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Research Article

EYpA: Cultural Integration and Adaptation of the Honest, Open, Proud Program for Use in People with Multiple Sclerosis in Greece

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Background: MS patients can often experience stigma due to their diagnosis. Stigmatized patients tend to seek isolation, which in turn causes reduced use of healthcare services, negative health outcomes, and poor quality of life. A recent approach to reducing self-stigmatization is to support individuals in their disclosure decisions through empowerment programs.

Objective: This study focuses on the cultural adaptation and piloting of the Honest, Open, Proud (HOP) program into Greek, offering newly diagnosed MS patients an empowerment-based intervention to assist in making disclosure decisions.

Methods: Adaptation followed the established Medical Research Council (MRC) framework for developing and evaluating complex interventions, including theoretical revision, material adaptation, and feasibility testing.

Results: The intervention was delivered online to Greek newly diagnosed patients with MS (n=12). Attendance was very good in every session (>90% attendance by participants).

Conclusion: EYpA was positively received by both participants and facilitators. This culturally sensitive adaptation could address a key gap in Greece's post-diagnostic care for people with MS by empowering them in their disclosure decisions.

Multiple Sclerosis (MS) is the most common demyelinating disease of the Central Nervous System[1] and the most common non-traumatic cause of neurological disability in young adults in the Western world[2]. The disease can occur at any age, but most often its onset is found in young adults aged 20-40 years[3]. In

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Greece, it is estimated that more than 22,000 people are ill, with women constituting 2/3 of patients (65.8% of the total) and the most affected ages belonging to the 25-39 group for both sexes[4].

MS patients face multiple different consequences of MS on their physical and overall health and in many cases often experience negative prejudice, judgment, and exclusion from society due to their illness[5]. Stigmatized patients tend to seek isolation, which in turn causes reduced use of healthcare services, negative health outcomes, and poor quality of life[6][7][8]. The feeling that they "have (or are believed to have) a characteristic that differentiates them and characterizes them as different and leads to devaluation in the eyes of "others" is considered a stigma[9].

Stigma was first defined by Goffman in 1963[10] as "the state of the individual excluded from full social acceptance," with the obvious consequence of social isolation and feelings of rejection. A recent revision defines stigma as "a social process, experienced or expected, characterized by exclusion, rejection, blame, or devaluation resulting from experience, the perception, or reasonable prediction of an adverse social crisis about an individual or group"[11]. People who experience stigma in their social environment, such as those with neurological disease and/or disability, tend to consent to society's devaluation of them, and negative stereotypes become an accepted part of their perception of the disorder/condition they are experiencing. This negative effect ultimately acts as a barrier, according to the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO), reducing their functional performance[12]. Rao et al.[5] categorized the concept of stigma in neurological patients into the following categories: Perceived stigma (characterized by the awareness of a discriminatory stereotype in the patient's social environment), practical/social stigma (referring to the actual experience of a discriminatory behavior towards the individual)[13], and self-stigmatization (the internalization and acceptance of the negative stereotype, which leads the person to shame and low self-esteem).

It has been shown that the experience of discrimination and social withdrawal due to stigma can strongly affect patients' self-confidence and self-efficacy. Patients who experience stigma are prone to increased psychological distress, such as anxiety and depression[13][14] and exhibit negative health outcomes[15]. Stigma is a powerful stressor in patients' daily lives and is also known to reduce the quality of life in patients with neurological conditions[16]. The few studies that have investigated experiences with stigma in MS patients have confirmed the link between stigma and quality of life. Anagnostouli et al.[17] revealed that both public and self-stigmatization are associated with reduced quality of life in

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people diagnosed with MS Disease. In another study, MS patients reported hiding their diagnosis from their general environment for fear of expected stigma about treatments (e.g., negative experiences and/or concern about prescribed treatment) and expected isolation stigma (feeling socially isolated because of the stigma of the disease)[18]. Although this research was based on a small sample of convenience, it fits in with previous qualitative methodology research, highlighting that social stigma is a primary concern of people living with MS[19]. Very few studies have looked at possible effects of STIGMA on MS[20]. However, in a recent study, people who reported feeling stigmatized because of their disease reported lower overall quality of life, were more likely to suffer productivity losses at work, needed more informal care, and in several cases tried to conceal their illness to avoid being stigmatized[21].

