

Multiple Sclerosis-Reece Stigma Scale (MS-RSS) Turkish Adaptation: Validity and Reliability Study

Multipl Skleroz-Reece Damgalama Ölçeği (MS-RSS) Türkçe Uyarlaması: Geçerlilik ve Güvenirlilik Çalışması

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ABSTRACT

Objective: Stigma is a behavior that affects the bio-psycho-social lives of patients with multiple sclerosis, as it does in other chronic diseases, as well as their treatment processes. The aim of this study is to adapt the short and reliable Reece Stigma Scale-Multiple Sclerosis (RSS-MS) into Turkish under the name of Multiple Skleroz-Reece Stigma Sakala (MS-RSS) and to conduct its validity and reliability study. Materials and Methods: The study sample consisted of 416 individuals diagnosed with Multiple Sclerosis who voluntarily agreed to participate in the study. The "Personal Information Form" and the "MS-RSS" translated into Turkish were applied to individuals who agreed to participate in the study. Confirmatory Factor Analysis (CFA) was conducted to examine the construct validity of the scale. To calculate the reliability of the scale, internal consistency coefficient (Cronbach's Alpha) and item-total correlations were analyzed. Results: It was found that the minimum Chi-square value was statistically significant and the other fit index values were within the desired range. In CFA, the Standardized Regression Coefficients (std. β) were above 0.30, positive and significant. Cronbach's Alpha coefficient was 0.844 and item-total correlations ranged between 0.334 and 0.742. Conclusion: In conclusion, the MS-RSS can be used as an effective tool in assessing the perception of stigma among MS patients.

ÖZ

Amaç: Stigma, diğer kronik hastalıklarda olduğu gibi multipl skleroz hastalarının da biyopsikososyal yaşamlarını ve tedavi süreçlerini etkileyen bir davranıştır. Bu çalışmanın amacı, kısa ve güvenilir bir ölçek olan Reece Stigma Ölçeği-Multiple Sclerosis'i (RSS-MS) Multiple Skleroz-Reece Stigma Sakala (MS-RSS) adıyla Türkçeye uyarlamak ve geçerlik ve güvenilirlik çalışmasını yapmaktır. Gereç ve Yöntem: Çalışmanın örneklemi Multipl Skleroz tanısı almış ve çalışmaya gönüllü olarak katılmayı kabul eden 416 birey oluşturdu. Çalışmaya katılmayı kabul eden bireylere "Kişisel Bilgi Formu" ve Türkçe'ye çevrilmiş "MS-RSS" uygulandı. Ölçeğin yapı geçerliliğini incelemek için Doğrulamalı Faktör Analizi (DFA) yapıldı. Ölçeğin güvenilirliğini hesaplamak için iç tutarlılık katsayısı (Cronbach's Alpha) ve madde-toplam korelasyonları analiz edildi. Bulgular: Minimum Ki-kare değerinin istatistiksel olarak anlamlı olduğu ve diğer uyum indeksi değerlerinin istenen aralıkta olduğu bulundu. DFA'da Standardize Regresyon Katsayıları (std. β) 0,30'un üzerinde, pozitif ve anlamlıydı. Cronbach'ın Alfa katsayısı 0,844 ve madde-toplam korelasyonları 0,334 ile 0,742 arasında değişiyordu. Sonuç: Sonuç olarak MS-RSS, MS hastalarında damgalanma algısının değerlendirilmesinde etkili bir araç olarak kullanılabilir.

1. Introduction

Multiple Sclerosis (MS) is a chronic autoimmune disease that affects the central nervous system (Lepore et al, 2024; Terzi et al, 2009). It is estimated that 2.5 million people have MS worldwide (Rodríguez-Menéndez, Martínez-Piédrola, Menéndez-González & Pérez-de-Heredia-Torres, 2024). MS, which has an increasing prevalence worldwide, is among the most common diseases affecting

young adults and causing progressive neurological disability (Dobson & Giovannoni, 2019; Hudgens et al, 2024). The disease has a heterogeneous structure and can cause various signs and symptoms related to motor, sensory, visual, sexual, mood, etc. depending on the affected area (Kister et al, 2013). Today, there is no definitive treatment for the disease other than symptomatic treatment (Thompson, Toosy & Ciccirelli, 2010). The aim of the preventive drugs used is to control the attacks and

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to stop or slow down the progression of the disease (Hauser & Cree, 2020).

