Research Article

Helping Hispanic Family Caregivers of Persons With Dementia "Get the Picture" About Health Status Through Tailored Infographics

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Abstract

Background and Objectives: Caregivers need to understand their health status and the disabilities of the care recipient to engage in effective health management. Infographics tailored with personal health data are a promising approach to facilitating comprehension, particularly for individuals with low health literacy/limited English proficiency. Such approaches may be especially important for dementia caregivers given the high care burden.
Research Design and Methods: Guided by the Health Belief Model and the Data-Frame Theory of Sensemaking, we conducted iterative participatory design sessions with Hispanic family caregivers (*N* = 16) of persons with dementia. We created multiple prototype infographic designs to display scores on validated instruments of topics such as caregiving burden, overall health, and psychological distress. We retained and refined designs participants judged to be easily comprehensible. Analysis focused on identifying the graphical elements that contributed to the comprehensibility of designs and on evaluating participants' reactions to the designs.
Results: Successful infographics used intuitive scaling consistent with caregivers' perspective of dementia as inevitable decline. Participants reacted to infographics by describing the self-management actions they would take to address the health issue at hand.
Discussion and Implications: Tailored infographics supported caregivers' comprehension of their health status and served as cues to engaging in self-management. As such, they should be presented in the context of informational support that can facilitate selection of appropriate next steps. This can mitigate the potential mental and physical health consequences of caregiving and enable caregivers to continue to care for their relatives with dementia with less damage to their own well-being.

Keywords: Audiovisual aids, Comprehension, Health literacy, Patient engagement

To "get the picture" means that one comprehends a message, but soon it may be a directive to health professionals wishing to communicate effectively with health care clients. For example, a clinician trying to help a client understand that their level of depression symptoms merits treatment may go and "get the picture"—an infographic tailored with the client's symptom score—to get the message across. There is a long tradition of using infographics and other visual aids (e.g., a ChooseMyPlate.gov nutrition poster, or a diagram of the heart) to convey health messages, but technological advances have now made it possible to easily tailor an image to display an individual's own health data with the goal of motivating health self-management actions (Arcia, Velez, & Bakken, 2015). Tailored infographics of personal health status and other information visualizations show promise as tools to communicate with those who might struggle with comprehension such as individuals with low health literacy or limited English proficiency (Arcia et al., 2016; Garcia-Retamero, Okan, & Cokely, 2012; McCaffery et al., 2012). However, not all infographics are created equal; poorly chosen imagery can be confusing—or worse—give the opposite of the intended meaning (Lazard & Mackert, 2015; Nystrom, Singh, Baldwin, Sittig, & Giardina, 2018). Rigorous research is needed to ensure that infographic designs convey the intended message in an easily comprehensible way that motivates the target audience to take appropriate self-management actions.

Caregivers of persons with dementia especially stand to benefit from tailored infographics because they face the dual challenge of managing the potentially complex health/medical needs of another person on top of their own health self-management. For Hispanic caregivers, the challenge can be exacerbated by a health care context that may not be meeting all of their cultural/language needs (Lucero et al., 2018). Hispanic caregivers' needs merit attention because compared to non-Hispanic Whites, Hispanics are disproportionately affected by dementia, including Alzheimer's dementia, less likely hold a medical/disease conceptualization of dementia, and thus less likely to seek assistance (Gallagher-Thompson et al., 2003; Gelman, 2010; Gurland et al., 1999; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Matthews et al., 2019; Vega, Cabrera, Wygant, Velez-Ortiz, & Counts, 2017). Furthermore, low health literacy and limited English proficiency disproportionately affect Hispanics (Sentell & Braun, 2012).

Despite a clear need for informational support, there are few examples of studies of visually-enhanced materials for caregivers, and even fewer specifically targeted to Hispanic caregivers. Noteworthy among these are studies that found that Hispanic caregivers could successfully gain a general understanding of dementia (Valle, Yamada, & Matiella, 2006) and learn depression- and stress-reduction strategies (Gallagher-Thompson et al., 2015) following interventions that used *fotonovelas*, which are photographic comic books that tell soap opera-type stories. Brown, Ruggiano, and Meadows (2017) developed a caregiving burden self-assessment tool in English based on the Zarit Burden Interview that uses stoplight imagery and presents tips and resources in the form of a static infographic. A photographic guide to caregiving for dementia is commercially available in book form, but only in English and is intended for a professional audience rather than for family caregivers (Grealy, McMullen, & Grealy, 2008). Dobos, Orthia, and Lamberts (2015) reported on the use of "digitally enhanced multimodal pictures" to communicate messages about Alzheimer's research and found that although the images could evoke emotional responses, they were largely unsuccessful at conveying specific scientific messages. Unfortunately, these examples offer scant guidance for designing infographics that can support comprehension and motivate self-management among Hispanic family caregivers for persons with dementia.

