

## Research Paper:

## Development and Validation of an Educational Booklet to Improve Occupational Performance of the Primary Caregivers of Individuals With Multiple Sclerosis

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## ABSTRACT

**Objective** Caring for individuals with Multiple Sclerosis (MS) can affect their caregivers' occupational performance in various areas such as work, rest/sleep, and social participation. Part of the rehabilitation process is educating caregivers. Primary caregivers need knowledge and information to deliver their caring role. Although face-to-face learning is useful, it can have some limitations. For example, a caregiver should refer to a specific center to receive information and interventions, which is often time-consuming and may trouble them to perform other roles, including their occupational roles. Written health education is used for complementing or strengthening verbal education and maximizing its effectiveness. These materials play an essential role in increasing knowledge, self-management, and commitment to treatment. When health professionals and health services are not available to caregivers, written health education materials can partially answer their questions and needs. It can also help reduce the costs of health care for caregivers. The present study aims to develop and validate the appearance and content of an educational booklet to improve the occupational performance of Primary Caregivers of Individuals with MS (PCIMS).

**Materials & Methods** This is a methodological study conducted. 1. Preparing the content based on grounded theory study of PCIMS and their challenges, and then preparing an initial draft, 2. Examining the face validity and content validity of the initial draft according to the opinions of 22 experts in MS, and 3. Examining the face validity and content validity of the initial draft according to views of 22 PCIMS. An Item-level Content Validity Index (I-CVI) value of  $\geq 0.78$  and a Scale-level Content Validity Index/Average (S-CVI/Ave) value of  $\geq 0.9$  were considered as the criteria for having acceptable validity in the second and third phases. The binomial test was also used to test the statistical reliability of the I-CVIs at a significance level of 0.05 and the expected proportion of agreement (test proportion) of 0.8.

**Results** The minimum I-CVI and S-CVI/Ave values for the items of a scale designed to assess the face validity and content validity of the booklet were respectively reported 0.9 and 0.97, according to the panel of experts. Also, the minimum observed proportion of agreement for items under the binomial test was obtained 0.9, which was higher than the expected proportion of agreement (0.8). I-CVIs values, S-CVI/Ave value and the observed proportion of agreement between PCIMS were equal to 1. For participating experts and PCIMS, the booklet had appropriate validity, and their comments on the appearance and content of the booklet were applied to the final version of the booklet.

**Conclusion** The developed educational booklet has acceptable face validity and content validity, and specialists can use it for the rehabilitation intervention of PCIMS. Further studies are recommended to investigate the effectiveness of this booklet on improving the quality of life of PCIMS.

### Keywords:

Multiple Sclerosis, Caregivers, Occupations, Education, Validation study

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## Extended Abstract

### Introduction

**M**ultiple Sclerosis (MS) is one of the most common chronic, progressive, and unpredictable diseases that usually occur in early adulthood [1]. More than half of MS patients need the help of others over time to perform the daily living activities, which is usually provided by a primary caregiver [2]. A primary caregiver is a person who takes care of the patient voluntarily and without any remuneration and is usually one of the patient's relatives [3]. In addition to the patient's health, MS can affect the caregiver and disrupt their occupational performance [4]. The second edition of the occupational therapy practice framework categorized occupations into various areas, including activities of daily living, instrumental activities of daily living, work, rest/sleep, social participation, education, and leisure [5]. In previous studies, significant positive relationships between occupation and health have been well demonstrated [4, 6, 7]. Occupational performance is to perform or execute a specific occupation [8]. With a grounded theory analysis, Heward et al. reported that the occupational performance of caregivers of MS patients might be impaired in various areas, including work, leisure, and social participation due to the disease, making life difficult for them [4]. In a systematic review study, McKeown et al. concluded that caring for a person with MS had a negative impact on the caregiver's professional and social life [9]. Numerous studies have also found that MS can affect the marital relationships of couples who experience MS [1, 10-12]. These caregivers often prioritize the needs of patients and are reluctant to talk about their needs with health professionals [13]. Therefore, studies have recommended that, besides addressing the needs of patients with MS, the specific and different needs of their primary caregivers should be addressed and that these caregivers need particular interventions [14]. Some believe that it is better to use educational interventions for this purpose [15, 16]. The current study aims to design and develop an educational booklet to enhance the occupational performance of primary caregivers of individuals with MS, reduce their care pressure, and improve their quality of life.