Because of the foregoing, people diagnosed with MS are specifically asked early in the course of the disease to choose whether to disclose their diagnosis to their employer, colleagues, and friends. Hiding can prevent discrimination, but it can also be stressful, resulting in fear of discovery, the need for constant self-monitoring to avoid revealing too much, and a sense of detachment from one's true self. Few studies have addressed this issue in MS, in part because this field lacks a formal, validated measurement tool to assess the impact of disclosure and/or concealment of diagnosis. Recently, in 2022, Kever and Leavitt[22] created the Diagnosis Disclosure and Concealment in MS (MS) questionnaire, a self-reporting tool that assesses (1) the frequency of concealment behaviors and (2) the expected consequences of disclosing the diagnosis of the disease. In their survey, they reported that about 25% of respondents conceal their diagnosis, especially in professional settings. Higher concealment behaviors were associated with younger age, shorter disease duration, and lower physical disability. Nearly 50% of respondents believe that talking openly about the diagnosis can have undesirable professional and interpersonal consequences. Younger age, depression, and higher anxiety were associated with greater expectations of negative consequences.

Because of all this, there is a clear necessity to provide empowerment programs to newly diagnosed MS patients to be able to manage the diagnosis as well as its disclosure in their environment by reducing self-stigmatization. So far, efforts to empower MS patients have revolved around axes of managing the symptoms and effects of the disease, but have ignored factors related to the disclosure of the disease to third parties, as well as eliminating stigma[23].

There are a number of programs to reduce self-stigmatization that are not specific to MS and have not been tested in this population[24][25]. Almost all of these programs were created for patients with mental illness in the light that mental illness, according to Goffman[10], is a "defamatory stigma" for individuals, resulting in many being faced with the dilemma of whether and how to disclose their condition to others, with the usual result of concealment as a basic reaction to stigma. In psychoeducational interventions, such as Ending Self-Stigma developed by Patricia Lucksted and Amy Drapalski[26], for patients with mental illness, participants learn facts that contradict their self-stigmatizing beliefs. However, there is limited evidence for the effectiveness of such approaches. Programs based on cognitive therapies aim to correct self-stigmatization as a distorted self-concept, but their benefit is also unclear[27]. Acceptance-based approaches use the principles of acceptance and commitment therapy and mindfulness to reduce self-stigma and improve self-esteem[28], and narrative programs help participants develop more balanced life stories[29].

Another recent approach to reducing self-stigmatization is to support individuals in their disclosure decisions through empowerment and support programs such as the Honest Open Proud (HOP) program[30]. Corrigan and Lundin aimed to eliminate stigma due to mental illness, and in 2011, they turned the book chapter into a standalone program with two main goals: self-disclosure and elimination of stigma[31]. The program's focus on disclosure decisions is based on models that highlight the role of concealment as part of a hidden stigmatized identity[32][33]. These models point out that the decision by the individual to disclose his/her condition is a key component in successfully dealing with stigma and therefore a mechanism for reducing it, as well as the anxiety that accompanies it, self-stigmatization and its consequences such as depression and reduced well-being or quality of life[34]. Notably, HOP has been successfully adapted for several populations, including people with dementia[35].

Aim of the study

The aim of this study is the translation, cultural integration, and adaptation of the Honest Open Proud (HOP) program[30] to the needs of Greek MS patients so that it becomes a comprehensive empowerment program that can then be used to destigmatize newly diagnosed and non-diagnosed MS patients in Greece and help them make their decisions about disclosing their diagnosis.

Materials and Methods

The HOP program was created by Corrigan and Lundin as a book chapter[30]. Corrigan and Lundin aimed to eliminate stigma due to mental illness, and in 2011, they turned the book chapter into a standalone program with two main goals: self-disclosure and elimination of stigma[31]. The program's focus on the disclosure decision is based on models that highlight the role of concealment as part of a hidden stigmatized identity[32][33]. It is not HOP's goal to push people toward disclosure (although the program's English name has been misunderstood as such). Not disclosing in a stigmatizing environment can be a perfectly reasonable choice. HOP can lead individuals to make either a careful "empowered disclosure" or a non-disclosure that is not determined by self-stigma or shame but is a conscious decision of the individual. The aim of the HOP program is for individuals to acquire skills and strategies so that they can make the best possible decisions for their personal situation[30].

The program is short-term, implemented by experienced coordinators (1-2 people), has a duration of 3 lessons (about 9-10 hours), although current versions include a fourth remedial session about a month after the third lesson, and takes place in groups of 8-15 people as follows:

1. It can be completed as a daily seminar (9-10 hours), and one month later, the three-hour repeat examination is conducted.
2. It can be completed in 4 meetings (2-3 hours each meeting), including the repeat exam one month later. Each session corresponds to each of the three courses of the program and the repeat examination.
3. It can be completed in 9 sessions (1 hour duration each session) corresponding to the exercises of each session. It may include a supplement of three sessions one month after completion of the basic program. Each supplement corresponds to the follow-up examination of the programme.

