be that by not using them, they are less aware of issues with learning or performance.

As discussed previously, one study has shown that when unaffected limbs or the limbs of people without BIID were touched, there was activation in the right SPL, but this activation was not seen when the affected limbs of individuals with BIID were touched (McGeoch et al., 2009). Further research might test how SPL activation is modulated during learning or imitation with the affected limbs, especially as the SPL is known to be involved in action observation and imitation (Buccino et al., 2004). Comparing SPL activation between BIID participants and controls during a learning and imitation task could help define the SPL’s role in those processes.

We found that respondents who reported one difference with the limb (sensation, difficulty with learning/imitation, etc.) were likely to report multiple differences. This suggests that some individuals with BIID tend to perceive their limb as physically different from their other limbs as well as psychologically frustrating or distracting, while others note that they simply do not want the limb(s) to be there.

### BIID Post-Amputation

There was an overwhelming presence of phantom limbs post-amputation, with ten of the eleven participants who have obtained amputations reporting phantom limb sensations. This result is consistent with the findings that 90-98% of individuals in the general population have

phantom limb sensations post-amputation; Ramachandran & Hirstein, 1998) and the large percentage of participants who would use prosthetics after an amputation raise interesting questions about an individual with BIID’s body schema. A current hypothesis proposes that a mismatch between the genetically-determined body map and the physical body leads to BIID, and that this discrepancy is evident by the lack of activation in the right SPL when the affected limbs are touched (Ramachandran & McGeoch, 2007). The right parietal lobe is also thought to play a role in phantom limbs as well as with body schema overall. We would expect, then, that if individuals with BIID do not incorporate the affected limbs into their body schema, that, once the limb was removed, there would be no phantom sensation or desire to replace the limb with a realistic prosthetic device. However, the current study found that people with BIID do have phantom limbs and use realistic prosthetic devices despite the fact that there are other ways they could remain mobile (e.g., using a wheelchair or crutches).

An alternative hypothesis is that individuals with BIID may have a discrepancy between the commands from the motor cortex to the parietal lobe and from the sensory feedback to the same regions in the parietal lobe. A copy of the motor command from motor regions (often called “the forward model” or “corollary discharge”) is sent to parietal regions. Similarly, sensory feedback on the executed motor plan is also sent to the parietal regions (the “inverse model”) (Miall & Wolpert, 1996; Wolpert, Goodbody, & Husain, 1998; Wolpert & Ghahramani, 2000). Evidence suggests that the integration of these models occurs in the superior parietal lobe and is responsible for creating an estimate of the body’s current state which may be important for error monitoring of motor action, the feeling of self, and agency (Wolpert et al., 1998). Furthermore, it has been suggested that many motor control and awareness disorders such as optic ataxia, anarchic hand sign, delusions of control in schizophrenia, and phantom limbs, can be explained as a consequence of abnormalities in the forward and inverse models (Blakemore, Wolpert, & Frith, 2002). Since the SPL is less active in individuals with BIID, it is possible that the feeling that their limbs should not be there stems from a mismatch between forward and inverse models, crucial in producing a bodily sense of self.

## CONCLUSION

This study examined several facets of Body Integrity Identity Disorder with the largest sample size of BIID participants to date. While a minority reported differences in learning and imitation, we found that those who did tended to report other physical differences as well. We also found that individuals with BIID generally have phantom limbs post-operation and use prosthetics, and we suggest that this is due to a discrepancy between the forward and inverse models. Our study is consistent with a previous study on BIID, but, in addition to using a larger sample group, also focused more on perceived physical differences than the previous study.

These results reveal areas that should be studied further. Future studies should focus on determining whether there is a difference between participants with BIID and a control group when it comes to learning and imitating new movements, both in terms of performance and of neural activity. Since some participants reported multiple physical differences while others tended not to, future studies could examine differences between these groups. Work should also be done to explore the phantom experiences and neural activity of individuals with BIID post-amputation. Neuroimaging studies could be used to see if there is a difference between people with BIID who desire amputation versus paralysis or some other physical difference. More in-depth interviews would result in qualitative data about experiences with BIID and phantom limbs, allowing researchers to better understand the disorder and develop new studies. By looking deeper into Body Integrity Identity Disorder, we will be able to better understand the psychological and neural processes associated with the self, body representations, and agency, as well as develop a greater understanding of individuals who suffer from the depression, frustration, and “constant consuming agony” described by individuals with BIID.

## ACKNOWLEDGEMENTS

This work was supported by the University of Southern California Provost's Fellowship and Student Undergraduate Research Fund. The authors had no conflict of interest.

