

Migraine Education Day Assessment– Final Report

by Anastasia Hudgins, PhD, for Ethnologica, LLC

Migraine Education Day Assessment– Final Report	1
Summary	2
Findings	2
Recommendations	2
Migraine Education Day – Data Analysis	4
Introduction	4
Tools	5
General Limitations	5
Who Are the Participants?	5
Demographic information	5
Experience with migraine:	5
How people learned about the workshop	6
What participants hoped to get out of the MED (before participation)	6
Most important things attendees learned in the MED (after participation)	6
Findings	7
Finding I: The people who attended the MED experience more internalized stigma than enacted stigma	7
Finding II: Some attendees expressed concern that enacted stigma affects their careers, income, and social networks.	8
Finding III: After having gone through the MED event, people can name and recognize their own experience of stigma.	9
Finding IV: People are leaving the event with a different way to explain their experience with migraine.	10
Case Study 1	11
Case Study 2	12
Case Study 3	12
Finding V: Education / information, and the group experience of identifying stigma together can lower barriers that stigma erects. This may manifest in an increase in advocacy among people with migraine and an increase in people seeking relief either through medical interventions or through mind/body practices	13
Finding VI: The MED helps redefine migraine from a personal problem to a shared, medical condition	14
Finding VII: Supporters of people with migraine may also be affected by their loved one’s internalized stigma	15
Event-Specific Feedback	16
Comments about the food	16
Comments about logistics and the venue	16
Comments about the flow of the event	16
Speaker evaluation:	17

Summary

Findings

Finding I: The people who attended the Migraine Education Day experience more internalized stigma than enacted stigma.

Finding II: Some attendees expressed concern that enacted stigma affects their careers, income, and social networks.

Finding III: After having gone through the Migraine Education Day event, people can name and recognize their own experience of stigma.

Finding IV: People are leaving Migraine Education Day with a different way to explain their experience with migraine.

Finding V: Education / information, and the group experience of identifying stigma together can lower barriers that stigma erects. This may manifest in an increase in advocacy among people with migraine and an increase in the number of people seeking relief either through medical interventions or through mind/body practices.

Finding VI: The Migraine Education Day's events help redefine migraine from a personal problem to a shared, medical condition.

Finding VII: Supporters of people with migraine may also be affected by their loved one's internalized stigma.

Recommendations

1. Endeavor to reach a broader, more diverse population in order to expand the reach of the Migraine Education Day. Advertise the event using targeted social media. Reach patients of physicians, nurse practitioners and nurses at public health clinics.
2. Continue to focus on internalized stigma in future Migraine Education Day events.
3. Continue to collect Stigma Scale for Chronic Illness (SSCI) survey data on the experience of stigma at future Migraine Education Day events. Develop a plan to collect and analyze data to publish in peer-reviewed journals.
4. Consider administering the truncated SSCI scale to people who have migraine during other migraine-related events, making sure to obtain proper ethical research approval so that the study can be published in peer-reviewed journals.
5. Facilitate education for the general public about migraine to minimize enacted stigma. This could take the form of a podcast, social media campaign, academic or professional conferences, advertising at sporting events, or a "Story Corps"-style event, etc.
6. Continue to focus on internalized stigma in future Migraine Education Day events.
7. Offer Migraine Education Day events in more cities.

8. Where it is not yet feasible to expand Migraine Education Day events geographically, distribute educational literature and the stigma “toolkit” to doctors’ offices and headache clinics around the country. Translate the information into major languages.
9. Solicit poetry and prose accounts of the experience of migraine and compile them into a book for others to appreciate.
10. Encourage the development of a migraine community by supporting nascent communities and social networks. Foster development of community after the Migraine Education Day events through social media, Skype calls, local meet-ups, etc.
11. Hold arts-based workshops focused on internalized stigma that would allow people with migraine to communicate their experiences visually to a broader community, and that would allow them to continue to defuse the power of internalized stigma. Feature the art work at public events and forums with the goal of communicating to a broader audience.
12. Develop materials that inform a broad audience about the social constructions of migraine – especially how migraine has historically been gendered. Communicate that the result has been that people with migraine have been excluded from receiving medical care and that research into the condition has long been limited and under-funded. Include information about current approaches to migraine so as to encourage people to seek care.
13. Miles for Migraine should communicate to potential funders, particularly pharmaceutical companies, the following: the effects of internalized stigma; the Migraine Education Day events’ role in alleviating this stigma; and the potential for behavior change as people’s identity shifts from “guilty” or “blameworthy” to “patient” or “empowered person.”
14. Conduct further research to understand the effects of internalized stigma on social relationships between the migraine patient and their support community and social networks.