In general, the disease is classified into four categories according to its course: Relapsing-remitting MS, Secondary progressive MS, Primary progressive MS and Progressive-relapsing MS (Gharibi et al, 2020). Relapsing-remitting MS, which accounts for approximately 85% of patients and is characterized by the onset of symptoms followed by their resolution or complete or partial disappearance; Secondary progressive MS is the form that starts with attacks and then gradually worsens; The form in which the disease progresses from the beginning without relapse or recovery is called Primary progressive MS, and the form in which the disease progresses despite occasional attacks is called Progressive-relapsing MS (Goldenberg, 2012). The clinical course of the disease is unpredictable and varies greatly from person to person (Spencer, Silverman & Cook, 2019). While the disease does not affect the quality of life in some patients, it can cause disability in some patients by showing a progressive feature (Lublin et al, 2022) Considering this structure of the disease that varies from person to person, it is observed that the quality of life of individuals is affected in different ways.

When we look at its effects, it is seen that MS disease has physical, psychological and social dimensions, and therefore it is a biopsychosocial disease (Moral-Torres et al, 2021). Stigma is the main factor that affects the social lives of MS patients (Abolhassani, Yazdannik, Taleghani & Zamani, 2015). When we look at the literal meaning, stigma, or stigmatization, is a term that refers to the negative evaluation of individuals by others due to a certain characteristic (Tworek, Thompson, Kane & Sullivan, 2023). In other words, it is the feeling of being disapproved of and excluded from society by those who have characteristics or exhibit behaviors that society considers unusual (Pérez-Miralles et al, 2019). It is known that people with chronic diseases experience three types of stigma: internalized, experienced, and anticipated stigma (Earnshaw & Quinn, 2012). Internalized stigma refers to individuals internalizing stigma as a result of experiencing negative situations due to their illness; experienced stigma refers to the degree to which individuals perceive the prejudice and discrimination they face, and anticipated stigma refers to the expectation of negative attitudes, behaviors, or beliefs in the future (Eldridge-Smith, Loew & Stepleman, 2021).

After receiving a diagnosis of a chronic disease, including MS, individuals may worry that their illness will affect how others view them and that they may face stigma (Cadden, Arnett, Tyry & Cook, 2018). Stigma affects the person's quality of life, causing decreased self-esteem, loss of self-confidence, social isolation, loss of work and educational opportunities, unemployment, and psychological disorders such as depression and anxiety (Broersma, Oeseburg, Dijkstra & Wynia, 2018; Grothe, Grothe, Wingert, Schomerus & Speerforck, 2022; Maurino et al, 2020; Ochoa-Morales et al, 2021; Pérez-Miralles et al, 2019; Sharifi, Kohpeima Jahromi, Zahedi, Aram & Ahmadi, 2023; Vitturi et al, 2022). In order to avoid this, it can be seen that MS patients may tend to hide the disease in the early stages of the disease, even if they do not have any symptoms (Cook, Germano & Stadler, 2016; Kever & Leavitt, 2022). From this perspective, there is a need for studies on stigma, which greatly affects the quality of life of MS patients.

When the Turkish literature is examined, it is noteworthy that although there are scales measuring stigma in chronic diseases, there is no specific scale specific to MS disease. At the same time, it is seen that the studies addressing the stigma experienced by MS patients in the Turkish literature are limited (Çakır & Yurtsever, 2020; Koçhan, 2022). In this context, it is thought that addressing the issue of stigma, which greatly affects the lives of MS patients but has not been sufficiently addressed, will make significant contributions to the literature. Based on this, this study aimed to adapt the Reece Stigma Scale-Multiple Sclerosis (RSS-MS) scale into Turkish under the name Multiple Sclerosis-Reece Stigma Scale (MS-RSS) and to conduct its validity and reliability study. In this context, it is expected that the findings obtained will show that the scale in question can be used as a valid and reliable measurement tool to measure the perceptions of MS patients in Turkey regarding the stigma they experience regarding the disease. Considering that MS affects the individual's life in various ways, it can be said that the disease is a biopsychosocial disease and requires holistic intervention. It is important to work on this issue in terms of allowing the social aspect of the disease to be emphasized. Thus, it is thought that the social aspect of the disease can also be addressed in the interventions to be applied to the patients and that the quality of life of the individuals can be increased.

