




Effectiveness of film as a health communication tool to improve perceptions and attitudes in multiple sclerosis

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Abstract

Background: Health communication tools like film are capable of reducing health disparities and could be effective in addressing negative illness perceptions of MS in Hispanics/Latinx.

Objective: To test the feasibility of using a culturally appropriate short narrative film to examine illness perceptions overtime and attitudes in Hispanics/Latinx affected with MS.

Methods: Participants were assigned to view a short narrative film (n = 130) or not (n = 106). The Brief Illness Perception Questionnaire (BIPQ) was used to examine illness perceptions at baseline, one and three months. Focus groups were conducted at 6 months. Measures of sociocultural integration were obtained. Individual group BIPQ domains were evaluated over time using paired sample t-test. Multivariate linear regression was used to examine predictors of BIPQ change.

Results: A more positive perception of *treatment* ($p < 0.0001$) and *understanding* ($p = 0.0003$) were seen at 3 months for those exposed to film. Focus groups were effective in highlighting that the perceived disease prognosis, family support and awareness of MS contributes to attitudes. Exposure to film was found to be the strongest predictor (Beta:6.31, $p = 0.01$) of BIPQ change at three months.

Conclusion: Our results provide support that a short narrative film of MS in Hispanics/Latinx is a feasible intervention to change perceptions of MS to a more positive view.

Keywords: Multiple sclerosis, Latino/Hispanic/Latinx, illness perceptions, film, attitudes, health literacy, education

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Multiple sclerosis (MS) is an immune mediated progressive disease of the central nervous system that negatively affects quality of life. The variable course and progression of MS presents challenges, and social determinants of well-being include illness perceptions. An individual's illness perceptions (IP) figure prominently as a complex, multidimensional process comprising cognitive representations or beliefs that patients have about their illness,¹ which recently have been found to be associated with treatment adherence, management, and functional recovery in MS.^{2,3}

IP may be influenced by the patient's own beliefs about the disease,⁴ which in turn may be influenced

by his or her cultural background. We have previously shown that Hispanics/Latinx diagnosed with MS are more likely to believe MS is the result of stress and quote cultural distress syndromes (incorporation of cultural factors that may influence disease).⁵ In addition, a greater proportion of those that reported the latter were not on disease modifying treatments highlighting potential negative effects on outcomes. Nevertheless, the study was not able to examine IP domains and attitudes that would support them.

Health communication interventions, like film, have been shown to be effective tools in promoting positive attitudes and health literacy.^{6,7} The use of

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audio-video technologies to promote self-care and improve outcomes has been well accepted among underrepresented communities.⁸ Unlike printed materials and traditional health education videos, film is accessible to those with low literacy levels and can be tailored to the social norms and values of a specific population. Utilizing culturally tailored messaging with relevant characters and contextual narratives that reflect the concerns and diverse beliefs of the population could be an effective means of promoting positive IP, attitudes and behavioral shifts.⁹ The purpose of this study was to pilot-test the effectiveness of a short film on illness perception trajectories and illustrate common negative versus constructive attitudes of coping with MS in a Hispanic/Latinx population.

Methods

Design and study population

This was a prospective pragmatic study to examine illness perceptions (IP) and assess the feasibility of film as an intervention to affect change in self-defined Hispanics/Latinx individuals with a diagnosis of MS. Participants were recruited from the Alliance for Research in Hispanic MS collaboration described elsewhere.¹⁰ Inclusion criteria were: 1) Age 18 and older; 2) have a diagnosis of MS confirmed through medical record; 3) self-identify as Hispanic/Latinx; and 4) ability to read or speak

English and/or Spanish. We excluded MS patients with serious cognitive dysfunction or mental illness that would require answers from surrogates/caregivers. Eligibility was confirmed by the MS specialist (L. Amezcua, A. Chinae, and S. Delgado) at each site. Participants were assigned to view a short narrative film (n = 130) or not (n = 106) using disease duration (5 years or less vs. >5 years) as stratification with a pre- and post-viewing assessment at time 0 (narrative film only) and re-contacted for follow-up surveys at one and three months (Figure 1). This study was approved by the institutional review board at each institution, and all patients provided informed consent before participation.

