Background: Breast implant–associated anaplastic large cell lymphoma (BIA-ALCL) has entered the spotlight, as several high-profile media outlets have begun to relay the evolving science to the public. This study aimed to gauge the baseline knowledge and concern regarding BIA-ALCL among adult laywomen within the United States.

Methods: Mechanical Turk was used to survey 500 American women on self-reported demographics, prior experience with breast implants, and 11 questions regarding their knowledge and concern regarding BIA-ALCL. Responses were reviewed for quality control before study inclusion.

Results: Overall, 12 percent of respondents had received breast implants and 73 percent knew someone with implants; 13.6 percent of respondents (including 51.7 percent of respondents with implants) had previously heard of BIA-ALCL. After providing information about its risk, 58.4 percent of respondents were still willing to receive a reconstructive implant and 45.8 percent a cosmetic implant; 35.8 percent reported they would be less likely to receive an implant. Of the respondents with breast implants, 66.7 percent reported some degree of concern regarding BIA-ALCL and 35.0 percent are strongly considering removing their implants. Those who had heard of BIA-ALCL consumed information from several sources, predominantly health professionals or media/health care blogs. Different sources of information were not associated with a respondent’s degree of concern.

Conclusions: Only a minority of American women have heard of BIA-ALCL and understand its association with breast implants. As plastic surgeons who perform breast reconstruction, we can promote the spread of information through the popular media and health care blogs to address this growing concern, particularly among women with existing breast implants. (Plast. Reconstr. Surg. 146: 30, 2020.)

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As the scientific community works to advance our understanding of BIA-ALCL, the media has begun to break stories on the topic to promote understanding among the general population and potential breast implant consumers. In response to the 2017 U.S. Food and Drug Administration report identifying 359 cases and nine deaths linked to BIA-ALCL and the 2019 update report increasing the case number to 414, the media released several high-profile articles. According to an analysis of the media’s influence on awareness in 2017, 83.3 percent of online news articles were published within 1 month of study publications—the majority (76.7 percent) citing U.S. Food and Drug Administration reports on BIA-ALCL or press releases from the American Society of Plastic Surgeons or the American Society for Aesthetic Plastic Surgery (56.7 percent). Given the new and rapidly evolving nature of the field and the important role of information in patient perceptions and behavior, the purpose of this study was to survey laywomen knowledge of and perceptions regarding BIA-ALCL and cosmetic/reconstructive breast implants. We sought to understand the influence of variables including previous exposure to breast implants and the source of information on the perspectives of potential breast implant consumers.

PATIENTS AND METHODS

Survey

Amazon Mechanical Turk and Qualtrics (Qualtrics, Provo, Utah) were used to survey laywomen perceptions of BIA-ALCL and the impact of prior experience on their understanding of the risks. This survey was limited to Mechanical Turk respondents who were women living in the United States, and was accessible by means of a computer-based or mobile-device Internet browser. A series of demographic questions preceded each survey, which included age, sex, race, education level, and annual household income. Each respondent was prevented from completing the survey more than one time and was compensated $0.25 to complete the survey. The survey was completed by team members to estimate its length and the appropriate compensation amount before its release to a test trial of 20 participants. After reviewing for clarity and quality control, the final survey was released on December 6, 2018, and limited to 480 Mechanical Turk respondents (n = 500). A series of five questions were asked regarding the respondent’s personal experience with breast implants and whether they knew someone who had received implants. Regardless of implant status, all respondents were asked whether they would consider breast implants in the future for cosmetic or reconstructive purposes. Respondents ranked their confidence in their knowledge about risks and benefits associated with breast implants on a three-point scale.