2. Material and Methods

2.1. Population and Sample of the Research

MS patients living throughout Turkey constitute the universe of the study (although the exact number is not known, it is estimated that there are 50,000-70,000 MS disorders in Turkey). The sample group of the study consisted of 416 individuals diagnosed with MS who voluntarily agreed to participate in the study. Although there is no single opinion in the literature regarding the sample size for the factor analysis to be conducted within the scope of evaluating the validity of the scale to be used in the study, there are opinions that the sample size should be at least 5 times (Bryman & Cramer, 2001), 10 times (Nunnally, 1978), and 15 times (Gorusch, 1983) the number of variables used in the study. The fact that the scale, whose validity and reliability study was conducted within the scope of the study, consisted of 9 items shows that the sample size was sufficient for the study. The study group was reached through patient groups on social media and patient pages. The survey applied to the sample group reached using the convenience sampling method was conducted online.

2.2. Data Collection Tools

The data of the study were collected using an internet-based data collection technique (Google Forms) between 15.01.2024 and 30.03.2024. The data collection form took an average of 10 minutes to be filled out by each participant. The "Personal Information Form" and the "Multiple Sclerosis-Reece Stigma Scale (MS-RSS)" developed by the researcher were applied to the individuals who agreed to participate in the study. "The permission required for the translation and adaptation of the Reece Stigma Scale-Multiple Sclerosis (RSS-MS) into Turkish was given by Dr. Elizabeth Smith via e-mail on November 28, 2023. After reading the informed consent form at the beginning of the study, the participants proceeded by selecting the "Yes" option in the statement "I have been informed about the research. I agree to participate in the study voluntarily."

Personal Information Form: The personal information form, created by the researchers to evaluate the sociodemographic characteristics of the participants, consists of questions including sociodemographic characteristics such as gender, age, education status,

employment status, income status and health status (MS disease diagnosis and treatment process).

Reece-Stigma Scale-Multiple Skleroz (RSS-MS): The Reece Stigma Scale-Multiple Sclerosis (RSS-MS) was adapted by Eldridge-Smith et al. (2021) to measure stigma in individuals with Multiple Sclerosis. The original scale, the Reece Stigma Scale, was used to measure stigma perception in individuals living with HIV (Reece, 2003). The relevant statements in the scale were replaced with statements related to MS and applied to the MS patient population. The 9-item scale used a 5-point Likert type with marking between "1-Never" and "5-Always" for each item. There are no reverse items in the scale. The Cronbach alpha value of the scale was reported as 0.91.

2.3. MS-RSS Language Adaptation

The translation of the MS-RSS scale from English to Turkish was carried out by two separate translation companies. These translated texts were first re-evaluated by the researchers and the Turkish version was structured. The final translated text was re-examined by a competent Literature Teacher in terms of Turkish language rules and semantic integrity. In addition, the understandability of the questions in the scale and the semantic integrity of the final translated text were evaluated by 5 experts in the field of medical social work. The scale was sent to the experts using the Davis technique and they were asked to evaluate the understandability and cultural appropriateness of the questions, and the evaluation criteria were as follows: "1 point: Not appropriate; 2 points: Somewhat appropriate (items/statements need to be adjusted to the appropriate form); 3 points: Quite appropriate (appropriate, but minor changes needed); 4 points: Very appropriate (no changes needed, can remain the same)." Based on expert opinions, the number of those who chose the 3 and 4 point option was divided by the total number of experts and the content validity index (CVI) of each question was calculated. The content validity of the questions with a CVI above 0.80 was evaluated as appropriate (Delgado-Rico, Carrtero-Dios & Ruch, 2012; Polit, Beck & Owen, 2007). The entire scale was reviewed and necessary corrections were made, taking into account the experts' suggestions. As a result, the final version of the text was created. (Table 1) The text was translated back into English by an independent translator and this translation was examined by comparing

it with the original English expressions of the authors. Thus, the final version of the form was determined.

2.4. Analysis of Data

IBM SPSS Statistics for Windows, Version 26.0 and IBM SPSS Amos Version 26.0 programs were used for statistical analysis in the study. The conformity of the data to normal distribution was examined based on skewness and kurtosis coefficients and the distribution was found to be normal (George & Mallery, 2010). The statistical significance level was accepted as $p < 0.05$.