## REFERENCES

- Bayne, T., & Levy, N. (2005). Amputees by choice: Body integrity identity disorder and the ethics of amputation. *Journal of Applied Philosophy*, 22(1), 75-86.
- Blakemore, S., Wolpert, D. M., & Frith, C. D. (2002). Abnormalities in the awareness of action. *TRENDS in Cognitive Sciences*, 6(6), 237-242.
- Brugger, P., Kollias, S. S., Muri, R. M., Crelier, G., Hepp-Reymond, M. C., & Regard, M. (2000). Beyond re-membering: Phantom sensations of congenitally absent limbs. *Proceedings of the National Academy of Sciences of the United States of America*, 97(11), 6167-6172.
- Buccino, G., Vogt, S., Ritzl, A., Fink, G. R., Zilles, K., Freund, H. J., et al. (2004). Neural circuits underlying imitation learning of hand actions: An event-related fMRI study. *Neuron*, 42(2), 323-334.
- First, M. B. (2005). Desire for amputation of a limb: Paraphilia, psychosis, or a new type of identity disorder. *Psychological Medicine*, 35(6), 919-928.
- Laumann, E. O., Gagnon, J. H., Michael, R. T., & Michaels, S. (1994). *The Social Organization of Sexuality: Sexual Practices in the United States*. Chicago: The University of Chicago Press.
- McGeoch, P.D., Brang, D., Song, T., Lee, R. R., Huang, M., & Ramachandran, V.S. Apotemnophilia – the Neurological Basis of a ‘Psychological’ Disorder. Available from Nature Precedings <<http://hdl.handle.net/10101/npre.2009.2954.1>> (2009).
- McManus, I. C. (2009). The history and geography of human handedness. In I. E. C. Sommer & R. S. Kahn (Eds.), *Language Lateralization and Psychosis* (37-57). Cambridge: Cambridge University Press.
- Miall, R. C., & Wolpert, D. M. (1996). Forward Models for Physiological Motor Control. *Neural Networks*, 9(8), 1265-1279.

- Money, J., Jobaris, R., & Furth, G. (1977). Apotemnophilia: Two Cases of Self-Demand Amputation as a Paraphilia. *The Journal of Sex Research*, 13(2), 115-125.
- Ramachandran, V.S., & Hirstein, W. (1998). The perception of phantom limbs. *Brain*, 121, 1603-1630.
- Ramachandran, V. S., & McGeoch, P. (2007). Can vestibular caloric stimulation be used to treat apotemnophilia? *Medical Hypotheses*, 69(2), 250-252.
- Wolpert, D. M., & Ghahramani, Z. (2000). Computational principles of movement neuroscience. *Nature Neuroscience* 3, 1212-1217.
- Wolpert, D. M., Goodbody, S. J., & Husain, M. (1998). Maintaining internal representations: The role of the human superior parietal lobe. *Nature Neuroscience* 1(6), 529-533.

APPENDIX**Survey 1**

What limb(s) do you want removed and where? (Check all that apply.)

*Left arm above elbow, Left arm below elbow, Left leg above knee, Left leg below knee, Right arm above elbow, Right arm below elbow, Right leg above knee, Right leg below knee* [Note: an "Other" category was added to the second survey to clarify responses.]

At what age did you start feeling this desire?

What memories/associations do you have involving the beginning of this desire?

Has the line where you desire an amputation changed over time?

*Yes, No, I prefer not to answer*

If the line has changed, how often has it changed, and when was the last time it changed? Also, where did it shift and under what context(s)?

On average, how much does your desire for amputation interfere with your daily life (1 = does not interfere at all, 10 = interferes to the point that I cannot focus on anything else)?

Does the intensity fluctuate?

*Yes, No, I prefer not to answer*

If so, when (while working, early in the morning, while using the limb, etc.), how much, and what situations make it fluctuate the most?

Is there a difference in sensation between the undesirable limb(s) and others? (Check all that apply.)

*More pain, Less pain, More sensitivity to touch, Less sensitivity to touch, More sensitivity to temperature, Less sensitivity to temperature, Other*

Does it feel different to use the undesirable body part(s) (less comfortable, more awkward, heavier, etc.)?

*Yes, No, I prefer not to answer*

If so, please describe the difference.

Which is your dominant hand?

*Right, Left, Ambidextrous*

Is it more difficult to learn new actions or imitate new movements using your undesired limb(s) than your unaffected limbs? (For instance, would it be harder to learn to play guitar using an undesired hand?)

*Yes, No, I prefer not to answer*

If so, please explain.

Is there a difference in performance of the limb(s) you want removed (more/less success when using it, for example)?

*Yes, No, I prefer not to answer*

If so, please explain.

Can you describe (in as much detail as possible) a situation in your daily life in which the undesired body part is especially intrusive?

Have you been treated for BIID before?

*Yes, No, I prefer not to answer*

If you have been treated for BIID, what did the treatment consist of (how long did it last, what did it involve, are you currently receiving treatment)?