A series of eight questions were asked regarding respondent’s perceptions and prior knowledge of BIA-ALCL. Respondents were asked to select the current association between BIA-ALCL and breast implants: strong (understood to be a real risk); unsure; or weak (research suggests an association is unlikely). A paragraph on the current knowledge of BIA-ALCL drawn from the U.S. Food and Drug Administration was presented to respondents and they were assessed for any change in opinion. Respondents were presented with information on smooth versus textured implants and were assessed for their implant preferences for reconstructive or cosmetic purposes. (See Appendix, Supplemental Digital Content 1, which shows education provided to respondents within question stems. Illustrated is the information provided to respondents on ALCL, autologous reconstruction, and U.S. Food and Drug Administration recommendations, http://links.lww.com/PRS/E100.) As an alternative to implants, respondents were presented with information on autologous reconstruction and asked their preference between methods. Respondents were asked a yes/no question regarding whether plastic surgeons should discuss the risks of BIA-ALCL with patients considering implants. Respondents were asked whether they had heard of BIA-ALCL before beginning the survey and, if affirmative, what the sources of their information were. Respondents were permitted to select multiple sources, such as health care professional, social media, and the U.S. Food and Drug Administration website.

Respondents who answered affirmatively to receiving breast implants in the past were asked to rank their concern of developing BIA-ALCL on a three-point scale. Respondents were provided with information on the U.S. Food and Drug Administration’s recommendations for implant follow-up and were asked to rank their consideration of implant removal on a three-point scale given that knowledge. All respondents were asked a final question regarding any change in likelihood of receiving implants in the future given the information they were presented with in the survey.

Statistical Analysis

Descriptive statistics were calculated for the survey cohort and individual questions. Statistical analyses were performed using chi-square and
Fisher’s exact tests; $p$ values were two-sided and considered significant at $p < 0.05$. All statistical analyses were performed using IBM SPSS (IBM Corp., Armonk, N.Y.).

## RESULTS

### Mechanical Turk Raters

A total of 500 respondents completed the survey. Each respondent spent an average of 5.6 minutes to complete the survey. The majority of respondents were Caucasian (71.4 percent), had completed at least a 2-year college degree (69.4 percent), and had an annual income between $25,000 and $99,999 (60.4 percent). Demographics of the Mechanical Turk respondents are summarized in Table 1.

### Influence of Previous Implant Exposure

Many respondents had some degree of exposure to breast implants. Table 2 summarizes respondents’ previous implant exposure through personal experience (12 percent) or knowledge of at least one person with breast implants (73 percent). Nearly 50 percent of respondents would consider receiving a breast implant in the future for reconstructive or cosmetic purposes. After providing information detailing the association between BIA-ALCL and textured implants, respondents showed a clear preference for smooth implants in both reconstructive and cosmetic settings (Table 3). Table 3 further summarizes respondents’ consideration of alternatives to textured implants, as 42.4 percent would consider autologous reconstruction and 17.0 percent would prefer implant-based reconstruction with smooth implants. After all the information presented in the survey (see Appendix, Supplemental Digital Content 1, http://links.lww.com/PRS/E100), approximately one-third of respondents reported they would be less likely to receive implants.

### Table 1. Demographics

| Characteristic               | Value (%)         |
|------------------------------|-------------------|
| Mean age ± SD, yr            | 37.79 ± 11.69     |
| Race                         |                   |
| White                        | 357 (71.4)        |
| African American             | 32 (6.4)          |
| Asian                        | 84 (16.8)         |
| American Indian or Alaskan Native | 4 (0.8)  |
| Native Hawaiian or Pacific Islander | 1 (0.2) |
| Multiracial                  | 22 (4.4)          |
| Hispanic                     |                   |
| Yes                          | 46 (9.2)          |
| No                           | 454 (90.8)        |
| Education                    |                   |
| Less than high school        | 4 (0.8)           |
| High school graduate         | 51 (10.2)         |
| Some college                 | 98 (19.6)         |
| 2-year degree                | 72 (14.4)         |
| 4-year degree                | 188 (37.6)        |
| Master’s degree              | 74 (14.8)         |
| Professional degree          | 15 (2.6)          |
| Income                       |                   |
| <$10,000                     | 58 (11.6)         |
| $10,000–$24,999              | 80 (16.0)         |
| $25,000–$49,999              | 142 (28.4)        |
| $50,000–$74,999              | 109 (21.8)        |
| $75,000–$99,999              | 51 (10.2)         |
| ≥$100,000                    | 60 (12.0)         |