When considering health-related visualizations more generally, some best practices are emerging regarding the use of pictograms to accompany medication administration instructions (Yin et al., 2017), icon arrays to convey health risks (Ancker, Senathirajah, Kukafka, & Starren, 2006), reference range number lines to display laboratory values (Zikmund-Fisher et al., 2017), and tailored infographics to support comprehension of personal health status among Hispanics (Arcia et al., 2016). Nevertheless, optimal ways of conveying information about the topics important to caregivers have yet to be determined.

Objective

Our goal is to promote Hispanic caregivers' and care recipients' health through the provision of timely, relevant information in a culturally acceptable format that supports comprehension of health status and motivates self-management actions. To that end, the objective of our study was to develop tailorable infographics that communicate to caregivers the intended meaning and motivate them to address the target health issue. We envisioned that tailored infographics could be deployed via an online system such as a patient portal, or in the context of clinical visits (on paper or on a screen). The purpose of this article was to inform best practices by reporting on the elements that contributed to successful (i.e., comprehensible and motivating) prototype infographic designs and caregivers' reactions to those designs.

Research Context

The context for this study was the New York City Hispanic dementia caregiver Research Program (NHiRP) for which the overarching goal was to understand the needs of Hispanic caregivers of persons with dementia and tailor evidence-based clinical interventions to meet these needs. We conducted a project in NHiRP to develop and evaluate infographics aimed at meeting caregivers' information needs. The topics to be visualized were selected from among the domains evaluated in the NHiRP study, based on validated research instruments.

Theoretical Frameworks

This work was guided by the Health Belief Model (HBM) and the Data-Frame Theory of Sensemaking theoretical frameworks. In the HBM, the likelihood of an individual taking preventive health action is influenced by various factors such as perceived threat of disease and cues to action (Janz & Becker, 1984). When used to support comprehension, the function of the tailored infographic is to report the individual's result alongside sufficient contextual cues to promote appropriate interpretation of that result. As such, we see tailored infographics as cues to action (i.e., motivating self-management) in that they can alert the viewer to the threat of particular health condition and/or their susceptibility to that threat.

We were also guided by the Data-Frame Theory of Sensemaking. Frames are schemas or mental constructions that individuals use to make sense of the data/stimuli they encounter (Klein, Phillips, Rall, & Peluso, 2007). As such, we designed tailored infographics to be as congruent as possible with commonly existing frames so as to maximize the likelihood of comprehension. For example, most people in our culture share the frame that when paired together, the colors green and red have positive and negative connotations, respectively (Aslam, 2006).

Methods

All study procedures were approved by the institutional review board of Columbia University Irving Medical Center. We conducted iterative participatory design sessions of approximately 2 hr each, in English and Spanish, during November and December 2016. Sessions were held in the northern Manhattan neighborhood of Washington Heights, at Columbia University School of Nursing and at the community-based facility of the Columbia Clinical and Translational Science Award (CTSA).

Participants

Individuals were eligible if they had participated in the parent NHiRP study, for which the criteria were the following:

1. self-identified as Hispanic,
2. aged 18–90 years,
3. self-identified as a caregiver related to the care recipient,
4. physically able to provide care,
5. without a diagnosis of a major psychiatric disorder other than depression,
6. no depression with psychotic features or suicidal ideation or attempts in the last 5 years, and
7. expected to live in New York City for the subsequent 12 months.

Also, the care recipient had to have been diagnosed with dementia by a clinician and reported at least one memory/cognition and one daily functioning symptom. Participants were scheduled to one design session according to preferred language (English or Spanish) and received $50 for their time.