Data collection. Sociodemographic and clinical characteristics were collected using the patients’ medical records and baseline questionnaires. All data was captured in the electronic data system of RedCap (<https://redcap.med.usc.edu/>). Level of education was categorized according to the distribution of educational attainment in the United States: (1) completed high school or less; (2) trade school or some college; or (3) completed 4-year college or higher. Household income was also collected. To assess level of acculturation we used the Short Acculturation Scale for Hispanics (SASH) at enrollment.¹¹ This is a 5-point Likert 12 item scale used to measure US acculturation in the Hispanic/Latinx population. Total scores range from 1 to 5 and an

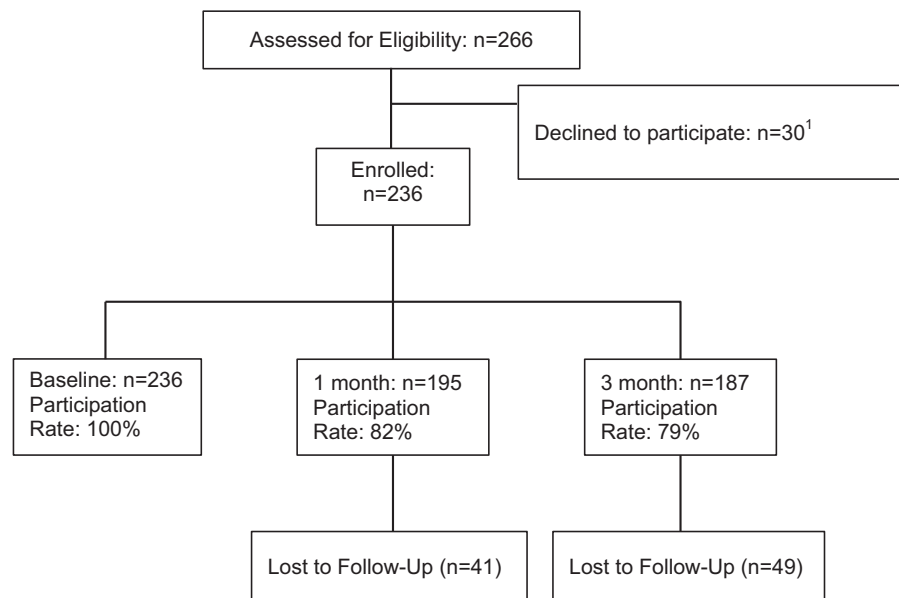


Figure 1. Flow of study participants. Most common reasons for declining to participate were lack of time, transportation issues, and perception of no personal benefit.

¹Reasons for non-participation include lack of time, hesitance, transportation issues, and perception of no personal benefit

²NR: non-responder.

overall average of 2.99 or higher in SASH indicates greater acculturation.

Intervention-narrative film

A pre-produced film-narrative titled *Dentro De Mí* (13-minutes in duration) was used as the intervention. The film portrays non-fictional stories of Hispanics/Latinx of different ethnic backgrounds affected with MS and living in the US. It was filmed using both English and Spanish with corresponding Spanish and English subtitles. The film is grounded in cognitive behavioral theory and emphasizes perceptions, cultural idioms and myths about treatment and course of MS, and raises consciousness of healthy behaviors in MS.

