MEDINFO 2019: Health and Wellbeing e-Networks for All
L. Ohno-Machado and B. Séroussi (Eds.)

doi:10.3233/SHTI190399

Development of Pictograms for an Interactive Web Application to Help Hispanic Caregivers Learn About the Functional Stages of Dementia

Adriana Arcia[a], Niurka Suero-Tejeda[a], Suzanne Bakken[b]

[a] School of Nursing, Columbia University, New York, NY, USA,
[b] School of Nursing and Department of Biomedical Informatics, Columbia University, New York, NY, USA

Abstract

Caregivers of persons with dementia need anticipatory guidance about the stages of dementia in order to prepare for the caregiving situations they will face. The study objective was to develop a set of pictograms representing the functional stages of dementia for eventual inclusion in a tailored, educational web application. We used a hybrid iterative participatory design process. A graphic designer prepared prototypes in a flat, minimalistic style. These were then culled and refined based on feedback from 16 Hispanic caregivers in six design sessions in English and Spanish. The resulting 19 pictograms representing the functional stages and substages of dementia were acceptable to and easily comprehended by participants. Short, plain-language captions support comprehension and aid discrimination between similar scenarios. Our participants preferred candid depictions of all aspects of dementia, including bodily functions, but acceptability may vary by population so further testing is warranted prior to deployment with a new population.

Keywords:

Consumer Health Information, Health Literacy, Patient Participation

Introduction

Caregivers require timely anticipatory guidance to prepare them for the complex and changing care needs of persons with dementia. Caregivers may need to acquire new skills or equipment, connect with community resources, or recruit additional caregiving assistance as the care recipient's condition progresses. An important way to prepare for the demands of caregiving is to understand the abilities or deficits associated with each of the 16 functional stages and substages of dementia [14; 15]. Numerous digital information resources about dementia exist, such as websites and mobile applications, but barriers like Low Health Literacy (LHL) and Limited English Proficiency (LEP) may limit the comprehensibility of these text-heavy resources for some caregivers in the United States [3].

Hispanics suffer disproportionately from dementia, including Alzheimer's dementia, and the associated caregiving burden, compared to non-Hispanic Whites [13]. Hispanics are also over-represented among individuals with LHL and LEP [16]. As a result, there is a need for culturally-competent resources that are designed specifically to meet the information needs of Hispanic caregivers.

One promising approach to supporting comprehension of health information among people with LHL and/or LEP is the use of visual enhancements, such as infographics [1] or photos. A photographic guide to caregiving for dementia is commercially available, but it is targeted to professional caregivers rather than family members and is only available in English [10]. Several studies report on the use of *fotonovelas*—soap opera-type stories in a photographic comic book format—to help Hispanic caregivers gain a general understanding of dementia [18] or learn strategies to reduce depression and stress [7]. However, our search did not uncover any research on visually-enhanced resources intended to make information about the functional stages of dementia easy for Hispanic caregivers to understand and use.

To meet this need, our objective is to develop an interactive web application, entitled **I**nteractive **F**unctional **A**ssessment **St**aging **N**avigator (I-FASTN), to inform caregivers about the functional stages of dementia. The application will be tailored to the user in that it will highlight the specific functional stage of the care recipient while also allowing the user to review the other stages. Screens for each functional stage will offer links to additional caregiving tips and strategies relevant to that stage. A long-term objective is to make I-FASTN available within patient portals through the Fast Health Interoperability Resource (FHIR) Health Level Seven standard and the Substitutable Medical Applications and Reusable Technologies (SMART) platform that enables systems to behave as 'iPhone-like platforms' through an application programming interface (API) and a set of core services that support easy addition and deletion of third party apps, i.e., the core system is stable and the apps are substitutable [12].

The first step in the creation of I-FASTN was content development. Therefore, the objective of this study was to develop a set of pictograms to represent the functional stages of dementia. For specific examples of functional deficits, we drew from both Functional Assessment Staging (FAST) [15] and the Global Deterioration Scale (GDS) [14]. We accomplished our objective through a hybrid iterative participatory design process in which experts create a starting set of prototype images which are then culled and refined based on participant feedback.