Stimuli

We gave each participant a stack of prototype infographic designs printed in color on card stock, one to a page. Designs displayed the scores of validated instruments and were tailored to fictitious caregivers and care recipients using simulated data. The topics shown were the following:

- caregiving burden: Zarit Burden Interview (Zarit, Orr, & Zarit, 1985),
- overall health: EuroQol Group health status measure (EQ-5D) (Rabin & de Charro, 2001),
- feeling in control: Pearlin Self-Mastery Scale (Pearlin & Schooler, 1978),
- psychological distress: Kessler Psychological Distress Scale (Kessler et al., 2002),
- depression: Geriatric Depression Scale (Yesavage et al., 1982),
- caregiver reactions to care recipient's behavior patterns: Revised Memory and Behavior Checklist (Teri et al., 1992), and
- cognitive decline: Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) (Jorm & Jacomb, 1989).

Spanish-language text was generally taken directly from the official Spanish versions of the instruments used in the parent study survey. Additional translations were made collaboratively by two bilingual members of the study team (A. Arcia, N. Suero-Tejeda) as needed. Visual layouts and graphic elements were created based on insights from prior work and in accordance with foundational graphic design principles from Gestalt theory including similarity, repetition/consistency, and proximity/grouping (Graham, 2008). We implemented these principles by (a) using a limited number of colors and shapes to create a cohesive family of information, (b) keeping the appearance and placement of standard information the same, and (c) placing related elements in an organized hierarchy of information that leads the eye through the composition. Prior research has shown that viewers are prone to assigning unintended meaning to overly illustrative imagery (Arcia et al., 2016; Houts, Doak, Doak, & Loscalzo, 2006) so we deliberately used flat, minimalist images so as to avoid markers of gender, ethnicity, age, etc. that might limit the caregiver's ability to identify with the image. We began sessions with multiple designs for each topic and narrowed them down over the course of the sessions.

Procedures

Study staff obtained informed consent. Staff comprised a session leader (N. Suero-Tejeda) and coleader (A. Arcia), both of whom are experienced at conducting participatory design sessions, and a visual user interface and user

Table 1. Participant Characteristics

Characteristic	N	(%)
Gender		
Female	13	(81)
Male	3	(19)
Session language		
English	6	(38)
Spanish	10	(62)
Marital status		
Never married	2	(12)
Married	4	(25)
Separated/divorced	7	(44)
Widowed	3	(19)
Education		
Some high school	2	(12)
High school	7	(44)
Associate's degree	4	(25)
Bachelor's degree	3	(19)
	M	Range
Participant age	61.8	49–86
Years spent caregiving	8.8	3–17

experience designer (N. Spiegel-Gotsch) with over 15 years of professional experience. Sessions were audio recorded and staff took notes. Participants considered designs one at a time and were asked "What information do you think we are trying to convey with this image? What does it mean to you?" After reviewing multiple designs for the same topic, the leader elicited participants' preferences via a voice or hand vote and then inquired about participants' reasons for preferring a particular design and solicited suggestions for improvement. If the topic was relevant to behavior change, the leader asked "Would this image motivate you to address the health issue?"

Immediately following design sessions study staff conducted a peer debriefing session to exchange impressions and decide, by consensus, upon design changes to be implemented for the next session. Sessions continued until participants' stated interpretations matched the infographics' intended meanings (i.e., evidence of adequate comprehension) and we reached *design saturation* meaning that participants' comments led to no further substantive design changes.

Analysis

The goals of our analysis were to identify the graphical elements that contribute to the comprehensibility of designs and to evaluate caregivers' reactions to those designs, with a focus on reactions related to self-management. To that end, an iterative, inductive approach informed by qualitative descriptive methodology was used to let key findings emerge from the data, which were then distilled into a findings summary as follows. The lead analyst (A. Arcia) conducted a simultaneous review of session audio recordings and

transcripts in their original language in order to capture subtleties of inflection and timing. Using standard word-processing software, thumbnails of each image shown during a session were annotated with verbatim quotations pertaining to the image, notes taken during the session, and analysis notes. Notes in the findings summary focused on:

- participant interpretations of infographic meaning (i.e., comprehension),
- reactions to the prototype infographic designs,
- statements about health self-management,
- reactions to variations in specific design elements (e.g., labeling, colors, illustration),
- preferred designs and reasons for preference, and
- feedback that led to design decisions.

The findings summary was reviewed by the session leader (N. Suero-Tejeda) and discussed to consensus. As analysis occurred in the original language, participant quotations were translated to English only as needed for dissemination of results; initial translations by the natively bilingual lead analyst (A. Arcia) were verified and discussed to consensus with the bilingual session leader (N. Suero-Tejeda).