Migraine Education Day – Data Analysis

Introduction

The Migraine Education Day (MED) took place in the Philadelphia area on March 24, 2018. Prior to the MED, discussion with Shirley Kessel revealed that there was concern that patients' experience with stigma may keep them from advocating for themselves, and that the limited public presence of those affected by migraine is a factor in the insufficient amount of research and awareness about the disease. Ethnologica was engaged in order to learn how migraine patients and their supporters experienced stigma, and what benefit they derived from their participation in the MED. To that end, Ethnologica designed two questionnaires to be given to all attendees – one was administered before the events of the day and the second was administered after the events had concluded. The report that follows is a synthesis of the findings from the questionnaires. Its focus is on the ways that social constructions of migraine affect the patient experience, including health-seeking behavior.

The Pre-Participation Questionnaire was designed to gather information about who the participants are, why they are at the event, how they learned about the event, their experience with stigma and their familiarity with the term stigma. The Pre-Participation Questionnaire also includes a modified version of the Stigma Scale for Chronic Illnesses (SSCI) which was used to measure the experience of internalized stigma and enacted stigma among attendees who have migraine. Internalized stigma is defined as the “stigma that occurs when people with devalued conditions come to believe that negative public attitudes apply to them” (Molina et al, 2013: 451). Enacted stigma refers to “the negative attitudes expressed by members of the public (e.g. healthcare professionals, clergy, or employers) that are experienced by an individual with devalued characteristics” (Molina et al). This scale allowed us to establish a baseline among respondents about which was more burdensome: internalized or enacted stigma, neither or both. This is an interesting and important question given the findings presented in Young et al (2013), where patients with chronic migraine scored higher on the stigma scale for chronic illness than episodic migraine or epilepsy patients, likely due to their reported inability to work, and that chronic migraine patients experienced more internal stigma than enacted stigma.

The Post-Participation Questionnaire was designed to assess how well people absorbed the lessons of the MED presentations, and to give respondents an opportunity to reflect on the insights the MED gave them in terms of their experiences with stigma. Additionally, the Post-Participation Questionnaire gave participants an opportunity to rate the day's speakers, and to give their opinion about the event itself, the location and other logistical concerns so as to provide input into planning next year's MED.

In their PLoS One article “Stigma of Migraine,” Young et al (2013) point to the negative health consequences of a stigmatizing illness, saying that stigma “affects the way individuals experiencing stigma seek and access medical care.” The findings of this brief study speak to this last point precisely, as discussed throughout.

Tools

The questionnaires employed a mixed-methods approach to assessing participants' experience with stigma. Open-ended questions allowed respondents the opportunity to express their thoughts and experiences, and to frame the day's events in ways that are meaningful to them – a process that leads to insights gleaned directly from the participants themselves. Ethnologica also drew from the truncated SSCI scale discussed in Molina et al, and altered it to be more relevant to the experience of migraine (i.e. the question “Because of my illness, people avoided looking at me” was replaced because migraine does not manifest in someone's appearance.). The goal in using the scale was to evaluate people's experiences with stigma, not their knowledge or awareness of it.

General Limitations

While the questionnaires yield valuable insights, there are some limitations to the study.

1. Some participants may not have provided full answers.
2. In analysis of some of the questions, a blank answer on a question is interpreted as the respondent being ignorant about a topic (with the exception of questions where a participant is told to skip questions that are not relevant to their migraine experience, i.e. they don't have migraine). It is certainly possible that the person did not want to answer a particular question.
3. There was not 100% response rate for both questionnaires. Although 46 people took the first questionnaire and 46 people took the second questionnaire, 8 who took the first questionnaire did not take the second questionnaire. Six people took the 2nd questionnaire, but not the first.
4. Quantitative tools, such as the SSCI scale, could potentially be interpreted by the respondent in ways other than how the researcher intended; additionally, close-ended questions on surveys may limit respondents' ability to express their own perspective.
5. The insights about the migraine experience revealed through qualitative methods may not represent a wide-spread phenomenon or a widely-shared experience, and may not be reproducible in a similar population.

