Article
The Loneliness of Migraine Scale: A Development and Validation Study

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Abstract: Patients with migraine often isolate themselves during their attacks. This disease-related loneliness seems to reverberate interictal, as some patients report failing relationships, losing jobs, or suffering from reduced social contacts. We developed a 10-item self-report questionnaire, the loneliness of migraine scale (LMS), and conducted an online survey. The questionnaire comprised diagnostic questions for migraine, the loneliness of migraine scale, the Generalized Anxiety Disorder Scale (GAD-7), the Patient Health Questionnaire (PHQ-8), and the Headache Attributed Lost Time Index (HALT-90). We computed item statistics, the psychometric properties of the LMS and assessed correlations between loneliness, migraine days, anxiety, and depression. We included 223 participants with (probable) migraine, reporting 8 ± 6 headache days with a disease duration of 11 ± 11 years. The mean scores of the HALT were 88 ± 52, of the GAD-7 10 ± 5, for PHQ-8 11 ± 6, and of the LMS 28.79 ± 9.72. Cronbach’s alpha for all ten items was 0.929. The loneliness scale correlated with the GAD-7 (r = 0.713, p < 0.001), with the PHQ-8 scale (r = 0.777, p < 0.001) and with migraine days (r = 0.338, p < 0.001). The LMS is a reliable and valid questionnaire measuring the loneliness of migraine patients. Feelings of loneliness were common and correlated highly with migraine days, anxiety, and depression.

Keywords: migraine; interictal burden; disease-related loneliness

1. Introduction
As pain levels rise, many migraine patients retire to the solitude of their bedrooms [1]. Social withdrawal is an inherent part of the disease and takes its toll. Often, social activities are missed; obligations cannot be met; friends, partners, and children feel rejected [2]. Unfortunately, the consequences of being unable to contact others reverberate in the interictal phase; some patients report failed relationships, lost jobs, or reduced social contacts [2].

The undesired absence of other people can lead to loneliness, i.e., a feeling of lacking social support and being alone despite oneself. It differs from isolation, in which the absence of others is not associated with a sense of deprivation [3]. Loneliness is linked to higher cortisol levels [4,5] and fragmented sleep; [6] it is associated with an increased risk of depression [7] and death [8–10].

Loneliness has many facets. Being lonely can have very different meanings to people, and the feeling of loneliness can occur in various situations. To structure those many meanings of the construct loneliness, we defined categories of loneliness in line with earlier approaches [11,12].

Loneliness can be defined as a discrepancy between desired and actual social contacts [3]. Broadening the sense of the term, we distinguish four additional dimensions of loneliness, depending on whether it is literal or figurative, sought actively, or forced upon a person (see Table 1). We understand “literal loneliness” as due to the absence of...
other people; “figurative loneliness”, on the other hand, refers to a feeling or expectation of lacking social support and being on one’s own. We assumed these four dimensions to be relevant for migraine. On the one hand, patients generally actively isolate themselves during a migraine attack. On the other hand, passive loneliness can occur between the episodes, and might result from avoidance behavior and anxiety. Further, literally being lonely and feeling lonely stem from very different emotional states. Feeling lonely reflects more the lack of social support and feeling understood, whereas being lonely might be linked to chronic social isolation. It seems possible for one dimension of loneliness to transition into or favor another.

Table 1. Different manifestations of loneliness.

| “Literal” Loneliness | “Figurative” Loneliness |
|----------------------|------------------------|
| “Active” Loneliness  | Active and literal loneliness implies “self-imposed social withdrawal”. With active and figurative loneliness, patients avoid talking about their problems and attempt to keep them secret. This approach is called “self-concealment” [11]. |
| “Passive” Loneliness | Passive and literal loneliness refers to experienced rejection and stigmatization (enacted stigma and social pain). In passive and figurative loneliness, patients expect to be discriminated against and rejected. |

Previous studies evaluated the concept of loneliness in general [11,12] and loneliness related to health conditions such as cancer [13] or being part of a minority [14]. However, to our knowledge, no scale investigates disease-related loneliness in migraine patients. What discriminates migraines from other diseases such as cancer is that the discrepancy between the actual time of symptoms in a narrow sense (headache) is limited, but the time of disease burden is not. Whereas cancer patients might have symptoms most of the time, one can anticipate a more or less constant disease burden. As migraineurs are “healthy” and able to work in the interictal phases, they are not freed of their duties in daily life. The interictal burden migraineurs carry leads to restrictions in social life in a very different context than other diseases, making a particular loneliness scale necessary.