Results

Sixteen participants—13 women and 3 men—each participated in one of the six sessions; three in English and three in Spanish (see Table 1). Their average age was 61.8 years (range 49–86) and on average, they had spent 8.8 years caregiving (range 3–17). Eleven were adult children of the care recipient, and five were spouses. At the time of participation, 12 were actively caregiving; the care recipient of the other four caregivers had died, but all caregivers, who had been enrolled in 2013 and 2014, were still being followed yearly by the parent study.

By the conclusion of the sessions we had narrowed down to one or two successful (i.e., comprehensible and motivating) designs for each topic. Key elements that contributed to comprehensibility were intuitive scaling, acceptable labeling, colors, imagery, and consistency with the viewer's topic-specific frames. Participants saw the infographics as cues to take preventive health actions. Verbatim quotations from participants are presented in double quotes throughout this section.

Evidence of Comprehension

By the time we neared the final iterations of a design, overwhelmingly, participants extracted the meaning we intended:

> "Bueno, yo diría que cuando uno está 100% bien de salud ya es máximo. Como tiene un 65% de salud no está tan mal, ¿verdad? No está tan mal. La persona no es que esté totalmente saludable pero no está tan mal como para decir que ya está en las últimas. *[Well, I would say that*

when your health is 100% that's the maximum. Since she has 65% health she's not too bad, right? She's not too bad. It's not that she's totally healthy, but she's not so poorly as to say she's on her last legs.]" (Group 2, Figure 1)

"Porque empieza de cero y va subiendo escalones poco a poco, hasta llegar al agotamiento. *[Because it starts at zero and goes up the steps little by little, until reaching exhaustion.]*" (Group 2, Figure 2)

"I think Victor is doing okay, the Victor score is 15, somewhat in control. He is teetering, he is going towards the red side the red scale but he seems to be okay . . . he is not in Nirvana yet but he is not out of control raging." (Group 5, Figure 3)

There were isolated instances in which a participant gave an interpretation different from what we intended, however, these instances were acceptable to us because we expect that there is no design that will be universally comprehensible.

Intuitive Scaling

For some topics, the original scaling of the instrument seemed counterintuitive to participants, who—only seeing the total score—were not privy to how it was calculated. For example, in the NHiRP survey, six items from the Kessler Psychological Distress Scale were administered with five response options about symptom frequency ranging from "none of the time" (coded as 1) to "all of the time" (coded as 5) yielding total scores ranging from 6 to 30. Per participant request, we rescaled Kessler scores to 1–25 as shown in Figure 4.

On the basis of participants' spontaneous references to "percentages"—even when the scaling was not a percentage—we inferred that 0 or 1 to 100 is a familiar, accessible metric for this population. However, an intuitive minimum score of 0 or 1 appeared to be much more critical to the acceptability of scaling than a top score of 100. For example, some participants occasionally questioned a maximum score, such as 88 on the Zarit Burden Interview ("Yeah, I don't understand why it doesn't have a 100," Group 5, Figure 2) but were willing to accept it; other participants either did not notice or were untroubled by the maximum score. In a couple of instances, participants could be heard making sense of a score by converting it to a percentage, such as calculating that a 14 on the Geriatric Depression Scale is nearly 50% because the scale goes up to 30 ("14 y leve. Tiene un 50% prácticamente *[14 and mild. She's at 50%, practically]*." Group 2, Figure 5).

Acceptable Labeling, Colors, and Imagery

Labeling

We observed that labels and images work synergistically because images are evocative and attention getting and labels add specificity. One participant explained, "Because the word depression is under it, I then associate the picture
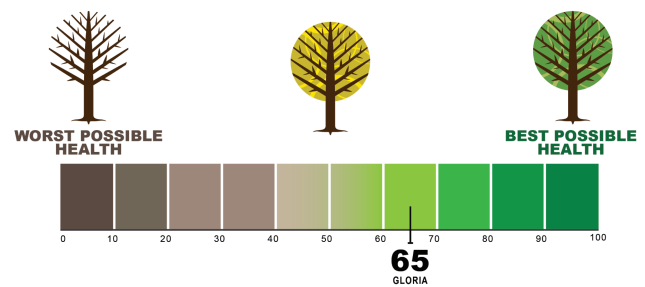
Overall Health