Who Are the Participants?

Demographic information

- 37 women and 9 men filled out the Pre-Participation Questionnaire.
- The ages of attendees ranged between 20-71.
- 44 of 45 of the participants who responded to the question about race or ethnicity self-identify as white or Caucasian. One identified as Hispanic.

Experience with migraine:

- 32 people who took the Pre-Participation Questionnaire described themselves as having migraine.
- 14 described themselves as attending the MED in support of someone who has migraine.
- 1 person described herself both as someone who has migraine *and* as healthcare provider wanting to learn more about migraine.

How people learned about the workshop

- 13 people learned about it from their doctor or a hospital-based headache clinic.
- 12 people learned about it from a friend or family member.
- 12 people learned about it from having participated in the past with M4M events, or through M4M.
- 3 people learned about it from Migraine World Summit.
- 2 people learned about it from migraine.com.
- 2 people learned about it from social media.

What participants hoped to get out of the MED (before participation)

- 13 people wanted information.
- 11 people wanted education, or to learn more (It's unclear how/if respondents differentiated between information and education).
- 8 people wanted community, support, or to expand their social network.
- 7 people wanted information to help a loved one or to be a better caretaker.
- 6 people wanted to gain coping strategies.
- 5 people identified new treatments as important.
- 1 wanted to know what to expect in the future (his girlfriend has migraine).
- 1 wanted other patients' insights.
- 1 said they wanted to help themselves.
- 1 wanted advocacy information.

Most important things attendees learned in the MED (after participation)

- 32 mentions of information about treatments including drugs, yoga and acupuncture. A specific breakdown of the language people used is:
 - 6 "new treatments"
 - 12 "drugs & devices"
 - 13 acupuncture/yoga/alternative treatment
- 26 mentions of information about triggers
- 17 mentions of stigma – reducing, countering, self-blame
- 16 mentions of learning about community of migraine patients and their supporters / of not feeling alone
- 5 mentions of facts and statistics (this may be more about delivery of information than about how the information was meaningful to the respondent – i.e. learning about the statistics of migraine in the general population may have helped someone feel less alone)
- 5 mentions of self-compassion
- 3 mentions of resources
- 3 mentions of learning that migraine is a disease
- 3 mentions of educating others based on what the migraine patient/supporter knows
- 2 mentions of whole body
- 2 mentions of the medical field's lack of knowledge

- 1 mention of disability
- 1 mention of the feasibility of pregnancy with migraine
- 1 mention of nutrition

Findings

The findings presented here relate primarily to the experience of stigma, especially internalized stigma. Internalized stigma may cause people with migraine to blame themselves for their medical problem, and interpret it as a failure to fulfill their social roles. This calls to mind what medical sociologists refer to as the “sick role,” a term first coined by Erving Goffman. The sick role relates to the privileges and responsibilities accorded to a sick person. If a person is sick, they have the privilege of not fulfilling their normal roles in their social circle while they fulfill their obligation to get well. A chronic illness, especially one that has no visible symptoms, can challenge the sick role, causing the patient and those in their social and professional circles to question whether the patient is shirking their normal responsibilities. The person with migraine may feel that he or she is failing to fulfill their end of the social bargain on how one comports oneself, thereby internalizing the stigma and judging themselves based on an abstract ideal. Learning that other people with migraine also share this experience helps minimize the effects of the internalized stigma. Additionally, a diagnosis – even the understanding that migraine *is* a disease – can minimize the effects of internalized stigma. The findings from this study indicate that the education and information about internalized stigma and migraine provided during MED event greatly assist people with migraine and their supporters as they navigate the social aspects of a biological condition.

Finding 1: The people who attended the MED experience more internalized stigma than enacted stigma.