Construct validity and scale model fit were examined with Confirmatory Factor Analysis (CFA). In the evaluation of model fit with the findings obtained from CFA, χ^2/df (ratio of Chi-square statistics to degrees of freedom), RMSEA (Root Mean Square Error of Approximation), GFI (Goodness of Fit Index), AGFI (Adjusted Goodness of Fit Index; fit indices based on residuals), NFI (Normed Fit Index; fit indices based on independent models), CFI (Comparative Fit Index) values, which are widely used in the literature, were taken into consideration (Çokluk, Şekercioğlu & Büyüköztürk, 2010).

The reliability of MS-RSS was examined with Cronbach Alpha. A Cronbach Alpha coefficient above 0.80 indicates that the scale has a very good level of reliability (Chan & Idris, 2017).

2.4.1. Validity Study

Validity in research refers to how accurately a study answers the study question or the strength of the study results and the accuracy of the measurement. Validity here reveals how well the assessment instrument actually measures the underlying outcome of interest. Determining validity can be viewed as creating an evidence-based argument about what and how well an instrument measures (Sullivan, 2011).

2.4.1.1. Construct Validity

Factor analysis is an approach to assessing construct validity. Factor analysis is a procedure that provides the researcher with information about the extent to which a set of items measure the same underlying concept (variable) of a construct. Factor analysis assesses the degree to which individual items in a scale actually cluster around one or more concepts. Items designed to measure the same concept should load on the same factor (LoBiondo-Wood & Haber, 2017).

2.4.1.1.1. Confirmatory Factor Analysis (CFA)

In this study, confirmatory factor analysis (CFA) was used to understand whether the structure in the scale is compatible with the target culture and language. CFA is used to evaluate the psychometric properties of existing measures and to examine method effects (Harrington, 2009). CFA is generally used as a deductive approach to test whether some previously formulated theoretical models adequately explain the covariances between observed variables (Lance & Vandenberg, 2002).

3. Results

3.1. Socio-Demographic Characteristics

Of the 416 MS patients aged 18 and over who participated in the study, 73.6% were female, 26.4% were male, and the mean age was 39.66 ± 10.04 (Min: 18 – Max: 71 years). 67.3% of the participants were married, 53.8% were college/university graduates, and 48.3% were employed in an income-generating job. While 33.2% of the 416 MS patients who participated in the study did not know the stage of their MS disease, 48.3% reported that they had Relapsing–remitting MS, 9.1% had Primary Progressive MS (PPMS), 6.5% had Secondary Progressive MS (SPMS) and 2.9% had Progressive-Relapsing MS (PRMS) (Table 2).

3.2. Confirmatory Factor Analysis (CFA)

Before starting CFA, the basic assumptions were checked. In this context, the data set was examined in terms of sample size, missing and extreme values, normality, linearity and singularity, and it was seen that there was no obstacle to performing CFA. Before performing CFA to ensure the construct validity of the scale, Kaiser Meyer Olkin (KMO) Test and Bartlett's Test were performed for sample adequacy. Accordingly, it was found that the KMO value was 0.879; the Bartlett value was 1379.48 ($p = 0.000$). These findings show that the sample size is suitable for CFA (Cerny & Kaiser, 1977; Kaiser, 1974; Tabachnick & Fidell, 2015).

When examining the model fit indices, it was seen that the NFI (0.84) value was below the acceptable fit limits and therefore covariance was created between the items e7 and e8, e8 and e9, e7 and e9 with the highest MI values in the change indices and when the NFI (0.964) value was re-examined after the modification, it was seen that the value was at a good fit level. The Path Diagram resulting from the CFA is shown in Figure 1. In addition, the standardized

regression coefficients (std. β) are between 0.351 and 0.751 and are significant ($p < 0.001$), indicating that the model is statistically significant. (Figure 1) The fit index values of the model resulting from CFA and standard fit criteria are given in Table 3.

As a result of CFA, the fit indices of the model were evaluated and it was seen that the Chi-square fit test value ($\chi^2/df = 2.369$) and the RMSEA (0.066) and AGFI (0.948) fit index values were in the "acceptable" range; and the GFI (0.972), CFI (0.976) and NFI (0.959) fit index values were in the "good fit" range. Based on this, it can be said that the fit criteria of the measurement tool were in the standard value range and the measurement tool had a single-factor structure.