Methods

The Institutional Review Board of Columbia University Irving Medical Center approved this study. Written informed consent was obtained from all participants.

Participants

We recruited participants from the **N**ew York City **His**panic dementia caregiver **R**esearch **P**rogram (NHiRP), a study of family caregivers of persons with dementia. Participants were eligible for the present study if they met the NHiRP inclusion criteria: self-identified as Hispanic, 18-90 years old, related to the care recipient, physically able to provide care, not have a diagnosis of a major psychiatric disorder apart from depression, not have depression with psychotic features or suicidal ideation within the preceding 5 years, and expected to live in New York City for at least 12 months.

Procedures

Prior to starting design sessions, we prepared multiple prototypes to illustrate each functional stage and substage of dementia. In order to maximize our options for I-FASTN content, we aimed to identify as many prototypes as possible that participants indicated were clear representations of the intended meaning. We planned to undertake revisions until reaching design saturation, which is the point at which participant feedback yields no further substantive changes.

Iterative participatory design sessions were held in November and December of 2016 in New York City in English and Spanish. We collected basic demographic information from participants. Two investigators experienced in participatory design (AA, NST) led the sessions which were also attended by the experienced graphic designer (NSG) who had created the initial prototypes. In the sessions, we informed participants of the intended meaning (e.g., "Here we are trying to show difficulty managing complex tasks") and showed the captioned prototypes printed on 8.5" x 11" (22 cm x 28 cm) card stock. We solicited preferences among the prototypes by voice or hand vote and used open-ended questions to elicit suggestions for improvement. Sessions were audio-recorded and study staff took notes.

Analysis was concurrent with data collection: at the end of each session, study staff met to 1) synthesize the findings from the session, 2) identify poorly-performing prototypes to be removed from further consideration, and 3) come to consensus about revisions to the favored prototypes based on participant feedback. We then carried out any needed revisions between sessions. In later sessions after the set of prototypes had been narrowed down, we showed the pictograms in the context of preliminary layouts for the I-FASTN interface. After all the sessions were completed the study staff reviewed the notes, audio recordings, and resultant transcripts to audit the results and ensure important insights had not been missed.

Results

Thirteen women and three men (N = 16) participated in three English (n = 6) and three Spanish (n = 10) sessions. They ranged in age from 49 to 86 (M = 61.8) and had been caregiving for an average of almost 9 years. With respect to educational attainment, 12% (n = 2) had some high school, 44% (n = 7) were high school graduates, 25% (n = 4) had an associate's degree, and 19% (n = 3) had a bachelor's degree. Participants were predominantly born in or had family roots in Caribbean countries, rather than Spain or Central or South America.

We tested a total of 54 prototypes, which we subsequently reduced to a final set of 19 pictograms for the 16 stages and substages of dementia, as shown in Table 1. Stages 1, 4, and 5 each yielded two viable pictograms, so these were retained. Just over half of the pictograms (n = 10) underwent one revision, one went through two revisions and the remainder (n = 8) were unchanged from the original prototypes.

Participants' judgments about the extent to which the prototypes accurately represented a stage or substage were often unanimous and unequivocal, with clear favorites emerging early on. Participants narrowed down to the 19 final pictograms so quickly that by the fourth session we began to combine the pictograms into preliminary layouts for the I-FASTN interface to gather preliminary data for developing the interface. Participants in sessions four through six had no additional suggestions for improvement of the individual pictograms and thus we achieved design saturation. Participants displayed ease of comprehension with the final set of pictograms. For example, in sessions four and five participants were asked to review a preliminary I-FASTN layout for Stage 5 that had thumbnail images—less than 0.5" (1.27 cm) high—without captions of Stages 6a-6e printed in one corner of the page. In each of the two sessions, a participant spontaneously and correctly interpreted the meaning of the thumbnails. One man in session 5 explained: "Either they can't dress themselves, they are not bathing themselves, they need help going to the bathroom. Let me see this… they're having accidents."