The SSCI scale in the first questionnaire showed that more attendees with migraine experience internalized stigma rather than enacted stigma. In the 2nd questionnaire, when asked to rank internalized or enacted stigma as more burdensome (after having learned about it during the MED), respondents ranked them as follows:

- Internalized (18) 55%
- Externalized (9) 27%
- Both (3) 9%
- No answer (3) 9%

Patients described why internalized stigma was more burdensome than enacted stigma:

- “Internalized stigma because I don’t talk a lot about having migraines, but I am hard on myself.”
- “Internalized. Once I’m at peace with myself, I can confidently fight/dismiss external stigma.”
- “I have been lucky and have found most people to be kind and sympathetic but I myself have felt a bit isolated and down when I’m in a migraine attack.”

- “Internal stigma. I live in my own mind 24/7. I always want to be healthy and be the person I was “before” and forget to give myself grace.”
- “Internalized because I worry how the headache will affect my life, career, etc.”
- “Internalized because I hide it from others and feel sorry for myself.”
- “Internalized stigma because I used to believe it is my fault.”
- “When feeling down, I still feel “less than,” not living up to my potential, a burden on my husband. When feeling good, I want to advocate.”
- “Internalized, but comes from outside because I don't see other people with migraine so I make myself feel bad.”

It is interesting that in the first questionnaire people described the ways that stigma affected them. By and large, they described instances of enacted stigma – someone dismissing their pain, or thinking they were faking. But the SSCI scale told quite a different story: they were more likely to have experienced internalized stigma. The MED event helped them recognize this in themselves and gave them the tools to articulate it.

Recommendations:

1. Continue to collect SSCI survey data on the experience of stigma at future Migraine Education Day events. Develop a plan to collect and analyze data to publish in peer-reviewed journals.
2. Consider administering the truncated SSCI scale to people who have migraine during other migraine-related events, making sure to obtain IRB approval so that the study can be published in peer-reviewed journals.

Finding II: Some attendees expressed concern that enacted stigma affects their careers, income, and social networks.

Although internalized stigma figured more prominently in the SSCI scale and in the open-ended response found in the 2nd questionnaire, many people with migraine (and their supporters) expressed concern about enacted stigma, especially in the Pre-Participation Questionnaire. In the follow-up questionnaire, nine of the 33 people who responded to the question said that they found externalized stigma more burdensome. They said that others minimize their experience, fail to empathize with them, or even see them as “fakers” or drug-seekers.

People who said that enacted stigma (AKA externalized stigma) was more or equally burdensome than internalized stigma described their experience in the following ways:

- “Externalized, because they minimize my pain.”
- “I’m in a career transition and have concerns about the impact and it is also a burden to try to make transition happen.”
- “Stigma and lack of understanding/accommodation by school administrators/teachers has been burdensome.”

- “Others. The burden of carrying the baggage of others’ stigma is heavier. I only have control over myself and I don’t try to control the actions of others. I can ‘talk myself down’ and put my baggage on a shelf.”
- “By others. I’ve learned to deal with my disease and not blame myself but lost a lot of friends when my chronic migraine got severe.”
- “Externalized, because you cannot see a migraine and others do not get it. Therefore, they cannot empathize and it makes me feel like I am just a broken record.”
- “Stigma by others. I don’t stigmatize myself as much anymore, but others still hinder my ability to succeed in my goals.”
- “Both. One feeds the other.”

Enacted stigma has broad consequences for people with migraine, regardless of the social roles they may play – whether they are a student, an employee, a friend, parent or partner/spouse, or even a patient in a doctor’s office. When there are material consequences to the enacted stigma, such as a shrunken social network, lost wages or a lost job, the burden can be distressing.

Recommendations:

1. Facilitate education for the general public about migraine to minimize enacted stigma. This could take the form of a podcast, social media campaign, higher-education conferences, advertising at sporting events, or a “Story Corps”-style event, etc.

Finding III: After having gone through the MED event, people can name and recognize their own experience of stigma.

As discussed above, stigma can come from others (enacted stigma), or it can be internalized. With enacted stigma, people with migraine are negatively judged by society due to their inability to consistently fulfill their social roles. This judgment overlooks and minimizes the suffering they experience. With internalized stigma, on the other hand, people with migraine find themselves in a complex relationship where they share the values of the social group to which they belong - in mainstream US culture, those values include self-sufficiency, having a strong work ethic, and taking responsibility for one’s actions, among others. Yet they negatively judge themselves for not being able to fulfill these obligations due to the limitations the disease imposes on them. They know they are judged according to the group’s values, and they judge themselves by the same values of the group, as they are members of or are otherwise affected by that dominant group. The MED helped people name and recognize their experience with stigma.