Outcomes. IP were measured using the Brief Illness Perception Questionnaire (Brief IPQ) that assesses illness perception using five cognitive domains: *consequences* (the impact the illness has had in the patient's life); *timeline* (expected duration of illness); *personal control* (perceived control over the illness); *treatment control* (treatment effectiveness); and *identity* (the severity and extent of the illness as well as two emotional domains (concern and emotional response), and one domain that assesses understanding of the illness.¹² The eight items on the Brief IPQ are rated according to a 0-10 scale scored to determine the degree to which the illness is perceived as threatening or benign. A higher score indicates a more positive perception of illness. The ninth item is an open-ended causality question, in which participants are able to rank the three most important causal factors of their disease. The Brief IPQ has a good test-retest reliability, and concurrent, predictive, and discriminant validity in various population backgrounds.¹³

The multiple sclerosis self-efficacy scale (MSSE) consists of an 18-item scale subdivided into two subscales: function and control.¹⁴ It assesses patients' perspectives on how they achieve certain functions or have control of various aspects of their disease. It has a high internal consistency and test-retest reliability, and it has proven to be both sensitive and specific.¹⁵

Qualitative measures. To provide in-depth insights into patient perspectives on living with MS we conducted focus groups.¹⁶ Recruited participants were randomly invited to participate in one of three focus groups (10-12 participants per 1-2 hour session). The discussion was chaired by a public health researcher (A. Martinez), and two

neurologists (K. Polito and M. Robers) who observed the meeting. Audio of the discussion was recorded and transcribed verbatim. The dimensions of the Brief IPQ and the short narrative film were used as a guideline during the focus group discussion. To maintain the richness of the information obtained during the sessions, the bilingual research staff translated and presented direct quotes in the results section. In cases in which a Spanish word had no suitable English translation, we used the Spanish word and described its meaning in the text.

Statistical analysis. Descriptive statistics were used to describe the cohort. To examine the BIP changes of 1-8 domains between 0, 1 and 3 months, paired samples *t*-tests were conducted for each IP domain for those who watched the film and those that did not. Additionally, the perceived *cause* (item 9) that was indicated by the patients as the most important, at 3 months was coded and categorized into three categories: environmental, sociocultural, and biological causes by two authors (H. Chiong-Rivero and A. Martinez) independently. To examine the predictors of Brief IPQ changes we performed a multivariable linear regression analysis using the Brief IPQ total summary score as dependent variable to investigate access to film, level of acculturation and socioeconomic factors, including education and household income. The level of significance was set at $p < 0.05$ and SAS was used.

Results

A total of 266 patients with MS were invited to participate. Thirty declined to participate due to lack of time, transportation issues, and perception of no personal benefit. Two hundred and thirty six patients provided baseline data with 79-82% participating in follow-up (Figure 1). Baseline characteristics of those who participated in the study were notable for most being female (72.8%) and having a mean age of 40.0 years (standard deviation, SD 12.2) (Table 1). Most had relapsing MS, had a median age at diagnosis of 34.32 (SD 11.21), were highly educated (43.6% with college or more), had an annual income between \$60,000-99,000 (45.2%), and had mild ambulatory disability (EDSS of 2.7). There was no significant difference between those assigned to view the narrative film and those who were not assigned with regard to sex, age of diagnosis, age at onset, time to diagnosis, place of birth, acculturation, and level of education. As expected, a longer disease duration was observed for those not assigned to film narrative ($p < 0.01$).

Table 1. Demographics of participants.