Despite the ease with which participants interpreted uncaptioned pictograms, we concluded that they functioned best when accompanied by the captions included in Table 1, particularly to help differentiate between stages. For example, without captions, the distinction between Stage 5, "difficulty selecting appropriate clothing," and Stage 6a, "difficulty dressing without help," is an important one that might be lost on casual observation.

We noticed a general preference among participants for pictograms that featured people rather than objects. For example, the pictogram for Stage 3 originally had just the street signs; the person shown in the final version was added at participants' request. Participants also preferred imagery that was candid and unflinching. For instance, the initial prototype for 6e, fecal incontinence, showed the figure from the front with only the wavy lines to indicate the meaning. The more explicit depiction of sagging, soiled briefs was made per participants' specific request. In general, we noted that prototypes showing the presence of something were far more readily understood than those that attempted to show the same idea from the perspective of absence. For example, the pictogram for 7e showing a face with a drooping mouth was more readily understood as representing "cannot smile" than a smiling face marked with an X. Similarly, the final pictogram for Stage 4 in which a person appears confused as they think about money was preferred over a prototype showing a stack of cash with a slash through it.

Discussion

In this study, we worked with Hispanic caregivers to develop a set of pictograms that effectively represents the functional stages of dementia in a culturally acceptable manner. The pictograms are an important contribution to consumer health informatics and health communication because they facilitate access to necessary health information for a population at risk for health disparities. It is important to note that this work is distinct from research aimed at developing visualizations for non-literate populations [2] because we find that our population has little-to-no difficulty reading short passages of plain-language text. Rather, we have observed that comprehension deficits are related to uncertainty about having arrived at correct conclusions and limitations in understanding the basic

Table 1– Pictograms of the Functional Stages and Substages of Dementia.

Functional stages and sub-stages ***Captions***	**Related Pictogram(s)**	**Functional stages and sub-stages** ***Captions***	**Related Pictogram**
1. No objective or subjective functional decrement *Able to work; normal functioning*		6d. Urinary incontinence *Urinary incontinence*	
2. Subjective deficit only *Forgets where they placed familiar objects*		6e. Fecal incontinence *Fecal incontinence*	
3. Deficits noted in demanding occupational and social settings *Gets lost when traveling to new locations*		7a. Speech limited to about six words in the course of an average day *Speech limited to a few words*	
4. Deficits in performance of complex tasks of daily life *Difficulty managing complex tasks; unable to manage finances*		7b. Intelligible vocabulary limited to generally a single word in the course of an average day *Speech limited to one word*	
5. Deficient performance in choosing proper attire *Difficulty choosing appropriate clothing; can't remember the names of close family members*		7c. Ambulatory ability lost *Needs help to walk*	
6a. Requires actual physical assistance in putting on clothing properly *Difficulty dressing without help*		7d. Ability to sit up lost *Cannot sit up without support*	
6b. Requires assistance bathing properly *Unable to bathe properly*		7e. Ability to smile lost *Cannot smile*	
6c. Requires assistance with mechanics of toileting *Unable to manage the details of using the bathroom*		7f. Ability to hold head up lost *Cannot lift head by themselves*	

implications of a text. As such, pictograms support comprehension by using familiar imagery to reinforce the meaning of a text. For example, if a reader is uncertain about precisely what is meant in Stage 5 by "appropriate clothing," the pictogram gives a visual example of the incongruous combination of jacket and flip-flops.

The validity of these pictograms as representations of the stages of dementia is underscored by participants' quick, definitive judgments and strong interpersonal consensus when selecting from among prototypes. Participants' spontaneous interpretations of uncaptioned images, even when reproduced in thumbnail size, is robust preliminary evidence of the pictograms' comprehensibility. Group dynamics limit the ability to conclusively establish every participant's level of comprehension, but further testing may be undertaken by adapting methods outlined by the International Organization for Standardization in ISO 9186-1 for testing the comprehensibility of graphical symbols [5; 9].