Figure 1. This overall health infographic uses a tree metaphor and can be tailored to a caregiver with their score on EuroQol Group health status measures (e.g., EQ-5D).
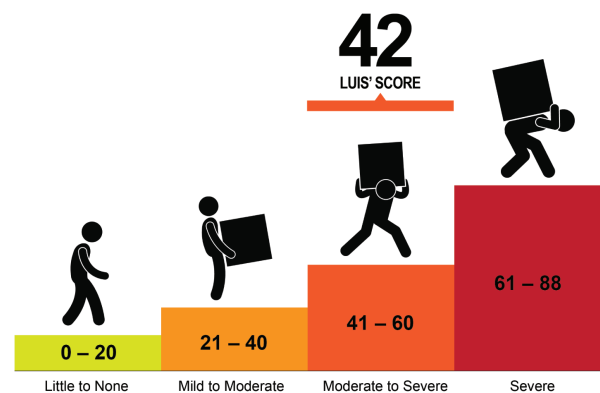
Caregiving Burden

Figure 2. An infographic about caregiving burden has been tailored to show that Luis, a fictitious caregiver, scored 42 (moderate-to-severe burden), on the Zarit Burden Interview.
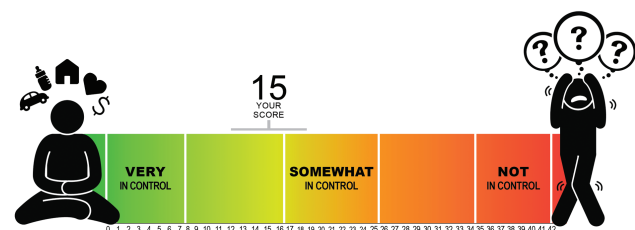
Feeling In Control

Figure 3. In the original scaling of the Pearlin Self-Mastery Scale, high values indicate feeling a in control. Here, the scaling has been reversed with "very in control" on the left and "not in control" on the right to match caregivers' frame of inevitable decline from left to right.

with depression. If I just saw the picture without the word, I would just interpret it as a person is crying" (Group 6, Figure 6). Therefore, we evaluated and refined every aspect of labeling in our designs. Most labeling changes

Maria's Psychological Distress
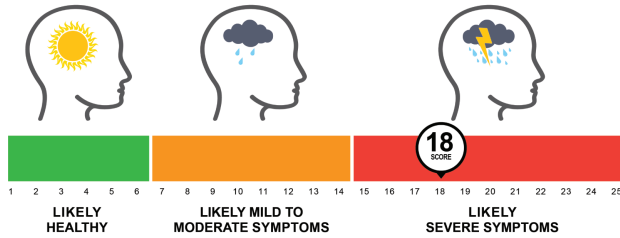
Figure 4. Participants preferred this weather-in-the-head design concept for the Kessler Psychological Distress Scale over one that had weather symbols but no heads. The original scaling of 6–30 has been rescaled to 1–25 to be more intuitive for viewers.

Ana's Depression Symptoms
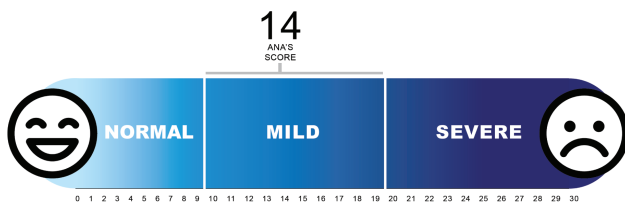
Figure 5. A blue gradient to display scores on the Geriatric Depression Scale was widely comprehended and preferable to a green–red gradient in which red could be erroneously interpreted as "happy" or "angry."

were intended to make the language more accessible to lay readers (e.g., "feeling in control" instead of "self-mastery"; "mental" instead of "cognitive"). In making these changes, we weighed the desire to be precise and faithful to the source material against the need to maximize comprehension. In the aforementioned examples, the loss of precision was minor compared to the gains in accessibility. However, in the case of the Kessler Psychological Distress Scale, the additional issues of connotation and stigma complicated our decision making. In Spanish, the word for distress, "trastorno," is one that seems to carry more stigma than "distress" does in English. The risk of using laden language is that viewers will have negative reactions to the design. As one participant put it, "Pero sí creo que el trastorno suena fuerte. Por lo menos uno no lo acepta, tu sabes? *[But I do think that 'trastorno' sounds strong. At least one doesn't accept it, you know?]*" (Group 4, Figure 4). We compared a title including "trastorno" with another that meant "anxiety and depression." Some participants preferred the former as a more accurate reflection of the instrument items whereas others preferred the latter because it sounded softer. We provisionally chose to retain "trastorno" but see the potential need for flexibility on this point.