3.3. Reliability Study

In this study, internal consistency (Cronbach's Alpha) reliability analyses were conducted within the scope of MS-RSS reliability analysis. Cronbach's Alpha internal consistency coefficient was calculated to determine whether the items in the scale measured the determined conceptual structure consistently with each other, and the Cronbach's Alpha value was found to be 0.844.

As stated by Nunnally and Bernstein (1994) and Hair et al. (2010), the value that should be sufficient for the scale to be reliable is 0.70 and above. Based on this, it can be said that MS-RSS, whose Cronbach's Alpha coefficient was found to be 0.844, is a highly reliable scale. The very high level of Cronbach's Alpha coefficient calculated within the scope of internal consistency reliability of the measurement tool indicates both the reliability of the measurement tool and its construct validity (Baykul, 1979). Cronbach's Alpha coefficient shows the homogeneity of the measurement tool; as it approaches 1, it shows that the measurement tool has a one-dimensional structure. The correlation coefficient of each item in the scale is given in Table 3.

Pearson Product Moment Correlation was used to calculate the item-total correlation. When the item-total score correlations of the scale consisting of 9 items were evaluated, it was found that the correlations of the items varied between 0.334 and 0.742. (Table 4)

4. Discussion

Individuals diagnosed with MS experience changes in their lives due to their medical conditions, including

stigmatization experiences. When the Turkish literature is examined, it is noteworthy that although there are scales measuring stigma in chronic diseases, there is no specific scale specific to MS disease. At the same time, it is seen that the studies addressing the stigma experienced by MS patients in the Turkish literature are limited (Çakır & Yurtsever, 2020; Koçhan, 2022). In this context, it is thought that addressing the issue of stigma, which greatly affects the lives of MS patients but has not been sufficiently addressed, will make significant contributions to the literature. In this context, the aim of the study is to adapt the short and reliable MS-RSS scale to Turkish and to conduct a validity and reliability study. Confirmatory Factor Analysis (CFA) was conducted to examine the construct validity of the scale. Internal consistency coefficient (Cronbach's Alpha) and item-total correlations were examined to calculate the reliability of the scale. The findings obtained after this study suggest that the MS-RSÖ can be used as an effective tool in the assessment of stigma perception among MS patients.

The fit indices of the model obtained as a result of the CFA were examined and it was found that the MS-RSS χ^2/df value was below 3 and the RMSEA value was below 0.08. In addition, it was found that the Minimum Chi-square value was statistically significant and the other fit index values were within the desired range. The factor loading value in CFA is the Standardized Regression Coefficient. In this study, the Standardized Regression Coefficients (std. β) were found between 0.351 and 0.751 and above 0.30 were positive and significant. According to Harrington (2009), it is desired for the factor loadings not to be below 0.30; 0.71 and above is transferred as excellent, 0.63 as very good, 0.55 as good, 0.45 as good/acceptable. When all criteria are taken into consideration, the findings obtained from CFA show that the MS-RSS has sufficient structural validity and model fit.

A very high level of Cronbach's Alpha coefficient calculated within the scope of internal consistency reliability of the measurement tool indicates both the reliability of the measurement tool and its construct validity (Baykul, 1979). As stated by Nunnally and Bernstein (1994) and Hair et al. (2010), the value that should be sufficient for the scale to be reliable is 0.70 and above.

In this study, MS-RSS reliability was evaluated with Cronbach's Alpha internal consistency coefficient. The Cronbach's Alpha internal consistency coefficient value of the MS-RSS scale was found to be 0.844. According to this finding, it can be said that MS-RSS is a reliable scale (Chan & Idris. 2017).

As the statistics of MS-RSS items, the item-total correlation, which expresses the relationship between the score obtained from each item and the total score, was calculated (Büyüköztürk, 2018). An item-total correlation of 0.30 and higher means that the scale representation power of those items is sufficient (Akbulut, 2010; Büyüköztürk, 2018; Field, 2009; Nunnally & Bernstein, 1994). In addition, r values between 0.35-0.65 indicate a moderate level of relationship, values between 0.65-0.85 indicate a sufficient level of relationship, and values above 0.85 indicate a high level of relationship (Cohen, Manion & Morrison, 2007). When the item total score correlations of the scale consisting of 9 items were evaluated, it was found that the correlations of the items varied between 0.334 and 0.742. According to this finding, when it is considered that the scale items with a value of 0.30 and above in the interpretation of the item total correlation are considered sufficient in terms of representing the feature they are expected to measure, it can be said that the scale items are highly discriminatory.