	Film (130)	No film (106)	Total (236)	p=
Gender				
Male	36 (27.69%)	28 (26.42%)	64 (27.12%)	0.83
Female	94 (72.31%)	78 (73.58%)	172 (72.88%)	
Age at registry	36.26 (10.7)	44.69 (12.45)	40.04 (12.24)	<0.01
Age at onset	32.45 (10.9)	31.36 (11.21)	31.96 (11.03)	0.44
Age at diagnosis	34.65 (10.7)	34.18 (11.71)	34.43 (11.15)	0.75
Disease duration	3.88 (4.12)	13.45 (7.92)	8.23 (7.77)	<0.01
EDSS	2.46 (1.96)	2.99 (2.15)	2.7 (2.06)	0.04
Place of birth				
Non-USA	62 (47.69%)	48 (45.28%)	110 (46.61%)	0.71
Ethnic Background				
Mexican	44 (33.85%)	34 (32.08%)	78 (33.05%)	0.02
Central America	29 (22.31%)	9 (8.49%)	38 (16.1%)	
South America	6 (4.62%)	3 (2.83%)	9 (3.81%)	
Mixed Hispanic	6 (4.62%)	6 (5.66%)	12 (5.08%)	
Caribbean	45 (34.62%)	54 (50.94%)	99 (41.95%)	
Education				
High school or less	51 (39.23%)	31 (29.25%)	82 (34.75%)	0.07
Some College or Training	31 (23.85%)	20 (18.87%)	51 (21.61%)	
College or more	48 (36.92%)	55 (51.89%)	103 (43.64%)	
Household Income				
<60,000	54 (43.9%)	40 (38.1%)	94 (41.23%)	0.47
60,000–99,000	51 (41.46%)	52 (49.52%)	103 (45.18%)	
>100,000	18 (14.63%)	13 (12.38%)	31 (13.6%)	
SASH				
Less acculturated	43 (46.74%)	42 (39.62%)	85 (42.93%)	0.31
More acculturated	49 (53.26%)	64 (60.38%)	113 (57.07%)	
MSSE				
Control	74.88 (23.28)	71.14 (21.32)	73.19 (22.45)	0.06
Function	85.04 (20.66)	79.36 (22.7)	82.48 (21.74)	0.01
BIPQ				
Consequences	5.33 (2.96)	5.93 (3.11)	5.6 (3.04)	0.12
Timeline	9.13 (2.12)	8.93 (2.5)	9.04 (2.3)	0.74
Personal control	6.34 (2.84)	6.08 (3.01)	6.23 (2.91)	0.56
Treatment control	7.57 (2.6)	7.97 (2.76)	7.75 (2.67)	0.07
Identity	5.36 (3.02)	5.71 (2.75)	5.52 (2.9)	0.42
Concern	7.28 (2.84)	6.93 (3.16)	7.12 (2.99)	0.56
Understanding	7.7 (2.19)	8.53 (1.97)	8.08 (2.13)	<0.01
Emotion	6.16 (3.14)	6.28 (3.13)	6.21 (3.13)	0.78

Total Brief IPQ scores, at baseline, noted significant differences in understanding between the groups ($p < 0.01$). MSSE scores differed in that those assigned to film had higher scores (85.04; SD 20.66) in functional status compared to those not assigned to film (79.36; SD 22.7; $p = 0.01$).

Brief IPQ and MSSE changed for each group. The trajectories of each Brief IPQ domain differed by

who was exposed to film or not (Supplementary Figure 1). A positive intervention was noted in perception of *treatment control* ($p < 0.0001$ (Figure 2) and *understanding* over the three months examined ($p = 0.0003$; Figure 2) in those exposed to film despite noting a change in their perception of *time-line*; understanding that MS is long lasting. Higher self-efficacy function scores on MSSE at one-month were also noted.