When queried about whether the events of the MED help them name and recognize stigma, 80% of respondents said yes, 5% said no, and 15% were neutral (some indicated they learned about stigma in another event, so it was not new information for them).

Twelve people wrote about this in terms of the discussion and lectures as providing new information.

- “I learned that negative self-talk will increase my pain.”
- “Yes. I understand what it means now.”
- “Yes. I hadn’t considered self-stigma/internalized stigma.”
- “Yes. I know it’s more prevalent than I realized and that I also do it.”
- “I didn’t really realize how much stigma there was in my life until today.”
- “I didn’t realize what it was before, and [now] realize I experience it daily.”

Four people identified educating others as an important part of reducing stigma in others.

- “Yes. How important it is to help destigmatize migraine. Learn and spread the word.”
- “It helped me realize how easily and often it happens. The more people who take the time to learn the facts and spread those facts, the less it will affect people with migraine.”

One person talked about learning tactics to deal with internalized stigma:

- “Yes. I did not experience external stigma as much; it has more so been internal. Now, I know how to face it.”

The MED helps people to name and recognize their experience with stigma and in some cases to limit its effects on their lives. For some, the day’s events gave them a vocabulary to express their experience and ways to protect themselves. For others, learning about stigma created a desire to advocate and educate others so as to ease the burden for people with migraine.

Recommendations:

1. Continue to focus on internalized stigma in future MED events.
2. Offer MED events in more cities.
3. Where it is not yet feasible to expand MED events geographically, distribute educational literature and the stigma “toolkit” to doctors’ offices and headache clinics around the country. Translate the information into major languages.
4. Solicit poetry and prose accounts of the experience of stigma and compile them into a book for others to appreciate.

Finding IV: People are leaving the event with a different way to explain their experience with migraine.

Taken as a whole, both the open-ended and close-ended question responses reveal that the majority of attendees’ relationship to migraine has changed as a result of the MED. 75% of respondents said that learning about stigma helped them to see their experience with migraine differently and 15% said it didn’t (9% were neutral). In explaining how their viewpoints had changed, people’s answers broke down into the following categories:

- They had gained a heightened awareness of the importance of self-care

- They had gained a heightened awareness of the importance of advocacy and education
- They had a growing understanding of the illness
- They developed an understanding of how to deal with stigma (both external and internal)
- They realized that they were not alone.

Specific quotes in response to the question were:

- “I learned compassion and became more self-aware.”
- “Even learning the appropriate terminology was educational – i.e. using ‘person with migraine’ instead of migraine sufferer, etc.”
- “I understand more that it is a legitimate disease and it’s not my fault.”
- “Learning about stigma helps me understand I am not the only one with the same problems. There are others who understand.”
- “Yes. I need to stop internalizing so I can communicate what I need.”
- “Makes me want to help. Makes me want to be part of change. Makes me want to help advocate and fundraise.”

The following case studies illustrate the transformation that took place among many attendees. These case studies focus on those attendees who were unable to define stigma at the outset of the day, but who articulated an increased awareness at the end of the day.

Case Study 1

“Ariel” (ID#8812) is a 29-year-old white woman with migraine. She works as a claims processor, and she lives in the Brookline neighborhood of Pittsburgh. She learned about the event from a Migraine Summit email and hoped she would get “info!” from the day’s events.

She said that migraine *often* interferes with her daily activities. Even though she ranked high on propensity towards internalized stigma in the survey, she initially had a limited understanding of what stigma is. She wrote: “I may be wrong, but I believe it is when someone already has a viewpoint on a topic, whether good or bad.” In other words, she provided the definition of “opinion.” That indicates that she has an understanding that stigma is subjective, but not that it is based on social constructions of reality. Her SSCI survey indicated that she experiences a high degree of internalized stigma.

In her post-participation questionnaire, she listed internalized stigma as among the most important things she learned – “This is a disability and I shouldn’t hurt myself emotionally.” Learning about stigma helped her name and recognize stigma, and she said: “I did not experience external stigma as much; it has more so been internal. Now I know how to face it.” The MED helped her see her experience with migraine in a different light. She said “I see it for the disease it is and appreciate my support even more now.” She thinks that training for healthcare providers is the most important step in reducing stigma against people with migraine.