### Materials and Methods

This research is a methodological study. In the first phase, a grounded theory analysis was conducted by the research team (3 occupational therapists, one nurse, and one biostatistics specialist) to investigate the occupational performance of primary caregivers of individuals with MS as part of a doctoral dissertation [17]. This phase was used to extract the content of the educational booklet. For the recommen-

dation section of the booklet and dealing with occupational problems, a review was conducted on related studies in PubMed and Web of Science databases. Finally, a draft of the educational booklet was prepared and printed based on the structure proposed by Hoffmann and Worrall for designing written health education materials [18].

In the second phase, a draft version of the booklet was sent to 22 experts and a scale to check its face validity and content validity. The scale had 17 items (Table 1) rated on a 4-point Likert-type scale (strongly disagree=1, disagree=2, agree=3, strongly agree=4) and 6 areas according to Hoffmann and Worrall [18], including content, language, organization, layout, images, and motivation. The number of experts was calculated using the formula of  $n = Z\alpha^2 \cdot p(1-p) / e^2$ , where  $Z\alpha$  (confidence level) was set 95%,  $P$  (expected proportion of agreement between experts) was 85%, and  $e$  (margin of error) was 15% [19]. The inclusion criteria for selecting experts were having a specialty in the field of health that deals with patients with MS and their caregivers, having at least one year of work experience in the MS Association of Kerman Province, Iran located in Samen Al-Hojaj Hospital, have at least a bachelor's degree, and willingness to cooperate. The experts were asked to critically read the booklet, complete the 17-item tool in two weeks, and express their comments for modifying and completing the booklet in the recommendation section. After two weeks, the completed scales were collected, and the corrective recommendations were applied by the research team.

In the third phase, to evaluate the face validity and content validity of the booklet from the perspective of the target audience, 22 primary caregivers of individuals with MS were selected using a convenience sampling method from the MS Association of Kerman Province. The sample size was determined using the above-mentioned formula. They also completed the 17-item tool, and modifications were made according to their comments. For quantitative analysis of content validity, Item-level Content Validity Index (I-CVI) and Scale-level Content Validity Index/Average (S-CVI/Ave) was used [20]. A binomial test was used to estimate the statistical reliability of I-CVIs in SPSS V. 22 as used in other studies [21].

### Results

The content of this booklet was extracted as 6 factors affecting the quality of life and care pressure in primary caregivers of individuals with MS. These factors included family and social concerns, rest/sleep problems, job problems, marital problems, hiding the disease to avoid discrimination, and lack of knowledge about the disease and proper care. The final structure of this booklet included the follow-

**Table 1.** Experts' agreement on the educational booklet items

	Items	No. (%) <sup>*</sup>	OP <sup>**</sup>	TP <sup>***</sup>	P <sup>†</sup>	I-CVI
1. Content	1. The purpose is clearly stated in the text.	22 (100)	1	0.8	0.007	1
	2. The text is comprehensive.	22 (100)	1	0.8	0.007	1
	3. The text meets the needs of the target audience.	20 (90.9)	0.9	0.8	0.154	0.90
	4. The content is tailored to the culture of the target audience.	22 (100)	1	0.8	0.007	1
2. Language	1. The text is in understandable language.	21 (95.4)	1	0.8	0.048	0.95
	2. The text is perfectly legible.	22 (100)	1	0.8	0.007	1
3. Organization	1. The text has a logical sequence.	21 (95.4)	1	0.8	0.048	0.95
	2. Headings and subheadings are used appropriately.	22 (100)	1	0.8	0.007	1
	3. Sentences and paragraphs are short enough.	22 (100)	1	0.8	0.007	1
4. Layout	1. The selected font size and type is appropriate.	20 (90.9)	0.9	0.8	0.154	0.90
	2. The text and context have good contrast.	22 (100)	1	0.8	0.007	1
	3. The number and size of the pages are appropriate.	22 (100)	1	0.8	0.007	1
5. Images	1. Images help to understand the content.	22 (100)	1	0.8	0.007	1
	2. Images are easy to be perceived.	22 (100)	1	0.8	0.007	1
	3. The number of images is sufficient to cover the content.	20 (90.9)	0.9	0.8	0.154	0.90
6. Motivation	1. The text encourages the target audience to continue reading.	22 (100)	1	0.8	0.007	1
	2. The text is related to the experiences of the target audience.	22 (100)	1	0.8	0.007	1
S-CVI/Ave (mean I-CVI) <sup>**</sup>				0.97		