### Table 2. Respondent Exposure to Breast Implants

| Question                                         | No. (%) |
|--------------------------------------------------|---------|
| Have you had implants?                           |         |
| Yes, reconstructive                              | 10 (2.0)       |
| Yes, cosmetic                                    | 50 (10.0)      |
| No                                               | 440 (88.0)     |
| Do you know anyone with implants?                |         |
| Yes, reconstructive                              | 92 (18.4)      |
| Yes, cosmetic                                    | 272 (54.4)     |
| No                                               | 136 (27.2)     |
| Would you consider receiving implants?           |         |
| Yes, either reconstructive or cosmetic           | 99 (19.8)      |
| Yes, reconstructive only                         | 78 (15.6)      |
| Yes, cosmetic only                              | 52 (10.4)      |
| Unsure                                          | 113 (22.6)     |
| No                                              | 158 (31.6)     |

### Table 3. Respondent Preferences following ALCL Education*

| Question                                          | No. (%) |
|--------------------------------------------------|---------|
| Have you previously heard of BIA-ALCL?            |         |
| Yes                                              | 68 (13.6)       |
| No                                               | 432 (86.4)     |
| Would you be willing to receive implants for cosmetic purposes? |         |
| Yes, either smooth or textured                    | 45 (8.6)          |
| Yes, but only smooth                             | 168 (37.2)      |
| No, neither type                                | 289 (57.8)      |
| Would you be willing to receive implants for reconstructive purposes? |         |
| Yes, either smooth or textured                    | 63 (12.6)        |
| Yes, but only smooth                             | 229 (45.8)      |
| No, neither type                                | 208 (41.6)      |
| Would you prefer autologous tissue reconstruction? |         |
| Yes                                              | 194 (38.8)       |
| Unsure                                          | 221 (44.2)      |
| No, I would prefer implants                      | 85 (17.0)       |
| Should plastic surgeons talk with patients about the risk of ALCL? |         |
| Yes                                              | 449 (89.8)       |
| No                                              | 51 (10.2)        |
| Has your opinion of breast implants changed?      |         |
| Yes, more likely to receive implants             | 41 (8.2)         |
| Yes, less likely to receive implants             | 179 (35.8)       |
| Unchanged                                       | 280 (56.0)       |

*Educational material available in Appendix, Supplemental Digital Content 1, http://links.lww.com/PRS/E100.
for cosmetic or reconstructive purposes. Respondents who knew someone with implants showed a clear preference for smooth implants, whereas respondents who currently have implants showed no preference. Both groups were significantly more willing to receive an implant in the future than those who had no implant experience ($p < 0.001$).

Respondents who had previously heard of BIA-ALCL or who had implants were more likely to understand the association between implants and BIA-ALCL ($p < 0.001$) as detailed in Table 6.

**Influence of Information Source**

Before receiving the information presented in the survey, 13.6 percent of all respondents and 51.7 percent of respondents with implants had previously heard about BIA-ALCL (Table 3). As shown in Figure 1, respondents received their information from multiple sources—predominantly health professionals or media/health care blogs. The source of a respondent’s information regarding BIA-ALCL was not associated with their degree of concern or their desire to remove the implant (Table 7). Table 8 summarizes concerns of respondents with breast implants regarding BIA-ALCL and the degree of their consideration to remove the implants despite the information provided on the current U.S. Food and Drug Administration guidelines.

### DISCUSSION

This is the first survey to date examining the baseline knowledge and perceptions of American laywomen toward BIA-ALCL. Despite the increasing media coverage, only a small minority (13.6 percent) of women (51.7 percent of those with implants) have previously heard of BIA-ALCL. Nonetheless, there is a considerable degree of concern among the general public, particularly among women with existing breast implants. Our findings can help surgeons navigate the risks of BIA-ALCL with current and prospective patients and can guide future public education efforts on BIA-ALCL.