As previous studies showed that the ictal burden is only one aspect of the disease burden—albeit an important one—we assume loneliness might be a crucial factor driving the interictal burden. Moreover, loneliness is likely underreported, possibly because it grows slowly over time and might remain unnoticed by patients, their surroundings, and treating physicians over long periods. Perhaps, shame might also prevent patients from naming such feelings. This study aims to develop and validate a brief scale measuring disease-related loneliness of migraine patients.

2. Materials and Methods

2.1. Drafting the Questionnaire

We drafted the items of the loneliness of migraine scale based on clinical experience and the current literature on migraine and psychological illness-related burden; the aim was to assess each type of loneliness (see Table 1) with two items. Then, in a second step, a team of five clinicians (MSN, EE, ARG, MS, HP) with expertise in the treatment of headache discussed each item and changed the content and format wherever necessary.

The scale consists of ten items (see Supplementary Materials Table S1). Participants indicate their accordance with each of them on 5-point-Likert scales (ranging from 1 to 5). Thus, one can reach a total score of at least ten and a maximum of 50 points, with higher ratings indicating higher degrees of loneliness. All questions were written in German; see Supplementary Materials Table S1 for the original items. Note that we have changed the order of the items in the manuscript to match the various types of loneliness.
2.2. Study Design

Next, we conducted a validation study, which was purely observational, exploratory, anonymous, and cross-sectional. Participants answered the items of the loneliness of migraine scale. Moreover, we asked for demographic data (sex and age) and assessed the severity of the migraine (number of monthly attacks, disease duration, and the Headache Attributed Lost Time Index (HALT). Finally, participants also completed the Generalized Anxiety Disorder Scale (GAD-7) and Patient Health Questionnaire (PHQ-8) to evaluate construct validity. Because no existing scale measures loneliness in migraineurs, we examined construct validity using the GAD-7 and PHQ-8, as anxiety, depression, and loneliness are related [15].

The GAD-7 is a self-report scale that assesses the presence and severity of an anxiety disorder. It consists of seven items; answers are given on a 4-point-Likert scale (0 to 3), with higher scores implying more anxiety symptoms. The thresholds indicating a general anxiety disorder were $\geq 10$ (with a sensitivity of 0.89 and specificity of 0.82) and $\geq 8$ (with a sensitivity of 0.77 and specificity of 0.82) [16,17].

The PHQ-8 is an 8-item self-report questionnaire assessing the presence of depressive symptoms. Accordance with eight statements is indicated on 4-point-Likert scales (0 to 3), with higher scores indicating more depressive symptoms. A sum score $\geq 10$ indicates the presence of depressive symptoms [18].

The HALT-90-Index measures the time lost due to headaches during the last 90 days [19].

2.3. Participants

We invited potential participants through mailing lists and advertisements. Moreover, we commissioned SurveyMonkey Audience to motivate their clients to complete the questionnaire. The available data determined the sample size.

We included patients aged between 16 and 50 years with a diagnosis of migraine or probable migraine according to the International Classification of Headache Disorders, and sufficient knowledge of German to be able to read and understand the instructions and the questionnaire. The exclusion criteria were inability and unwillingness to participate in the study. Patients were enrolled from May 2021 to September 2021 and filled in the online self-completion questionnaire.

Ethics Statement

All participants provided informed consent prior to completing the questionnaire. As we collected the data anonymously, no formal ethical approval was necessary according to Swiss legislation. Accordingly, the ethics committee Zurich granted a waiver (REQ-2021-00607).

2.4. Psychometric Properties

Analyzing psychometric properties, we first calculated item difficulty, which refers to the amount of “experienced symptoms” by patients and reflects the “difficulty” to accord with the item. Low values indicate great difficulty, and high values low difficulty of the items [20]. Then, we assessed item discrimination, which reports the correlation of the value of a single item with the total score of the remaining items; higher values suggest that the item measures the same concept as the other items [20]. Finally, we calculated item variance, which equals the average squared deviation from the means and assesses whether all participants provided similar answers [20].