Case Study 2

“Maureen” (ID#2071) is a 60-year-old white woman with migraine. She is an optician and lives in zip code area 08055, which is the area near Medford, NJ (under an hour’s drive from Philadelphia). She said that migraine *often* interferes with her everyday activities. She learned about the event from her neurologist, and hoped to get “more information” out of the day’s events.

She did not answer the pre-participation question about participants’ knowledge of and experience with stigma, but her survey answers indicated a moderately high propensity toward internalized stigma. In her post-participation questionnaire, she said that among the most important things she learned was “self-compassion.” She said the day helped her see migraine differently: “I learned compassion and became more self-aware.” Asked to explain how the day’s events helped her name and recognize stigma, she wrote: “I know it’s more prevalent than I realized and that I also do it.” She said that internalized stigma was more burdensome to her, “because it is with me all the time.” She was able to apply a definition to stigma after the MED – “a negative view on a real situation.” What is important about her definition is that after having gone through the MED, she captures that there’s negative judgment about something that is “real” for the patient – biologically real.

Case Study 3

“Sara” (ID#4458) is a 31-year-old white woman with migraine. She said that migraine *always* interferes with her everyday activities. She works as a middle school math teacher, and lives in zip code 19454, which is in the North Wales section of Montgomery County, Pennsylvania (one of Philadelphia’s suburbs). She learned about the MED from an online link a friend sent her. Her goal in attending was to learn “options for treatment/to help.” She marked the box “I don’t know what this word [stigma] means,” but her SSCI survey indicated that she experiences a high degree of internalized stigma.

In her post-participation questionnaire, she wrote that one of the most important things she learned was that she “was not alone.” She also wrote “I liked the information about acupuncture.” She said that prior to the MED, “I didn’t realize what it was before and [now] realize I experience it daily.” While she was able to define stigma after the MED, her definition was one for externalized stigma: “The view/thoughts on migraine and the feelings projected towards you.” She said she experienced internalized stigma more than external, “but it comes from outside because I don’t see other people with migraine so I make myself feel bad.” She seems to be saying that her lack of community makes her feel like she was experiencing the problem alone and that she alone was responsible. She was also able to re-shape how she sees migraine after the MED. She wrote “Yes, I understand more that it is a legitimate disease and it’s not my fault.” She says that it is most important to provide training for healthcare providers.

Each of the individuals behind these case studies underwent a change in how they conceptualized their experience with migraine. A growing appreciation of stigma can transform their relationship to the disease, and how they respond to it, as discussed next in *Finding V*.

Recommendation:

1. Encourage the development of a migraine community by supporting nascent communities and social networks. Foster development of community after the Migraine Education Day events through social media, Skype calls, local meet-ups, etc.
2. Hold arts-based workshops focused on internalized stigma that would allow people with migraine to communicate their experiences visually to a broader community, and would allow them to continue to defuse the power of internalized stigma. Feature the art work at public events and forums with the goal of communicating to a broader audience.

Finding V: Education / information, and the group experience of identifying stigma together can lower barriers that stigma erects. This may manifest in an increase in advocacy among people with migraine and an increase in the number of people seeking relief either through medical interventions or through mind/body practices.

The combination of information about the nature of migraine, and the group experience of discussing identifying stigma and individuals' experiences appears to lead to transformation in how people think about migraine. People discussed having hope, not feeling alone, and realizing that they were not at fault.

After having gone through the event, attendees said that information about new treatments was the most important take-away from the MED. When asked to list the most important things they learned during the MED, 32 people mentioned information about treatments (including drugs, devices, treatments, acupuncture, yoga and alternative treatments). This number contrasts sharply with the five people who initially stated that they hoped to get "information about new treatments" during the MED. That speakers framed the discussion of migraine as a *medical* condition with *social* implications undoubtedly helped minimize the stigma, and led attendees toward new ways of thinking about the disease. And raising awareness about available and upcoming forms of treatment sparked a sense of hope and relief among many.