### What Is BIA-ALCL?

BIA-ALCL is a rare form of non-Hodgkin’s T-cell lymphoma that frequently presents as a late-onset seroma, on average 8 to 10 years after implant placement. These anaplastic lymphoma kinase–negative tumors, derived from a single clonally expanded T cell, demonstrate uniform expression of CD30 by immunohistochemistry.

Several studies have attempted to determine the epidemiology of BIA-ALCL; however, estimating the incidence and prevalence of such a rare and recently described entity has proven challenging. Initial estimates placed the incidence as low as 0.1 to 0.3 cases per 100,000 women with

### Table 4. Respondent Exposure to Implants Affects Willingness to Receive Cosmetic Implants

|                          | No Implants (%) | Yes, Only Smooth (%) | Either (%) | $p$  |
|--------------------------|-----------------|----------------------|------------|------|
| Respondent currently has implants | 21 (35.0)       | 19 (31.7)            | 20 (33.3)  |      |
| Respondent does not have implants | 268 (60.9)     | 149 (33.9)           | 23 (5.2)   | <0.001 |
| Respondent knows at least one person with implants | 193 (33.0)     | 134 (36.8)           | 37 (10.2)  |      |
| Respondent does not know at least one person with implants | 96 (70.6)      | 34 (25.0)            | 6 (4.4)    | 0.001 |

### Table 5. Respondent Exposure to Implants Affects Willingness to Receive Reconstructive Implants

|                          | No Implants (%) | Yes, Only Smooth (%) | Either (%) | $p$  |
|--------------------------|-----------------|----------------------|------------|------|
| Respondent currently has implants | 10 (16.7)       | 27 (45.0)            | 23 (38.3)  |      |
| Respondent does not have implants | 198 (45.0)     | 202 (45.9)           | 40 (9.1)   | <0.001 |
| Respondent knows at least one person with implants | 132 (36.3)     | 178 (48.9)           | 54 (14.8)  |      |
| Respondent does not know at least one person with implants | 76 (55.9)      | 51 (37.5)            | 9 (6.6)    | <0.001 |

### Table 6. Factors Influencing Baseline Knowledge on the Association between Breast Implants and ALCL

|                          | Strong (Known to Be a Risk) (%) | Unsure (%) | Weak (Not a Known Risk) (%) | $p$  |
|--------------------------|---------------------------------|-----------|-----------------------------|------|
| Respondent currently has implants | 16 (26.7)                      | 13 (21.7) | 31 (51.6)                   |      |
| Respondent does not have implants | 87 (19.8)                     | 240 (54.5) | 113 (25.7)                  | <0.001 |
| Respondent knows at least one person with implants | 71 (19.5)                     | 187 (51.4) | 106 (29.1)                  |      |
| Respondent does not know at least one person with implants | 32 (23.5)                     | 66 (48.5)  | 38 (28.0)                   | 0.611 |
| Respondent has previously heard of BIA-ALCL | 23 (33.8)                      | 14 (20.6) | 51 (45.6)                   |      |
| Respondent has not previously heard of BIA-ALCL | 80 (18.5)                     | 299 (55.3) | 113 (26.2)                  | <0.001 |
breast implants per year. More recently, a study from M. D. Anderson placed the lifetime prevalence of BIA-ALCL at 1:30,000. In a U.S. Food and Drug Administration–mandated trial of Biocell implants (Allergan, Inc., Dublin, Ireland) including 17,656 women and 31,985 textured implants, six cases of BIA-ALCL were identified, for a risk of one in 2943 patients. An Australian study similarly estimated the risk to be between one in 1000 to 10,000 women based on 60 nationally reported cases.