If you have been treated for BIID, did you have any success in lessening the desire for amputation?

*Yes, No, I have not been treated for BIID, I prefer not to answer*

If you have been treated for BIID, did you have any success in managing the intrusiveness of this desire on everyday life?

*Yes, No, I have not been treated for BIID, I prefer not to answer*

Do you have any of the following? (Check all that apply.)

*Anorexia, Bulimia, Gender Identity Disorder, Phantom body parts (feeling like you have a body part that is not actually there), Desire to be deaf, Desire to be blind, Desire to be paralyzed, Other*

Have you been treated for any of those conditions?

*Yes, No, I prefer not to answer*

If so, which, and what did the treatment consist of (how long did it last, what did it involve, are you currently receiving treatment)?

Have you been treated for any other psychological or neurological disorders?

*Yes, No, I prefer not to answer*

If so, please list them.

Have you been treated for any other physical problems to the limb (arthritis, chronic pain, numbness, etc.)?

*Yes, No, I prefer not to answer*

If so, what problems? Does it affect only the unaffected limb or other limbs as well?

Would you be willing to be contacted for further research? If so, please provide your email address.

Your email address will be kept strictly confidential and be used solely in relation to this study.

*Yes, No*

Where do you live (city, state)?

Would you be willing to travel to Los Angeles to participate in a study?

*Yes, No*

What would you like to see researched in regards to BIID?

Do you have any comments or feedback you'd like to add?

## Survey 2

How old are you?

What is your ethnicity? Please check all that apply.

*Options: Caucasian, Hispanic, Black, Asian, Native American, Pacific Islander, Other, Prefer not to answer*

What is your gender?

*Options: Male, Female, Other, Prefer not to answer*

What is your sexual orientation?

*Options: Heterosexual, Homosexual, Bisexual, Other, Prefer not to answer*

What is your relationship status?

*Single, In a long-term relationship, Divorced, Widowed, Other, Prefer not to answer*

Which is your dominant hand?

*Right, Left, Ambidextrous*

What type of BIID do you have?

*Desire for amputation, Desire for paralysis, Other*

If you desire amputation, what limb(s) do you want removed and where? (Check all that apply.)

*Left arm above elbow, Left arm below elbow, Left leg above knee, Left leg below knee, Right arm above elbow, Right arm below elbow, Right leg above knee, Right leg below knee, Not applicable, Other*

If you desire amputation, has the line(s) where you want amputation(s) changed with age?

*Yes, No, Other, Not Applicable*

If so, how (became clearer, shifted up/down or left/right, etc.) and at what age?

If you desire amputation, have you successfully obtained an amputation?

*Yes – I have obtained amputation of the limb(s) I did not want, Yes – but I still desire one or more amputations, No, Other, I do not desire amputation*

If you have successfully obtained an amputation, what were the circumstances under which you obtained it (self-amputation, in a hospital, in a foreign country, etc.)?

If you have successfully obtained an amputation, has the desire gone away?

Note: If you have always desired an amputation at multiple locations, but have not received amputations at all of those locations, please choose "Yes" if you are satisfied with the results of the ampu-

tation you have obtained.

*Yes, No, Not applicable*

If so, please describe the change.

If you have received an amputation, has it changed your perception of yourself? If so, how? For example, how did you see yourself beforehand, and how do you see yourself now? Do you feel more positively about yourself?

Please also indicate whether you use a prosthetic limb now.

If you have successfully obtained an amputation, have you experienced any phantom limb sensations (feeling like your limb is still there)?

*Yes, No, Other, Not applicable*

If you have not obtained an amputation, have you experienced any phantom body part sensations? If so, where?

*Yes, No, Other, Not applicable*

If you have successfully obtained an amputation, what devices, if any, do you use (wheelchair, crutches, prosthesis, etc.)?

If you have not successfully obtained an amputation, what devices, if any would you want to use post-amputation (wheelchair, crutches, prosthesis, etc.)?

If you desire something other than amputation, have you successfully achieved your desired state?

*Yes – completely, Yes – partially, No, Other, I do not desire something other than amputation*

If you have successfully achieved your desired state (non-amputation), what were the circumstances under which you obtained it (self-inflicted, in a hospital, in a foreign country, etc.)?

If you have successfully achieved your desired state (non-amputation), has the desire gone away?

*Yes, No, Other, I do not desire something other than amputation*

If so, please describe the change.

Is there a sexual component to your BIID?

*Yes, No, Other, Prefer not to answer*

If so, please explain.

Would you be willing to be contacted for further research? If so, please provide your email address.

Your email address will be kept strictly confidential and be used solely in relation to this study.

*Yes, No*

Do you have any other questions/comments?