For this project, we chose to use pictograms in a flat, minimalistic style rather than more detailed illustrations for two reasons. One, prior research has shown that viewers, particularly those with LHL, are at risk of misconstruing the intended meaning of complex illustrations because of a tendency to focus on irrelevant details [8]. Two, we wanted to minimize details within the images that might prevent a diverse population of users from identifying with the figures in the pictograms. Implementation of the chosen style was facilitated by the inexpensive commercial availability of royalty-free stock images which we adapted as needed. This style is consistent with other studies that have successfully used what have been described as "restroom icons" to convey health-related risks [20] and "stick figures" to develop easily comprehensible symbols for wayfinding in health care settings [4; 11].

In addition to style, other aspects of the final set of pictograms are consistent with prior research. When Weiner and colleagues [19] set out to design an illustrated patient satisfaction questionnaire for low-literacy populations, they found that "a few words go a long way" which is in keeping with our conclusions about the value of short, plain-language captions. As in our study, their illustrations successfully used question marks to depict confusion but their attempts to use slashes to indicate the negation of an idea (e.g., illustration of the response option "not applicable") were as unsuccessful as ours. Foster and Afzalnia tested the comprehensibility of various symbols to represent a cash machine and found that images that depicted human interaction with an object (i.e., a hand holding a stack of bills) were more easily comprehended than images of the object alone [6]. In a similar vein, we found that participants generally preferred the images that contained people.

Although these pictograms were developed to suit the needs of Hispanic caregivers in the United States, we believe the images will be easily comprehensible to a broader range of users. However, not all groups may consider all of the pictograms to be culturally acceptable, particularly those that depict bodily functions [17]. Given that our sample predominantly has roots in Caribbean countries, our findings may or may not extend to Hispanics from other regions. Explicitly testing for cultural acceptability and comprehensibility is warranted before pictograms are deployed with a new population.

The next step for our project is to design and test the I-FASTN interface (i.e., heuristic evaluation with experts followed by usability testing with end users) using the pictograms presented in this report. Spanish-language captions and vector files of the pictograms are freely available for non-commercial use upon request from the corresponding author.

Conclusions

Application of hybrid participatory design methods resulted in pictograms that were acceptable and comprehensible to Hispanic caregivers as an essential first step in developing tools to meet their needs. Well-designed pictograms are a useful adjunct to text for meeting information needs in consumer health informatics tools.

Acknowledgements

We thank our graphic designer, Nicole Spiegel-Gotsch. This publication was supported by the **N**ew York City **Hi**spanic dementia caregiver **R**esearch **P**rogram (R01 NR014450-03S1), **Pr**ecision **i**n **S**ymptom **S**elf-**M**anagement (PriSSM) Center (P30 NR016587), and the National Center for Advancing Translational Sciences, National Institutes of Health, (UL1 TR001873). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

[1] A. Arcia, N. Suero-Tejeda, M.E. Bales, J.A. Merrill, S. Yoon, J. Woollen, and S. Bakken, Sometimes more is more: Iterative participatory design of infographics for engagement of community members with varying levels of health literacy, *Journal of the American Medical Informatics Association* **23** (2016), 174-183.

[2] P.A. Barclay and C.A. Bowers, Design for the Illiterate: A Scoping Review of Tools for Improving the Health Literacy of Electronic Health Resources, in: *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, SAGE Publications Sage CA: Los Angeles, CA, 2017, pp. 545-549.

[3] N.D. Berkman, S.L. Sheridan, K.E. Donahue, D.J. Halpern, and K. Crotty, Low health literacy and health outcomes: An updated systematic review, *Annals of Internal Medicine* **155** (2011), 97-107.