Then, we assessed the validity of the scale, which is defined as the capacity to measure what it is intended to measure. To that end, we first performed an exploratory factor analysis that assessed whether all items did indeed refer to one single underlying construct. The number of factors was determined using a parallel analysis. We discarded items that did not refer to that construct. In addition, we calculated the Kaiser–Meyer–Olkin-coefficient to ensure that correlations between the items exist at all. Furthermore, we performed Bartlett’s test of sphericity to ensure that the correlation matrix differs significantly from
the identity matrix [21]. Next, we assessed the reliability of the remaining items calculating Cronbach’s α.

To our knowledge, no other scale investigates the disease-related loneliness of migraine. However, since loneliness can be a symptom of anxiety [22] and depression [15,23,24], we evaluated construct validity by comparing the results of the included items with the PHQ-8 and GAD-7 questionnaires.

2.5. Further Statistical Analysis

We report categorical variables as proportions (%) and continuous variables as means and standard deviations (SDs). Spearman’s rho allowed the correlation between ordinate variables to be assessed. The effect size r for Spearman’s rho is interpreted as large when r = 0.5, medium when r = 0.3, and small when r = 0.1. We set the significance level at 0.05 and used SPSS 27.0.1.0 (IBM, USA) for the analyses. For each item, we indicate the number of participants that did not provide an answer as n.r. (not reported).

3. Results

3.1. Demographic Results

A total of 401 participants completed the questionnaire. Of them, 223 met the inclusion criteria, 84 were diagnosed with migraine, and 101 with probable migraine according to the validated diagnostic algorithm [25]. We were unable to validate the migraine diagnosis in the remaining 38 participants and excluded them accordingly. Moreover, we identified no participant who had deliberately given false answers that would have warranted their exclusion.

In the following, participants with migraine and probable migraine are combined; see Table 2 for their demographic and psychometric data.

Table 2. Demographic data, clinical characteristics, and scores.

| Participants | All (N = 185) | Women (N = 91) | Men (N = 94) |
|-------------|---------------|---------------|--------------|
| Age (years) Mean [SD] | 34 [8] | 33 [9] | 35 [7] |
| Monthly migraine days Mean [SD] | 8 [6] | 7 [5] | 9 [6] |
| Disease duration (years) Mean [SD] | 11 [11] | 12 [13] | 9 [8] |
| HALT Mean score [SD] | 88 [65] | 85 [64] | 91 [67] |
| GAD-7 Mean score [SD] | 10 [5] | 10 [5] | 10 [5] |
| GAD-7 ≥ 10 n (%) | 91 (49.2) | 43 (47.3) | 48 (51.1) |
| PHQ-8 Mean score [SD] | 11 [6] | 11 [6] | 11 [5] |
| PHQ-8 ≥ 10 n (%) | 104 (56.2) | 45 (49.5) | 59 (62.8) |

The table contains the demographic profile of the participants, including age in years, migraine frequency, disease duration, scores of HALT (Headache Attributed Lost Time Index), GAD-7 (Generalized Anxiety Disorder Scale), and PHQ-8 (Patient Health Questionnaire). N (number of participants), [SD] (standard deviation). N.r. not reported.

3.2. Quantitative and Qualitative Analysis

All participants answered all items of the loneliness of migraine scale; Table 3 lists the detailed item statistics. The corrected item-total correlation revealed high correlations between all items. All items loaded highly on one factor and confirmed that all items could be related to one underlying construct. According to the difficulty rating, all items were moderately difficult to easy to answer. The item variance ranged from 1.2 to 1.7 for all items.
Table 3. Exploratory factor analysis.