These results indicate that the scale is sufficiently reliable.

5. Conclusion

Considering that MS is a biopsychosocial disease, it is seen that interventions should be made in a way that includes a holistic perspective from a biopsychosocial perspective. Stigma seriously affects the lives of individuals with MS from a social perspective. It is known that MS patients are exposed to stigma in their work, private and social lives, and as a result, they experience anxiety in participating in social life or isolate themselves from society and disrupt the treatment process. MS-RSS is a 9-item, short, valid and reliable measurement tool and can be easily applied to patients in Turkey due to its validity and reliability in Turkish. Health professionals such as physicians, physiotherapists, psychologists and social workers who care for MS patients will be able to plan micro-mezzo and macro treatment and support approaches for biopsychosocial problems that they hide due to stigma by evaluating their patients with MS-RSS.

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Authorship contribution statement

ŞK: Contributed to original idea, methodology, data collection, writing. HSI: Contributed to data analysis, methodology, writing. TA: Contributed to methodology, data collection. DNÖ: Contributed to idea development, methodology, study design, analysis, writing, management.

Declaration of interest Statement

The authors declare that they have no conflict of interest in this article.

Ethics Committee Approval

Before the research, ethics committee approval was obtained from the Istanbul University-Cerrahpaşa Social and Human Sciences Research Ethics Committee with the decision numbered 2024/18 and dated 02.01.2024. Finally, after the necessary information about the research was provided, individuals who accepted to participate in the research on a voluntary basis were asked to proceed by selecting the "Yes" option in the statement "I have been informed about the research. I agree to participate in the study voluntarily."

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Appendices

Table 1. Multiple Sclerosis-Reece Stigma Scale (MS-RSS)

	1- Never	2- Rarely	3- Sometimes	4- Often	5- Always
1. I feel like having MS is a punishment for things I've done in the past.					
2. I feel like people are avoiding me because of MS.					
3. I'm afraid I'll lose my friends if they find out I have MS.					
4. I feel like people I know treat me differently because of MS.					
5. I feel like people look down on me because I have MS.					
6. I avoid dating because most people don't want to be in a relationship with someone who has MS.					
7. I avoid certain environments because I'm worried people will know I have MS.					
8. I am ashamed of having MS.					
9. I feel it is important to keep the fact that I have MS a secret.					

Scoring Instructions The scale consists of a total of 9 items and is one-dimensional. There are no reverse-scored items. The total score that can be obtained from the scale varies between 9 and 45, with higher scores indicating greater stigma/perception of MS.

Table 2. Disease level and socio-demographic characteristics of MS patients

Variables	Categories	n	%	Variables	Categories	n	%
Gender	Female	306	73.6	Educational Status	Literate	3	0.7
	Male	110	26.4		Primary school graduate	13	3.1
Marital status	Married	280	67.3		Secondary school graduate	26	6.3
	Single	101	24.3		High school graduate	110	26.4
	Divorced/Widow	35	8.4		College/University graduate	224	53.8
	Unknown	138	33.2	Working Status	Postgraduate degree	40	9.6
MS levels	Relapsing–remitting MS	201	48.3		Yes working	201	48.3
	Primary progressive MS (PPMS)	38	9.1		No working	152	36.5
	Secondary progressive MS (SPMS)	27	6.5		Retired	63	15.1
	Progressive-relapsing MS (PRMS)	12	2.9				

Table 3. Statistics of MS-RSS Items

	Item Score Average	Item standard deviation	Item Total Correlation	Cronbach's Alpha if Item is Deleted
M1	1.72	1.09	0.334	0.842
M2	1.47	0.81	0.605	0.826
M3	1.25	0.70	0.527	0.834
M4	2.06	1.13	0.585	0.825
M5	1.54	0.92	0.637	0.822
M6	1.83	1.35	0.576	0.829
M7	1.70	1.13	0.742	0.807
M8	1.44	0.90	0.557	0.829
M9	1.75	1.21	0.589	0.826