[4] J. Bolek and J. Cowgill, Development of a symbol system for use in the health care industry, in: *Proceedings of the 2005 Conference on Designing for User eXperience*, AIGA: American Institute of Graphic Arts, 2005, p. 23.

[5] K.A. Brantley and M.S. Wogalter, Oral and written symbol comprehension testing: The benefit of cognitive interview probing, in: *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, Sage Publications Sage CA: Los Angeles, CA, 1999, pp. 1060-1064.

[6] J.J. Foster and M. Afzalnia, International assessment of judged symbol comprehensibility, *International Journal of Psychology* **40** (2005), 169-175.

[7] D. Gallagher-Thompson, M. Tzuang, L. Hinton, P. Alvarez, J. Rengifo, I. Valverde, N. Chen, T. Emrani, and L.W. Thompson, Effectiveness of a fotonovela for reducing depression and stress in Latino dementia family caregivers, *Alzheimer Disease and Associated Disorders* **29** (2015), 146.

[8] P.S. Houts, C.C. Doak, L.G. Doak, and M.J. Loscalzo, The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence, *Patient Education and Counseling* **61** (2006), 173-190.

[9] ISO, *ISO 9186-1:2014 Graphical Symbols -- Test Methods -- Part 1: Method for Testing Comprehensibility*, International Organization for Standardization, Geneva, 2014.
[10] Grealy J, McMullen H, Grealy J. *Dementia Care: A Practical Photographic Guide.* Chichester, United Kingdom: John Wiley & Sons, Incorporated; 2008.
[11] S. Lee, S.S. Dazkir, H.S. Paik, and A. Coskun, Comprehensibility of universal healthcare symbols for wayfinding in healthcare facilities, *Applied Ergonomics* **45** (2014), 878-885.
[12] J.C. Mandel, D.A. Kreda, K.D. Mandl, I.S. Kohane, and R.B. Ramoni, SMART on FHIR: a standards-based, interoperable apps platform for electronic health records, *Journal of the American Medical Informatics Association* **23** (2016), 899-908.
[13] K.M. Mehta and G.W. Yeo, Systematic review of dementia prevalence and incidence in United States race/ethnic populations, *Alzheimer's & Dementia* **13** (2017), 72-83.
[14] B. Reisberg, S.H. Ferris, M.J. de Leon, and T. Crook, The Global Deterioration Scale for assessment of primary degenerative dementia, *American Journal of Psychiatry* **139** (1982), 1136-1139.
[15] S.G. Sclan and B. Reisberg, Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality, *International Psychogeriatrics* **4** (1992), 55-69.
[16] T. Sentell and K.L. Braun, Low health literacy, limited English proficiency, and health status in Asians, Latinos, and other racial/ethnic groups in California, *Journal of Health Communication* **17** (2012), 82-99.
[17] C.G. Spinillo, Graphic and cultural aspects of pictograms: an information ergonomics viewpoint, *Work* **41** (2012), 3398-3403.
[18] R. Valle, A.-M. Yamada, and A.C. Matiella, Fotonovelas: A health literacy tool for educating Latino older adults about dementia, *Clinical Gerontologist* **30** (2006), 71-88.
[19] J. Weiner, A. Aguirre, K. Ravenell, K. Kovath, L. McDevit, J. Murphy, D.A. Asch, and J.A. Shea, Designing an illustrated patient satisfaction instrument for low-literacy populations, *The American Journal of Managed Care* **10** (2004), 853-860.
[20] B.J. Zikmund-Fisher, H.O. Witteman, M. Dickson, A. Fuhrel-Forbis, V.C. Kahn, N.L. Exe, M. Valerio, L.G. Holtzman, L.D. Scherer, and A. Fagerlin, Blocks, ovals, or people? Icon type affects risk perceptions and recall of pictographs, *Medical Decision Making* **34** (2014), 443-453.

Address for correspondence

Adriana Arcia
School of Nursing, Columbia University, New York, NY, USA
Email: adrianaxarcia@gmail.com