One or two people coordinate the process. The program is conducted in a private area, manuals are distributed to the coordinators, and copies of the exercise book are distributed to each participant.

The 3 courses of the program cover the following topics:

1. Pros and cons of disclosure.
2. Different ways of disclosure.
3. Telling the personal story.

Repeat session with a combination of all the above and completion of the program.

Although the program was created to destigmatize people with mental illness, the original version has been adapted for different cultural contexts and target groups. Versions have already been created for people with other conditions such as Tourette's syndrome, dementia[35], cystic disorders (incontinence), and psychosis, but also for groups of people such as the military, veterans, university students, high school students, parents of children with mental illness, health professionals with mental illness, caregivers of patients with dementia, and people with suicidality. So far, the program has been used in Australia, Belgium, Germany, Switzerland, the United Kingdom, Canada, Chile, China, and the United States and has been translated into 3 languages (German, Spanish, Chinese)[36]. Following a similar adaptation logic as Bhatt et al.[35], this study sought to culturally adapt HOP for newly diagnosed MS patients in Greece, addressing the unique cultural and diagnostic context.

The adaptation process followed the Medical Research Council (MRC) guidelines for developing and evaluating complex interventions[37][38]. This process unfolded in three phases:

Phase 1 - Identifying Evidence Base and Theory

Existing literature on HOP and stigma reduction was reviewed to establish a theory of change. This was supplemented with findings from studies focusing on disclosure decision-making in MS[39].

Phase 2 - Cultural Adaptation and Material Development

A patient advisory meeting was held with members of the Hellenic Federation of Persons with Multiple Sclerosis (HFoPwMS), where preferences around format, content, and cultural relevance were identified. The adapted program, renamed EYpA (Greek acronym for "Honest, Proud, Open"), retained HOP's core structure (pros/cons of disclosure, methods of disclosure, storytelling) but incorporated Greek-specific terminology and MS-relevant examples.

Phase 3 - Feasibility Testing

The adapted program was piloted with 12 newly diagnosed MS patients recruited through HFoPwMS. Sessions were held online to maximize accessibility. Attendance was tracked, and qualitative feedback was collected from both participants and facilitators.

Recruitment and Eligibility

MS patients all over Greece were invited to participate in the pilot program through their MS Societies, all members of the HFoPwMS. Eligibility criteria were to have been diagnosed not over 2 years and to have not disclosed their diagnosis at least to one special social group (e.g., work environment, neighbourhood, etc.).

Ethics

The Ethics Review Committee at Panteion University approved the study and interviews (approval: 5025) on April 4, 2023. Respondents gave written consent for review and signature before starting interviews (Appendix 1).

A neuro-psychologist (with a specialization in the social psychology of close relationships) and a PhD candidate psychologist co-facilitated group 1. Both facilitators had experience working with people with MS. Each group underwent one intervention session a week (120 minutes) for a three-week period, followed by a 3-hour session one month after.

A schematic overview of the development and feasibility phases is shown in Figure 1.