<sup>\*</sup>Agreement rate; <sup>\*\*</sup>Observed proportion; <sup>\*\*\*</sup>Test proportion; <sup>†</sup>Binomial test; <sup>†</sup>Significance level in binomial test; <sup>\*\*</sup>Content validity at the scale level (average content validity at the item level).

ing sections: cover, table of contents, Introduction (containing the purpose), persuasive section (including the Introduction of famous and successful people who could control and manage MS well, and the advances in the treatment of this disease so far), the main text (introducing the 6 effective factors as well as separate suggestions for managing them), and a general conclusion at the end of the booklet.

The panel of experts included 2 neurologists, 2 general practitioners, 5 nurses, 3 psychologists, 2 social workers, 5 occupational therapists, and 3 physiotherapists with a work experience of 2-23 years. Table 1 presents the percentage of their agreement on the items of the scale of the booklet. All experts chose the “agree” or “strongly agree” option for 12 items (100% agreement and I-CVI=1). They also had a 95% agreement on two

items (I-CVI=0.95) and a 90% agreement on three items (I-CVI=0.90). The mean value of I-CVIs showed that the value of S-CVI/Ave was equal to 0.97, indicating an excellent content validity for the booklet. In the present study, based on other similar studies, for preparing and validating the educational booklet in the field of health [22, 23], the expected proportion of agreement between experts in the binomial test was considered 0.8, and the observed proportion of agreement was 0.9. This result indicates the acceptable face validity and content validity of the developed educational booklet. The applied corrective recommendations of the caregivers in the third phase of the study are shown in Table 2. They chose “agree” or “strongly agree” options for all items and agreed 100% with the items. Hence, the I-CVI value, the S-CVI/Ave value, and the observed proportion of agree-

**Table 2.** Applied corrective recommendations of the participants

Areas	Recommendations
Content	<ul style="list-style-type: none"> <li>- Add suggestions on how properly inject MS drugs to the “rest/sleep problems” factor</li> <li>- Add suggestions on how to use the Internet properly for searching treatments for an MS patient, along with other sources of information to the “lack of knowledge” factor</li> <li>- Add more solutions to the “marital problems” factor</li> </ul>
Language	<ul style="list-style-type: none"> <li>- Provide a brief explanation of the feeling of pity before making suggestions for its reduction in the “hiding the disease” factor</li> <li>- Provide a brief explanation of care obsession in the “job problems” factor</li> </ul>
Organization	Bring the “hiding the disease” factor before other factors due to its higher importance and prevalence among MS patients and their caregivers
Layout	Change Persian font type and size from “B Zar 12” to “B Nazanin 14” to be easy to read the text
Images	<ul style="list-style-type: none"> <li>- Delete most of the images from the “false beliefs” part in the motivation section due to creating a distraction from the text and being unnecessary</li> <li>- Add images related to the text in the “false nutritional beliefs” part of the “lack of knowledge” factor</li> </ul>

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ment for all items was equal to 1. Finally, the final and validated version of the educational booklet entitled “A Guide for Caregivers of Individuals with Multiple Sclerosis: Caregivers’ First-Hand Experiences” was printed in 26 colored single-column A5 double-sided sheets.