| Items                                                                 | Migraine and Probable Migraine N = 185 | Corrected Item-Total Correlation | Factor Loading | Difficulty Rating | Item Variance | Missing Values |
|-----------------------------------------------------------------------|----------------------------------------|----------------------------------|----------------|-------------------|---------------|---------------|
| **Mean**                                                              | **SD**                                  |                                  |                |                   |               |               |
| **Active and Literal Loneliness**                                     |                                        |                                  |                |                   |               |               |
| 1. “I do not arrange meetings with other people (family, friends) because they would be annoyed with me if I had to cancel because of a migraine attack.” | 2.64                                   | 1.30                             | 0.75           | 0.81              | 54.7          | 1.7           | 0             |
| 2. “I do not arrange meetings with other people (family, friends) because I would be annoyed with myself if I had to cancel because of a migraine attack.” | 2.74                                   | 1.32                             | 0.80           | 0.85              | 58.0          | 1.7           | 0             |
| **Active and “figurative” loneliness**                                |                                        |                                  |                |                   |               |               |
| 3. “It is better for me if only a few people know about my migraine.” | 2.94                                   | 1.12                             | 0.61           | 0.68              | 64.7          | 1.4           | 0             |
| 4. “If I have not been able to accomplish all given tasks because of a migraine attack, I will not admit it, but I make up another reason for it.” | 2.81                                   | 1.22                             | 0.68           | 0.74              | 60.3          | 1.5           | 0             |
| **Passive and literal loneliness**                                    |                                        |                                  |                |                   |               |               |
| 5. “I have had the painful experience that others (family members and friends) do not understand my migraines.” | 3.08                                   | 1.21                             | 0.68           | 0.75              | 69.3          | 1.5           | 0             |
| 6. “I have experienced severe rejection because of my migraine.”     | 2.79                                   | 1.28                             | 0.80           | 0.85              | 59.7          | 1.7           | 0             |
| **Passive and “figurative “loneliness**                               |                                        |                                  |                |                   |               |               |
| 7. “As a migraine sufferer, one has to act cautiously to avoid being stigmatized.” | 3.22                                   | 1.10                             | 0.60           | 0.66              | 40.7          | 1.2           | 0             |
| 8. “Others have negative attitudes towards me because of my migraine.” | 2.82                                   | 1.30                             | 0.72           | 0.78              | 60.7          | 1.6           | 0             |
| **Loneliness in the narrow sense**                                     |                                        |                                  |                |                   |               |               |
| 9. “Because of my migraine, I have fewer social contacts than I would like.” | 2.90                                   | 1.30                             | 0.79           | 0.84              | 63.3          | 1.7           | 0             |
| 10. “I feel isolated because of my migraine.”                         | 2.86                                   | 1.27                             | 0.78           | 0.83              | 62.0          | 1.6           | 0             |
| **Sum-score**                                                         | **28.79**                               | **9.72**                         |                |                   |               |               |

The table reports the exploratory factor analysis results, including mean scores with standard deviations (SD) of each item, the corrected item-total loading, factor loading, difficulty rating, item variance, and discriminatory power; no item had to be eliminated.

We performed an exploratory factor analysis to test the dimensionality of the construct. A Kaiser–Meyer–Olkin measure of 0.932 was reached; Bartlett’s test of sphericity suggested that the correlation matrix (see Table 4) differed significantly from the identity.
The rows list all items with numbers, and the columns contain the numbers of the items. The Screeplot confirmed one underlying factor (see Figure 1); the model explained 56.874% of the observed variance.

Table 4. Inter-item-correlation.