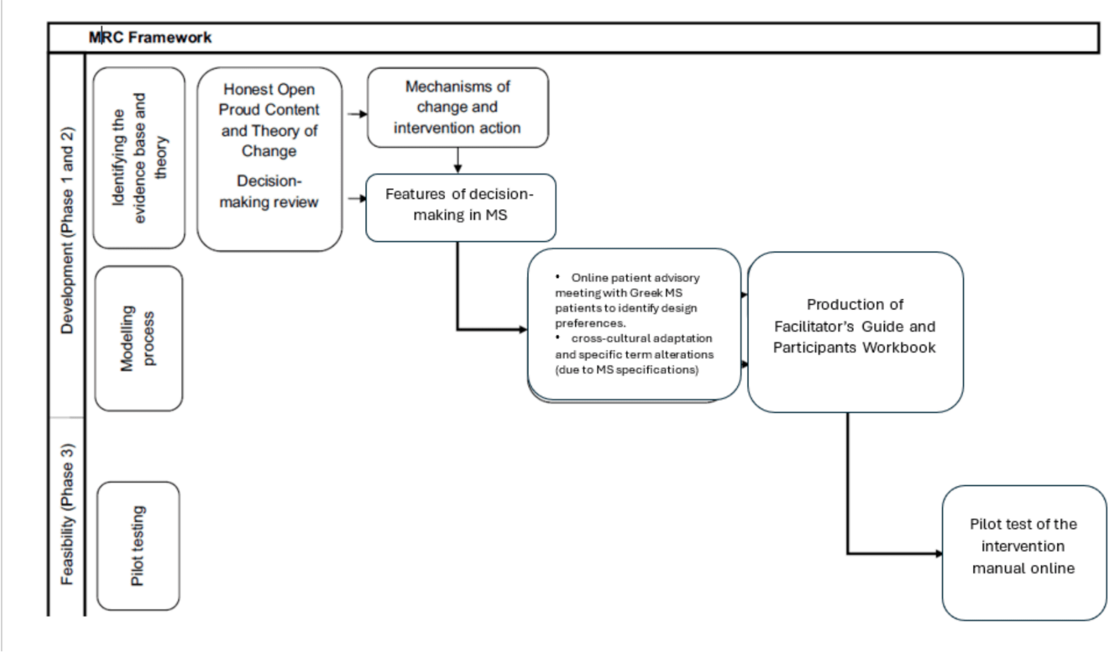

Figure 1. MRC framework for development and feasibility testing for complex interventions used in this study

After finishing the delivery of the program, facilitators gave all participants the opportunity to comment on the program, and their comments were collected and analysed through thematic analysis according to Braun and Clarke[40] methodology. Also, they marked their own reflections on the program and future delivery. Their reflections were grouped and analysed by the same methodology of thematic analysis[40].

Data Analysis

In order to calculate attendance feasibility, the mean was taken of the number of sessions each participant attended divided by the total number of sessions that could have been attended; this was then presented as a percentage. In this case, most participants had a percentage over 75%.

Comments made by the participants

From the analysis of the comments of the participants, 4 common themes emerged.

Many participants saw peer group facilitators as inspiring role models or teachers.

> "*We had workbooks for the exercises. This seemed odd to me at first, but soon I liked it. It was like school again*" Participant 4, line 17
>
> "*I liked the fact that the facilitator of the program could understand my way of view*" Participant 2, line 49
>
> "*You don't feel alone when you hear that the people delivering the program have faced also similar challenges*" Participant 9, line 68

Participants liked to learn about other participants' disclosure decisions and to hear their stories.

> "*When I heard that others had also similar thoughts about how to talk about it with their children, I felt that I was not the only one*" Participant 5, line 68
>
> "*I think that the most helpful feeling for me was the fact that all of us had second thoughts about revealing, but after we have shared our stories, we felt more secure*" Participant 8, line 127

Participants wished to discuss their experience of receiving their diagnosis (not explicitly included in the workbook), wanted to have more time discussing their feelings. They stated that they found the program very helpful and wanted to inform other patients to participate in future similar interventions or programs.

> "*I think that the program should last more. I wanted more sessions to discuss*" Participant 4, line 127
>
> "*Now, I think we have to inform the others!*" Participant 7, line 77

> “*This was actually helpful. I wish more people would participate in the future*” Participant 3, line 55

Facilitator Reflections.

Facilitators of the program stated that further exploration of social stigma is needed.

> *“To maximize the accuracy of the program’s outcomes, further exploration of social stigma is needed, not only among MS patients as informed by research from Anagnostouli et al.*[17]*, but also within the general population. Doing this will not only update both the workbook and the manual accordingly, but it will also assist future facilitators of the program to focus on more realistic aspects of fighting self-stigma in MS patients”.* Facilitator 1

Also, they stated that the homogeneity of participants was an issue for them.

> *“Although the program targets people newly diagnosed with MS, future participants should not have been diagnosed less than one year prior to participation. This allows time for them to adjust to the diagnosis. Additionally, participants should have similar characteristics in terms of age, education level, place of residence, and level of advocacy for MS rights. Finally, for optimal program outcomes, the gender ratio should be close to equal or equal”.* Facilitator 1 & 2.

Another theme that emerged from the analysis was the intersectionality of identities of the participants.