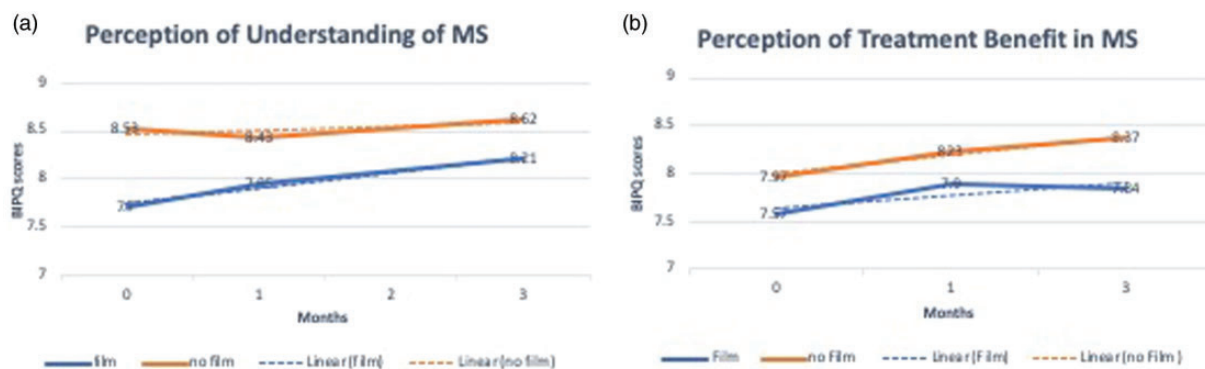


Figure 2. Trajectory of illness perception domains that had statistically significant changes over time when exposed to film. A significant incremental change in understanding in those exposed to film at 1 month ($p = 0.0003$) and at 3 months ($p = 0.0012$). A significant incremental change is also noted in the domain of treatment perception, particularly at month 1 ($p < 0.0001$) in those exposed to film.

Association between brief IPQ total score and clinical and demographic markers at 3 months

Multivariable logistic regression revealed exposure to film as the strongest predictor (Beta: 6.31, $p = 0.01$) of BIPQ change at 3 months (Table 2). Acculturation level was not significantly associated with Brief IPQ changes. Moreover, being female (Beta: -4.6, $p = 0.05$) and having high household income (Beta: -6.85, $p = 0.05$) were less likely to change.

Qualitative results and focus groups

The question on the most important perceived cause of MS was answered by 215/236 (91%). Most responses fell in the environmental factors including lifestyle changes ($n = 12,960\%$). Sociocultural ($n = 38$, 17.7%) and biological ($n = 48$, 22.3%) factors were less frequently reported (supplementary Table 1). Key words pertinent to environmental causes were consistent with lifestyle choices such as being overweight, work related stress, and unhealthy eating habits. Family history was one of the most commonly reported causes under the biological category, while a variety of psychological and emotional factors concerned the sociocultural category. These reports were complemented by focus group results where disease prognosis (*concern*), cultural and family response (*consequences*), and education and awareness (*understanding*) were three dimensions of IP repeatedly mentioned to be relevant to our patients' attitudes (Table 3). Attitudes observed towards disease prognosis (*concern*) seemed to differ between participants with longer disease duration and those with shorter disease duration. Nevertheless, a more positive attitude emerged after viewing the film and opened up the discussion of attitudes and perceptions as suggested by the

Table 2. Relationship between brief IPQ summary score and film.

	Beta	P value
Age	0.24	0.01
Gender: Female	-4.6	0.05
Disease duration	0.7	0.68
Ambulatory disability	-0.28	0.94
College education	-3.66	0.15
High household income	-6.85	0.05
Acculturation	3.3	0.14
Film as intervention	6.35	0.01

comments/phrases expressed (Table 3). The group emphasized that consequences of having MS depend strongly on family response and cultural background, and that family values play critical roles in how participants cope with MS (Table 3). The *understanding* of having MS was expressed in different ways during the focus groups: participants reported that at the time of their diagnosis, many had difficulty understanding and explaining their disease to others. As a result, a negative attitude related to how they dealt with their disease and the impact on their emotional and mental state was expressed during the focus group.

Discussion

In this study, we investigated IP in MS in those with Hispanic/Latinx background and compared the effectiveness of film to alter them over time. Three months after the exposure, those exposed to film had a significant positive change in their perception of *treatment* and *understanding*. Positive attitudes related to disease prognosis, family support and overall awareness of MS were also captured. These

Table 3. Attitudes towards MS and film intervention following focus groups.