## Discussion and Conclusion

According to the experts’ panel, the developed educational booklet in this study had acceptable face validity and content validity. In addition to paying attention to scientific content, health education tools should be tailored to the culture of the target audience [24-26]. One of the strengths of the designed booklet is its content prepared based on a grounded theory study. The advantage of such studies is that their content is both scientific and appropriate to the culture and conditions of the participants [27]. The use of grounded theory study to prepare the content of the booklet is a qualitative strategy for having content validity [28]. Brod et al. also believed that qualitative strategies are beneficial for developing a tool in the health sciences, and the grounded theory-based tools have very good content validity [29]. In the present study, the caregivers provided a series of corrective recommendations (Table 2), which were addressed. One of these recommendations was to add more suggestions for different parts of the booklet. In other studies, it has also been reported that in written materials, more attention should be paid to the behaviors of the target audience and adding related suggestions [30]. Another recommendation of caregivers was to give a brief explanation of the words “feeling of pity” and “care obsession” to make them understandable. In this regard, other studies have also recommended that common terms should be used in educational tools to avoid ambiguity [31]. Another recommendation was that the factor of “hiding the disease” should be

mentioned before other factors due to its great importance. Other studies also agree that in health education tools, more important and usable information for clients should be provided first [32]. Finally, they recommended that some unnecessary images in the booklet be removed and that more images be added to some sections to understand the text better. Kitching also believed that images cannot always help learning [33] and should only help understand essential information [34]. Excessive or inappropriate use of images can distract the reader from the text, but low and appropriate use can be attractive and encourage the reader to read the text [18].

In recent years, some studies have been conducted on designing and validating educational manuals in various fields of health, most of which have had a similar procedure as used in the present study, including Galindo Neto et al. [22] in construction and validation of an educational booklet for teachers in schools, Ximenes et al. [23] in construction and validation of educational booklet content for fall prevention in hospitals, and Oliveira et al. [35] in the development and validation of an educational booklet for healthy eating during pregnancy. In all these studies, the formula for calculating the number of experts was the same as in the present study, and the criterion for having acceptable content validity was to obtain a minimum I-CVIs score of 0.8. They also used a binomial test to evaluate the statistical reliability of the results.

The developed educational booklet can increase the knowledge of the primary caregivers of individuals with MS about this disease and its family, occupational and social challenges and make caregivers more prepared to face these challenges and reduce the pressure of care in them and increase their quality of life. Experimental studies are needed to evaluate the effectiveness of this booklet. To

our knowledge, there is no study to design and validate an educational booklet for primary caregivers of individuals with MS. However, in other areas of health, studies have been conducted to evaluate the effectiveness of educational booklets on the physical and psychological health of primary caregivers. For example, Al-Hadi Hasan et al. evaluated the effect of a psycho-educational intervention targeted at individuals diagnosed with schizophrenia and their primary caregivers. They found that this type of intervention increases their awareness and knowledge about this disease and improves their health [36]. In a study investigating the effect of written information on the distress and anxiety of primary caregivers of individuals with traumatic brain injury, Morris found that written information is valuable for caregivers and reduces their anxiety and distress [37]. In a randomized controlled trial, Bilgin et al. found out that an education program can reduce burnout in mothers with intellectually disabled children.

The present study had some limitations, including the use of a convenience sampling method. This sampling limits the generalizability of the study results. It is recommended that an audio version of the developed educational booklet made available for illiterate people.

The present study aimed to design and validate an educational booklet for primary caregivers of individuals with MS. To the best of our knowledge, this is the first educational booklet for primary caregivers of individuals with MS validated by a panel of experts and target audiences in terms of appearance and content. This booklet can help educate caregivers of individuals with MS, conducting scientific research on them, and facilitating their rehabilitation process by specialists. It is recommended that further studies be conducted to evaluate the effectiveness of this educational booklet on the quality of life and care pressure of the primary caregivers of individuals with MS.

## Ethical Considerations

### Compliance with ethical guidelines

Before the study, written informed consent was obtained from all participants. Ethical approval was obtained from the Research Ethics Committee of the University of Social Welfare and Rehabilitation Sciences (Code: USWR, REC.1395.398).

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This study was extracted from the PhD. dissertation of first author at the Department of Occupational Therapy,

School of Rehabilitation Sciences, University of Social Welfare and Rehabilitation Sciences, Tehran.

### Authors' contributions

Conceptualization, data collection, draft preparation: Mohammad Taghi Mohseni Takalu and Ebrahim Pishyareh; Methodology, validation, editing, and review: All authors; Data analysis: Mohammad Taghi Mohseni Takalu, Ebrahim Pishyareh and Enayatollah Bakhshi; Supervision: Seyed Ali Hosseini and Hamid Reza Khankeh.

### Conflict of interest

The authors declared no conflict of interest.