> *“Participants may possess multiple marginalized, minority identities. These could include experiencing mental illness, being immigrants, having a religious identity or sexuality that differs from the majority, and so on. To ensure the program’s inclusivity and effectiveness for these diverse experiences, a dedicated section in both the workbook and facilitator’s manual should address these intersecting identities.”* Facilitator 2

Also, there was a need for changing the delivery format of exercises along with future recommendations

> “*We should change the delivery format (eg, between small and large group discussion) to facilitate involvement from quieter participants and increase communication between and within dyads*”. Facilitator 1
>
> *“It is important to allocate time for participants to share their personal experiences of receiving the diagnosis, along with offering more comprehensive strategies to help them manage potential*

> *negative reactions from others".*
>
> Facilitator 1

Discussion

The aim of this study is the translation, cultural integration, and adaptation of the HOP program to the needs of Greek MS patients so that it becomes a comprehensive empowerment program that can then be used to destigmatize newly diagnosed and non-diagnosed MS patients in Greece and help them make their decisions about disclosing their diagnosis. This comes as a necessity for people with MS due to the fact that the experience of discrimination and social withdrawal due to stigma can strongly affect patients' self-confidence and self-efficacy. Findings from recently published studies regarding how MS patients experience stigma revealed that MS patients are prone to increased psychological distress, such as anxiety and depression[41][13] and exhibit negative health outcomes[14]. Also, the few studies done with people diagnosed with MS who were specifically asked early in the course of the disease to choose whether to disclose their diagnosis to their employer, colleagues, and friends found as a result that hiding the diagnosis can prevent discrimination, but it can also be stressful, resulting in fear of discovery, the need for constant self-monitoring to avoid revealing too much, and a sense of detachment from one's true self. Few studies have addressed this issue in MS, in part because this field lacks a formal, validated measurement tool to assess the impact of disclosure and/or concealment of diagnosis[21][22].

The review of existing studies indicates that an important gap exists within the diagnostic journey, one that could be bridged through empowerment-based approaches that provide targeted support to individuals diagnosed with MS. The "EYpA" (ΕΥπΑ) program represents the first empowerment-focused intervention specifically designed to support people with MS in making decisions about disclosing their diagnosis. The majority of participants in the online stakeholder consultation endorsed the program. In line with the MRC process evaluation guidelines, qualitative observations and facilitator feedback were gathered to evaluate how the program was implemented. This process aligns with previous adaptations of the HOP program for other populations[35]. Although variation exists in attitudes to MS after diagnosis, it is essential for patients to be able to talk about their diagnosis in order to not feel stigmatized[16].

The analysis of the comments from both participants and facilitators revealed some issues regarding the way the program was delivered and the need for improvement in the future. More specifically, participants found the program very helpful, but they needed more sessions and the opportunity to be heard more. From the facilitators' point of view, there was a need for more exploration of social stigma in the general population, homogeneity of the participants in future groups, along with a change in the format of the exercises. These comments are in accordance with previous studies exploring the implementation of HOP in different groups (dementia, psychiatric patients, adolescents with psychosis) [32][33][34][36]

The strengths of this study are that it has used the MRC framework in order to develop and test the intervention material before using it as an open intervention program. The MRC framework gives the opportunity for the materials produced to be tested in order to minimize the later problems of acceptability, intervention delivery, recruitment, and attendance. Also, this study gave the opportunity to MS patients, due to the online consultation and intervention production, to have an energetic way of constructing the materials of the intervention. This, as Bhatt et al,[35] stated, increases intervention validity, such that materials are more likely to be grounded in the values of the target population.

This study had some limitations. MS patients were invited to participate from their MS Societies, so facilitators had no opportunity to examine who should take part. Also, the only exclusion criterion for participating in the feasibility group was to have a diagnosis of MS no more than 2 years. Additionally, as facilitators mentioned, participants may possess multiple marginalized, minority identities. These could include experiencing mental illness, being immigrants, having a religious identity, or sexuality that differs from the majority, and so on, and this could alter the way they deal with disclosing their diagnosis.

With regards to future recruitment for this intervention, researchers should be aware of these limitations so as to perform a more efficient program targeting MS patients and giving them the opportunity to be strengthened in their decision-making regarding the disclosure of their diagnoses and the de-marginalization.

Conclusion

It seems that EYpA has been tested after the translation and cultural adaptation of the manuals and was delivered in a group of MS patients with good results, as participants and facilitators stated. It is possible that EYpA may help MS patients handle the disclosure of their diagnosis in various environments (work, family, partners, etc.) and thus help to minimize stigmatization and marginalization of this special population.

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Statements and Declarations

Conflict of interests

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethics Approval Statement

The Ethics Review Committee at Panteion University approved the study and interviews (approval: 5025) on April 4, 2023. Respondents gave written consent for review and signature before starting the interviews.

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