Theme	Phrases
Identity and MS	<p>“MS is not who I am; it is the beginning of who I’m not going to be.”</p> <p>“You either dwell on it or move forward.”</p> <p>“I told myself: I have MS, but MS does not have me.”</p> <p>“It is easy to fall into the darkness with this disease and be secluded.”</p> <p>“In the end, all that matters is my attitude and no one is going to give me a label to change that.”</p>
Disease Prognosis (Concern)	<p>“I feel a transition from darkness to light”</p> <p>“There are two ways you can go [MS]: you can go to the dark, or you can go in the light and continue to live.”</p> <p>“Perseverance!”</p> <p>“Take control of your life . . . to live and try to do all the things you want to do.”</p>
Family Support (Consequences)	<p>“To have that support [family] . . . to help you grasp the immensity of the diagnosis.”</p> <p>“We do need support. Obviously, we are here together, supporting each other.”</p> <p>“It’s sad that it happened to the siblings, but it’s good that they’re there, standing tall. They’re standing for each other.”</p> <p>“MS doesn’t just happen to you; it happens to the whole family.”</p>
Education and Awareness (Understanding)	<p>“It is very important to educate the family.”</p> <p>“A way of educating people is very important.”</p> <p>“The more you learn, the better you’re off.”</p> <p>“If he [dad] was better educated, he would’ve known.”</p> <p>“The video [film] might help people understand, I don’t look sick, but there are days when I literally can’t get out of bed.”</p> <p>“Education is power, and information is power, and we don’t feel as depressed and angry once we know.”</p>
Identification with Film and Character	<p>“It [film] shows us that we can either stay in that darkness or go in the light.”</p> <p>“No one is going to understand what you’re going through unless they see this film.”</p> <p>“Inspirational, the short-film can show others that life continues”</p> <p>“Feelings of heaviness, isolation, depression, hope, and acceptance are relatable”</p> <p>“I was watching it, it hit home!”</p>

findings persisted through 3 months of quantitative measurement and focus groups confirmed that film can foster lasting effects making it a practical clinical tool to promote positive perceptions in disease.

The results of our study parallel findings related to IP in MS in non-Hispanic whites. MS patients have been reported to have negative perceptions in treatment control among other domains.^{17–20} Nevertheless, in our study those perceptions turned positive with exposure to film. While not explored in this study, these perceptions have previously been reported to correlate with poor quality of life and disengagement.²¹ In one cross-sectional study of 850 MS patients, increased illness identity (viewed as a measure of the total number of symptoms) correlated with decreased physical function as well as increased bodily pain.¹⁹ More negative IP have been

reported with worse psychological, and quality of life outcomes than those without, while individuals who felt they understood the disease showed better psychological and quality of life outcomes.³ These studies support the importance that illness perceptions play a critical role in MS and there is a need to identify them to develop effective interventions that are culturally relevant.

Film has been used as a narrative-based intervention for the dissemination of health information and has been found to deliver behavioral shifts, particularly among underrepresented populations where culture has a strong tradition in storytelling.^{6,8} We found that Hispanics/Latinx with MS who were exposed to film construed more favorable positive perceptions. Film, video, blogs, and vlogs are being increasingly recognized as accessible tools that

have the potential to shape IP, provided they are culturally-rooted and grounded in clinical and scientific knowledge of the disease. Most films to date in MS have only examined the thematization of chronic illness, but could have the capacity to create a balance between entertainment and education, by offering positive counter-images to ill-conceived and erroneous representations of MS.²² Internationally, there have been large-scale interventions that use Latin American *telenovelas* as edutainment to promote health-related behavioral change, especially among those who have lower literacy levels, lower education, and lower socioeconomic status.⁷ While we did not specifically examine whether film could have greater effect on those with lower education and SES, film independently was found to be the strongest predictor of BIPQ scores change at 3 months while income and level of acculturation were marginal. Thus, our study supports the use of film as a future intervention to address health literacy barriers.