|   | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. |
|---|----|----|----|----|----|----|----|----|----|-----|
| 1. “I do not arrange meetings with other people (family, friends) because they would be annoyed with me if I had to cancel because of a migraine attack.” | 1.00 | 0.74 | 0.45 | 0.53 | 0.47 | 0.64 | 0.59 | 0.53 | 0.63 | 0.63 |
| 2. “I do not arrange meetings with other people (family, friends) because I would be annoyed with myself if I had to cancel because of a migraine attack.” | 0.74 | 1.00 | 0.51 | 0.60 | 0.54 | 0.63 | 0.48 | 0.64 | 0.68 | 0.69 |
| 3. “It is better for me if only a few people know about my migraine.” | 0.45 | 0.51 | 1.00 | 0.55 | 0.43 | 0.58 | 0.41 | 0.51 | 0.57 | 0.60 |
| 4. “If I have not been able to accomplish all given tasks because of a migraine attack, I will not admit it, but I make up another reason for it.” | 0.53 | 0.60 | 0.55 | 1.00 | 0.56 | 0.56 | 0.44 | 0.53 | 0.54 | 0.58 |
| 5. “I have had the painful experience that others (family members and friends) do not understand my migraines.” | 0.47 | 0.54 | 0.43 | 0.56 | 1.00 | 0.66 | 0.52 | 0.63 | 0.56 | 0.60 |
| 6. “I have experienced severe rejection because of my migraines.” | 0.64 | 0.63 | 0.58 | 0.56 | 0.66 | 1.00 | 0.54 | 0.69 | 0.67 | 0.69 |
| 7. “As a migraine sufferer, one has to act cautiously to avoid being stigmatized.” | 0.59 | 0.48 | 0.41 | 0.44 | 0.52 | 0.54 | 1.00 | 0.50 | 0.59 | 0.57 |
| 8. “Others have negative attitudes towards me because of my migraine.” | 0.53 | 0.64 | 0.51 | 0.53 | 0.63 | 0.69 | 0.50 | 1.00 | 0.64 | 0.63 |
| 9. “Because of my migraine, I have fewer social contacts than I would like.” | 0.63 | 0.68 | 0.57 | 0.54 | 0.56 | 0.67 | 0.59 | 0.64 | 1.00 | 0.70 |
| 10. “I feel isolated because of my migraine.” | 0.63 | 0.69 | 0.60 | 0.58 | 0.60 | 0.69 | 0.57 | 0.63 | 0.70 | 1.00 |

Figure 1. Screeplot. Figure 1 shows the scree plot, which confirms one underlying factor. Cronbach’s alpha for all ten items was 0.929.
Lastly, we assessed construct validity examining the relationship between "loneliness", GAD-7, and PHQ-8. The loneliness of migraine scale correlated significantly with the GAD-7 ($r = 0.713$, $p < 0.001$) as well as with the PHQ-8 scale ($r = 0.777$, $p < 0.001$). The scores of the loneliness of migraine scale correlated positively with the number of migraine days ($r = 0.338$, $p < 0.001$).

4. Discussion

In this study, we developed and validated the loneliness of migraine scale. Our major findings are as follows. First, our study shows that the scale is a reliable and valid self-report questionnaire measuring loneliness in migraine patients. Second, feelings of loneliness were common in our sample. Third, disease-related loneliness highly correlates with symptoms of depression and anxiety. Fourth, the different manifestations of loneliness assessed by the scale all refer to one underlying factor. Lastly, there is a medium correlation between the ictal burden and the extent of disease-related loneliness.

Our analysis confirmed excellent reliability and construct validity. Moreover, the item analysis did not lead to the elimination of any item.

The exploratory factor analysis showed that the scale has one underlying factor and thereby corroborated the hypothesis that loneliness is due not only to the discrepancy between desired and actual social contacts (see Table 2). Consequently, loneliness is not limited to the absence of other people but also comprises the feeling of being left alone.

While our scale detects different types of loneliness, it does not provide a distinction between them. One reason for that might be that our items might not discriminate sufficiently well between the different dimensions of loneliness. Another reason might be that suffering from loneliness is a more unified concept in migraineurs than we expected.

To our knowledge, no other questionnaire measures loneliness in headache disorders, so we could not compare different scales and thereby assess convergent validity. However, we did assess the correlation of our scale with other scales measuring symptoms of anxiety and depression because loneliness can be a painful symptom of anxiety and depression and even play a vital role in the development or maintenance of its psychopathology [15,22–24]. Furthermore, anxiety and depression are highly comorbid in migraine patients [26].

Anxiety correlated highly with the loneliness scale, and the correlation was even stronger for depressive symptoms. Thus, taken together, the loneliness of migraine scale has sufficient construct validity.

Our participants had, on average, eight headache days per month. Almost half of them reached the threshold for generalized anxiety disorder, according to the GAD-7 [16,17]. The co-occurrence of anxiety and headache disorders is well known and often underappreciated and undertreated [27]. Vice versa, loneliness is associated with anxiety disorders [28–30].

According to the PHQ-8 scores, more than half of our participants suffer from depression. Similar to anxiety, the relationships between depression and loneliness, [28] and depression and migraine [31] have not been studied before. Our results for headache days and depressive and anxiety symptoms are in line with previous migraine studies [31,32].