Stigma was the third most frequently mentioned important take-away from the MED ("triggers" was second). *Finding I*, above, discusses the fact that the majority of respondents with migraine experience more internalized than enacted stigma, even if they are not aware of it initially. Respondents discussed their new awareness of the phenomenon with a sense of relief, and for some a greater self-awareness that likely re-positions them in terms of their relationship to migraine, as it gives them the tools to master their disease. Comments such as "I understand more that it is a legitimate disease and it's not my fault," or "I have migraine disease all of the time, not just when I have an attack," or "I didn't really realize how much stigma there was in my life until today," or "Makes me want to help. Makes me want to be part of change. Makes me want to help advocate and fundraise" illustrate how change has occurred due to what participants have learned at the MED.

This change creates the possibility for behavioral change. When MED participants learn that migraine is a disease, not a personal failure, they are more likely to seek care. When MED participants learn that internalized stigma keeps them sidelined, they are more inclined to throw off the yoke of stigma and to exert more control over their experience. They may even become more engaged in advocacy work. When MED participants realize how even *they* are misinformed about migraine, they become enthused about spreading their new knowledge. In short, the MED helps people with migraine become less passive and to exert more agency over their search for solutions.

Recommendation:

1. Miles for Migraine should communicate to potential funders, particularly pharmaceutical companies, the following: the effects of internalized stigma; the MED events' role in alleviating this stigma; and the potential for behavioral change as people's identity shifts from "guilty" or "blameworthy" to "patient" or "empowered person." The implications for this are enormous for pharmaceutical companies.

Finding VI: The MED helps redefine migraine from a personal problem to a shared, medical condition.

The group setting of the MED affords people an opportunity to hear their experiences reflected in and validated by others. This creates a sense of community and helps people feel less alone in their experiences with migraine. In expressing their own frustrations and listening to those of others, people with migraine (and their supporters) were able to recognize their shared experiences. People became aware that their experience with migraine – the suffering, the internalized stigma, the enacted stigma, the feelings of isolation, the pain, and the frustration about limited options for treatment – were more than personal problems: together they constitute a bloc of people with a shared experience and a shared identity. As such, this community can recognize their own experience in those of others and together find new solutions to problems and new definitions of the problem. Pairing this newfound awareness with the medical information which was also part of the MED events, people with migraine are able to see that migraine is a medical problem. Together these give them the tools to redefine their illness and to redefine themselves.

People shared the following thoughts about stigma and how it makes them feel:

- "Internalized stigma [is more burdensome] because I used to believe it is my fault."
- "When feeling down, I still feel "less than," not living up to my potential, a burden on my husband. When feeling good, I want to advocate."
- "Internalized [is more burdensome], but comes from outside because I don't see other people with migraine so I make myself feel bad."
- "I understand more that it is a legitimate disease and it's not my fault."

- “Learning about stigma helps me understand I am not the only one with the same problems. There are others who understand.”

Recommendation:

1. Develop materials that inform a broad audience about the social constructions of migraine – especially how migraine has historically been gendered. Communicate that the result has been that people with migraine have been excluded from receiving medical care and that research into the condition has long been limited and under-funded. Include information about current approaches to migraine so as to encourage people to seek care.

Finding VII: Supporters of people with migraine may also be affected by their loved one’s internalized stigma.

Although supporters of migraine patients are more likely to identify enacted stigma as being most burdensome to migraine patients, the responses on some questionnaires indicate that the patient’s internalized stigma has a negative effect on their support person.

One respondent was a mother who was attending on behalf of her daughter, who was also present. The daughter described herself as being “hard” on herself, and had scored high in internalized stigma in the SSCI scale. In describing how she was affected by stigma, the mother referenced the stigma the daughter places on herself, not the stigma others place on her daughter. She said: “She does not want to talk about it. Makes us less involved, less compassionate.” While this lack of communication could be related to other issues in the family or differing styles of communication, the mother’s concerns touch on the shame of being chronically ill, which is a function of internalized stigma.

In another case, a man who has migraine attended the event with his wife. Comparing the married couple’s responses reveals how internalized stigma affects them. He is a 65-year-old man who said that migraine often interferes with his everyday activities. Although he scored moderately high on the propensity for internalized stigma, and low for enacted stigma, he said “no stigma for me” when asked how his experience with migraine is affected by stigma. His wife, on the other hand, said stigma “impacts our social life and our ability to consistently participate in activities.”