Capturing both quantitative and qualitative measurements of IP are important for expanding our understanding of how to provide successful interventions to overcome perceived barriers. Quantitative measurements such as the Brief IPQ provides the ability to complete traditional statistical analysis and show measurable changes with intervention and have been previously used to show association pathways between perceptions and health outcomes.^{2,3} Qualitative measurements and focus groups allow for a more nuanced understanding of patient perspectives by allowing participants to express their own thoughts rather than being restrained by assigned answers to a questionnaire. Categorizing free responses from a focus group into themes allows trends of important influences to be seen and has previously been used to understand patient experiences and perceptions in MS.^{16,23} Using both techniques, we were able to show both statistical significance as well as freely reported themes of improvement in perceptions of understanding and treatment control. The congruence of findings between the two techniques bolsters the evidence that the film can promote healthier perceptions and attitudes. The theme of family understanding and support came up repeatedly in the qualitative analysis, raising the possibility of expanding film to address family and caregivers' concerns.

Self-regulation as a framework to address negative IP in MS could be helpful. Studies in non-Hispanic whites with MS report perceptions of chance and stress to be the most likely causes of MS (44.4 and

43.4% of the sample, respectively),²⁰ or the results of a virus or germ (35%) followed by stress (21%).²⁴ On the casual item, we found environmental factors such as stress, unhealthy behaviors, eating, lack of exercise to be the most mentioned causes of MS which is consistent with our prior findings. However, a sociocultural context to the cause of MS was seen among those less acculturated to the US (mostly participants living in Puerto Rico) which we were not surprised to find as we have previously reported cultural distress syndromes in foreign born Hispanics suggesting deep cultural roots are much more ingrained.⁵ Addressing the ethnic or cultural underpinnings of patient perceptions may be useful in designing more personalized interventions.

Patients' and families' representation of MS can play a significant role in how they cope with MS.²⁴⁻²⁶ We speculate that some of the concerns expressed within the focus groups advocate for educational material that are accessible, culturally based, and promote family engagement. There is a critical role of family in *understanding* the disease and social functioning: if not present, it can make patients feel isolated and unsupported. Family lack of understanding and denial of patients having MS were salient attitudes that were reported to negatively impact their perception of MS, whereas having their family's support promoted positive perceptions and attitudes towards MS. To that end, many participants responded that one of the main reasons the film resonated with them was because it included key cultural perceptions and family values.

There are several limitations to our study including the loss to follow-up inherent to prospective, longitudinal studies. Nevertheless, retention rate over the whole study was ~80%, which is particularly above expected for a study that recruited unrepresentative groups in MS.²⁷ An additional limitation includes the possibility of selection bias distorting our results given the shorter disease duration was a feature in those exposed to film. Though the rest of the cohort's characteristic were well balanced between the two groups. The possibility of cognitive impairment impacting our results is also possible. While we did not specifically screen for cognitive dysfunction in this MS cohort, we excluded MS patients with serious cognitive dysfunction or mental illness. Studies of mild cognitive impairment have found that those with less insight into their condition view their disease as less serious (domain: consequence), yielding less emotional distress.²⁸ In a study of schizophrenia, those with

higher insight of schizophrenia reported more subjective cognitive impairment.²⁹ Thus, if we were to consider that those with longer disease duration (not exposed to film) had more cognitive dysfunction, we would have expected lower IPQ scores in the domain of consequence (see supplementary Figure 1 manuscript), which was not the case. There were also no statistically significant differences between those with longer and shorter disease duration (those viewing film) over time. Thus, the potential impact of longer disease duration representing greater cognitive dysfunction in our cohort is less likely. The combined quantitative and qualitative analysis of IP and attitudes also speaks to the strength of capturing the voice of diversity. Our results provide support that a short narrative film of MS is a feasible means to change perceptions of MS related understanding and treatment of MS, particularly in those with a shorter disease duration.

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Supplemental material

Supplemental material for this article is available online.

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