Several causal factors have been proposed to explain the pathogenesis of disease, including immunologic reactions to silicone implant composition, host genetics, bacteria, and biofilm adherent to the prosthesis surface. BIA-ALCL is known to be associated with textured implants with the risk correlating to the degree of texturing present on the implant’s surface. Compared to a smooth implant, texturing may provide a more favorable environment or simply an increased surface area for bacteria to colonize. Host factors may also play a role, including genetic predisposition, preexisting allergies and autoimmune conditions, or microbiome composition. The prolonged nature of one or more of these stimuli may cause chronic local inflammation, lymphocytic activation, and ultimately clonal expansion in patients with BIA-ALCL.

Raising Awareness

This is the first study that uses crowdsourcing to obtain the layperson’s perspective on the risk of BIA-ALCL. Although the self-reported

Table 7. Impact of Information Source on Consideration to Remove Current Implants

| Information Source          | Strongly Considering | Unsure | Not Considering | p   |
|-----------------------------|----------------------|--------|-----------------|-----|
| ASPS                        | 3                    | 1      | 2               | 0.277 |
| FDA                         | 5                    | 1      | 3               | 0.799 |
| Friends                     | 7                    | 1      | 4               | 0.489 |
| Health care blog            | 8                    | 1      | 3               | 0.893 |
| Health professional         | 7                    | 2      | 3               | 0.328 |
| Media                       | 8                    | 2      | 3               | 0.708 |
| Social media                | 6                    | 1      | 2               | 0.116 |

ASPS, American Society of Plastic Surgeons; FDA, U.S. Food and Drug Administration.

Table 8. Concerns of Respondents with Implants

| Concern                                      | Value (%) |
|----------------------------------------------|-----------|
| Are you concerned about ALCL?                | 6 (10.0)  |
| Very worried                                 | 34 (56.66)|
| Slightly/moderately worried                  | 34 (56.66)|
| Not worried                                  | 20 (33.33)|
| Are you considering removing your implants?  | 21 (35.0) |
| Strongly                                     | 12 (20.0) |
| Unsure                                       | 27 (45.0) |

Fig. 1. Sources of prior knowledge of BIA-ALCL. FDA, U.S. Food and Drug Administration; ASPS, American Society of Plastic Surgeons.
demographics of our participants ($n = 500$) were roughly in accordance with U.S. Census statistics, our subjects tended to be somewhat better educated, with a higher proportion of Asian Americans, compared with the general population.

Only a small minority of participants (13.6 percent) had previously heard about BIA-ALCL (Table 3). Just over half of those who had heard of BIA-ALCL reported learning about it from a health care professional. It is incumbent on plastic surgeons to raise awareness about this condition among both existing and prospective patients (Table 3). In addition to physician websites and professional organizations including the U.S. Food and Drug Administration and the American Society of Plastic Surgeons, several popular news outlets have recently published editorials and articles highlighting BIA-ALCL.

Our findings suggest that professional health care blogs and media outlets may be the most effective way to spread knowledge, particularly to those who are not in direct contact with health care professionals. As we work to improve on awareness, interested parties may consider dedicating time and resources to lay publications, television/radio interviews, and word of mouth to do so (Fig. 1).

Our findings can also help plastic surgeons navigate the risk of BIA-ALCL with prospective patients. After providing respondents with information on the risks of BIA-ALCL, only one-third reported that they would be less likely to receive an implant. Overall, the percentage of respondents who would ultimately consider receiving an implant was not different before and after the education (Tables 2 and 3). Prospective patients are not turned off by a conversation on BIA-ALCL—in fact, nearly 90 percent agreed that it is an important part of the preoperative consultation with prospective patients (Table 3). That said, respondents did prefer smooth implants to textured ones, and many would at least consider autologous tissue in the setting of breast reconstruction (Table 3).

Providers should keep these options in mind, especially when the risk of BIA-ALCL is particularly concerning to a specific patient. Respondents with breast implants and those who know someone with implants appear to navigate surgical decision-making and the risks of BIA-ALCL differently. Both groups were more willing to receive a breast implant in the future, even after education on the risk of BIA-ALCL (Tables 4 and 5). In the majority of women, positive personal or first-degree exposure to breast implants appears to quell any anxieties regarding ALCL; however, there does remain a significant cohort concerned by ALCL. As social scientists have argued, people have trouble comprehending the risk of rare events, either overweighting it or neglecting it altogether; open discussions between patient and provider about BIA-ALCL risk are essential for combating misconceptions.