In both these examples the internalized stigma affects the support person. In the first, it (is possible that it) interferes with the relationship between the patient and the support person as the daughter won’t discuss her problems. In the second, it interferes with social relationships outside the husband-wife dyad. Although these examples may be solely anecdotal, it is important to recognize that the effects of internalized stigma may extend beyond the person with migraine.

Recommendation:

1. Conduct further research to understand the effects of internalized stigma on social relationships between the migraine patient and their support community and social networks.

Event-Specific Feedback

Below is a collection of the comments participants made about the event, including the food, the logistics and the venue, the flow of the events, and an evaluation of the speakers.

Comments about the food

Most respondents said the food was good and that they appreciated the selection. There were some complaints about: too many diet drinks; no fruit; migraine-specific diet precluded most of the food on the menu; not enough vegetarian/gluten-free options; lunch was not served on time; labels on wraps would have been helpful.

Comments about logistics and the venue

Most respondents were happy with the venue. The biggest complaint was about the lighting. Some specific comments include:

- I attended both years - both times lunch was late but was excellent. Both years seminar was great. Question: I never see attendees of color ???
- Having the tables in the main room was a great help. They were not there last year.
- You can never have enough signs. Have one for each room with the number of the room. Have them in the lot. And have signs for extra bathrooms and their locations.
- Temp was too warm in the conference room. Otherwise fine.
- The lighting was HARSH. I had to get on a plane to come here so if you want to come to Cleveland, that would be great.
- Maybe sound quality. Had a hard time hearing a few of the speakers.
- Great, needed free pens...
- Seems to work well. Might be good to move it around the region to improve access for others.
- Good. Easy to get to. free parking, which is nice. Plenty of space.
- Good location and facilities. Suggestion: Provide us with agenda ahead of time.
- Excellent. However, more signs needed to direct people to entrance and garage
- I like the venue. The quiet room was very thoughtful. Not enough women's stalls.
- The day was extremely long - need to shorten
- Good! Lots of natural light! Could have used more info at breakout sessions.
- Softer lighting would be preferable

Comments about the flow of the event

- Would have liked to take home more information on what was discussed throughout the day.
- Things went very smoothly. When things fell behind, more time was added at the end, which was great.
- It was run smoother than last year. Well done!

- I thought everything was pretty good. Maybe a little more breaks.
- It felt rushed at times, but that just shows how much information is out there and that one afternoon will not answer all your questions.
- Need more breaks. Break-outs were very interesting and the change of format was fun.
- A lot of good information and not enough time. But there's only so much time in a day.
- I liked the time on acupuncture best - more time on "natural" approaches would be better in future
- Good. Thank you! Would have enjoyed a longer panel with more of the presenters
- Discussion wasn't necessary - I don't like to speak in front of others. Other information was great. Dr. Kempner was enjoyable and informative - great speaker.
- More info (reading material) on the issues spoken.
- A little confusing
- Group discussion / break out sessions weren't necessary and should be optional
- Smooth, very well organized. Brava Shirley!
- Perfect. Next year add another hour. We will stay.
- Kept moving; good. Dr. Hou was too clinical - would've have preferred WIIFM [?] and no jargon for audience.
- Fine but certain activities that had been initially scheduled were canceled during the conference
- Wonderful balance of lecture and experiential and community-building

Speaker evaluation:

	Didn't attend	Very Poor	Poor	Good	Very Good	Excellent
Paula K. Dumas	3	0	0	6	12	24
Dr. Angela Hou	0	1	1	11	12	20
Angela L. Kurzyna, MA, Psy.D., BCB	0	0	0	6	14	23
Joanna Kempner, PhD	0	0	0	4	13	27
Chris Molnar, PhD,	18	0	2	5	6	14
Caryn Richfield, PsyD	22	0	1	3	7	12
Lisa Goldstein, MD	17	0	1	4	7	16
Yoga Breakout Session, with Theresa Conroy	8	0	2	10	9	16
Acupuncture Breakout Session with Conover/Kira	4	0	3	9	8	20
William B. Young, MD, FAHS, FAAN	0	0	0	4	10	30
Group Panel with Select Presenters	2	0	1	5	9	19