Chronic illness and chronic pain are related to anxiety and depression [33,34]. In the case of migraine, most patients do not experience symptoms of the disease itself between attacks but of psychiatric comorbidities. Nevertheless, an impending migraine attack or the fearful expectation of one could maintain anxiety, depression, and avoidance behavior and potentially result in feelings of loneliness. Thus, loneliness may contribute relevantly to the risk of depression and anxiety in migraine, and loneliness might furthermore be an indicator of anxiety and depression.

The correlations between anxiety and loneliness ($r = 0.713$, $p < 0.001$) and depression and loneliness ($r = 0.777$, $p < 0.001$) are much stronger than between loneliness and migraine days ($r = 0.338$, $p < 0.001$). Thus, it seems likely that patients’ expectations and attitudes towards their migraine attacks lead to loneliness rather than the actual loss of time caused by migraine attacks. Furthermore, anxiety and depression may affect these expectations by influencing the perception of the disorder and its consequences. Consequently, our
findings confirm the impact of psychiatric comorbidities on loneliness as a driving factor of interictal disease burden.

Finally, because of the high correlation between anxiety and loneliness and depression and loneliness, the loneliness of migraine scale may be a suitable screening tool for psychiatric comorbidities.

5. Limitations and Strengths

Some limitations must be mentioned. First, as our study included slightly more men than women, and more women than men are affected by migraine in the general population, our sample might not be representative. Second, the number of participants was limited. Thus, further studies are required to confirm the psychometric properties of the loneliness of migraine scale. Third, the data were collected in a convenience sample and consequently do not allow testing for external validity. Fourth, as all items fitted the model, we did not have to discard any of them; however, if we had tested more items, we might have selected better items. Fifth, we did not examine disease-related loneliness longitudinally. Further studies should focus on the development of loneliness in migraine and changes over time. Sixth, given the high correlation between the scores of the depression and anxiety scales and the score of the loneliness of migraine scale, and because we did not perform discriminant validity analysis, we cannot exclude that our understanding of loneliness significantly overlaps with anxiety and depression. We established discriminant validity only with anxiety and depression scales but not, however, with other loneliness scales.

Our study has several strengths. First, the loneliness of migraine scale is, to our knowledge, the first scale to measure the loneliness of migraine patients. Second, the scale is easy to administer, as it is a relatively short self-test and has good psychometric properties.

6. Conclusions

In this study, we developed and validated the loneliness of migraine scale and found that loneliness is a common symptom in migraine patients. With the help of the scale, it is possible to measure disease-related loneliness. To our knowledge, no tool existed before to assess loneliness in migraine patients. Being aware of loneliness can help understand disease burden holistically and optimize treatment methods. Furthermore, the analysis of the collected data revealed a strong correlation between depressive symptoms and anxiety. We therefore emphasize the importance of being aware of social factors associated with disease and psychiatric comorbidities of migraine. Because of the marked correlation between anxiety, depression, and loneliness, we propose using the loneliness of migraine scale as a screening tool for comorbid anxiety and depression. We strongly recommend screening patients for and addressing loneliness in daily clinical practice. Discussing loneliness might ease the burden of disease and minimize stigmatization. Furthermore, we suggest doing follow-up measurements to comprehensively observe the disease burden in the long term. We suggest validating the questionnaire in other languages. Future studies are necessary to understand the impact of loneliness on treatment-related factors as adherence to pharmaceutical and non-drug treatment.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/ctn6020012/s1, Supplementary Table S1: Contains all original and translated items.

Author Contributions: M.S.N. performed the analysis, interpreted the data, and wrote the manuscript. E.E. helped initiate the study and revised the final manuscript. A.R.G. helped initiate the study, provided important intellectual content, and revised the final manuscript. M.S. helped initiate the study and revised the final manuscript. H.P. conceptualized and supervised the study, co-interpreted the data, and revised the final manuscript. All authors have read and agreed to the published version of the manuscript.

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Abbreviations

LMS Loneliness of migraine scale
GAD-7 Generalized Anxiety Disorder Scale
PHQ-8 Patient Health Questionnaire
HALT Headache Attributed Lost Time Index
n.r. Not reported

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