The Importance of Proactivity

The dissemination of information to existing patients with breast implants poses a significant challenge, as only 51.7 percent of participants with breast implants had previously heard of BIA-ALCL. Try as we may to spread awareness of the risks and appropriately reassure patients, many have been lost to follow-up, and an opportunity to reestablish contact may not exist. That said, nearly two-thirds of respondents with implants report some degree of concern regarding BIA-ALCL, and nearly one-third are strongly considering removing their implants (Table 8). At the time of this study, there is no recommendation to remove asymptomatic breast implants—doing so is elective and generally for patient peace of mind. This demonstrates the need for plastic surgeons to disseminate the latest information to their existing and prior patients.

For established patients who have not followed-up recently, surgeons may attempt reaching out by means of mail or otherwise to pass along this information and help them navigate the clinical decision-making. Reconstructive patients often follow up closely with their oncologic team, presenting an opportunity for education by either the oncologic or plastic surgeon. However, cosmetic patients are less likely to follow up in the long-term, and alternative means of education—including primary care physicians—may be useful for disseminating information on BIA-ALCL. Importantly, the source of a participant’s information regarding BIA-ALCL was not associated with their degree of concern or desire to remove the implant (Table 7). Therefore, professional health care blogs and popular media outlets may be effective avenues for continued dissemination of information.

Only approximately one-third of respondents who reported previous knowledge of BIA-ALCL believed that there was a true association between implants and the disease (Table 6). This included one-third of those who had previously heard about it from a health care professional (Table 6).
Importantly, respondents with a history of breast implants were more likely to believe the association (Table 6), but still only approximately 25 percent believed that association to be strong. This underscores the challenges of informed consent, especially among cosmetic patients whose drive for an improved appearance may affect their ability to accept the data. This may in part be attributable to the rapid evolution of the field and the difficulty for laypeople to keep up with it. We must continue to relay the evolving science of BIA-ALCL to the public, appropriately referencing the most up-to-date U.S. Food and Drug Administration and Society data. Patients should be directed to these official sources of information if they wish to stay abreast with the latest updates as they become available.

Limitations

This study is not without its limitations. The application of crowdsourcing in health-related research has grown considerably within the past few years. Mechanical Turk provides a reliable access to a wealth of layperson perspective that will continue to play an important role in plastic surgery research. Although the survey population is derived from participants across the country, Mechanical Turk users do not mirror the most recent U.S. Census data. On average, users tend to be younger and more educated. By restricting participants to women residing in the United States, the international application of our findings may be limited. In addition, the compensation rate of $0.25 and the brief survey length (average, 5.6 minutes) may have introduced selection bias into our sample for participants seeking short surveys regardless of reimbursement. All survey-based research is limited by the honesty of respondents in answering questions. Furthermore, BIA-ALCL research and its media coverage are both rapidly evolving; as such, knowledge and perceptions will continue to change over time, challenging the validity of our findings. Finally, although our findings indicate the need for dissemination of information to patients, additional studies are needed to identify the best plan of action.

CONCLUSIONS

Despite the growing awareness of BIA-ALCL, only a minority of laywomen in the United States have heard of ALCL and its association with implants. The majority of those who have heard of BIA-ALCL receive their information through the media and health care blogs—important avenues for plastic surgeons and professional societies to continue disseminating information. Prospective patients are unlikely to be turned off by a frank conversation about the risks of BIA-ALCL and agree that it is an important part of the surgical consultation and informed consent. Nearly half of women with implants, however, have not heard of BIA-ALCL, and report relatively high rates of concern and desire to remove their implants. As plastic surgeons, we must not only work toward advancing the knowledge on BIA-ALCL but ensure the rapid and efficient dissemination of that information to our patients: past, present, and future.

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