Problems with Celia's Memory and Behavior

Figure 6. This infographic shows how frequently Celia, a fictitious care recipient, experienced problems with memory, depression, and disruptive behavior, alongside the degree to which those problems bothered Celia's caregiver.

Colors

We employed stoplight colors (green, orange, red) for most graphics because their meaning is so readily understood (see Arcia et al., 2016). However, we used a blue gradient to illustrate depression, which participants generally preferred to other options. We also used a brown–green gradient for overall health, which participants understood as consistent with the metaphor of bare versus lush trees ("The greener is the healthier," Group 3, Figure 1). All figures reproduced in color online.

Imagery

When we hit upon the right imagery, participants were able to engage with designs readily: "Inmediatamente veo la gráfica yo entiendo lo que está tratando de decir sin tener que leerlo. *[Immediately, I see the graphic and I understand what it's trying to say without having to read it.]*" (Group 4, Figure 6). For example, most agreed that trees, ranging from bare to lush, were apt metaphors for overall health:

> "Se le está empezando a deteriorar la salud. Las hojas indican eso. *[Her health is starting to deteriorate. The leaves show you that.]*" (Group 2, Figure 1).
> "The trees are noteworthy because one of them is so bare so you don't want to be there, but the other one is full of green. I like that very much." (Group 3, Figure 1)

Weather icons inside silhouetted heads (Figure 4) were seen as more specific to mental health than weather icons alone. An early version of the icon to represent "likely healthy" that used a rainbow was replaced by a sun because a participant pointed out that rainbows appear after a storm has passed, which would add an additional, unintended layer of meaning.

The box-carrying figures we used to illustrate caregiver burden were easily understood and evocative of the caregiving experience: "Como dicen en mi país, más claro de ahí no canta un gallo. *[Like we say in my country, not even a rooster crows more clearly than that.]*" (Group 4, Figure 2); "It is a good reflection of burden because . . . it actually shows that the more burden you have, the more overloaded you are" (Group 6, Figure 2). Some participants preferred a version in which the figures were placed along a steep slope but we retained the steps shown in Figure 2 as a better reflection of the changes and plateaus inherent to dementia:

> "I think this one represents it better because this one goes in steps. It's going up in steps and that happens because they will move from one place to another. So, you could be okay for a while and then you get to a step and it's like it changes, and you say to yourself 'Now what are we doing today? Things have changed overnight! They have changed and now she is not doing this.'" (Group 5, Figure 2)

In the prototype design of caregiver reactions to the care recipient's behavior patterns, we needed to illustrate behavioral domains. The brain with a question mark to represent memory (Figure 6) was preferred over a hand with a string tied in a bow around one finger because the latter was considered old-fashioned. For depression, we used the head-in-hands figure instead of an icon of an eye with teardrops because the latter reminded one participant of gang tattoos (Phelan & Hunt, 1998). Some participants pointed out that some disruptive behaviors are nonverbal but they agreed that the shouting head was still comprehensible as a representation of both verbal and nonverbal disruptive behaviors.

Consistency With Viewers' Frames

Caregivers viewed all the designs through the frame of the inevitable decline of the person with dementia; they operated under the assumption that situations were dynamic, and getting worse:

> "Aquí empezó . . . estaba todavía mejor. Pero aquí va avanzando la enfermedad y aquí ya es cuando . . . *[This is where it started . . . it was still better. But here the disease advances and this is when . . .]*" (Group 1, Figure 1)
> "Empeorando. De la salud, de los problemas, discusiones, de conflictos, de la responsabilidad que uno tiene. Son demasiados y yo me las he tomado personal yo. *[Worsening. With respect to health, problems, discussions, conflicts, with the responsibility that one has. They're too much and I've taken them personally, I have.]*" (Group 1, Figure 4)

This perception was most evident when participants evaluated a design intended to depict the care recipient's change in cognitive functioning compared to 10 years ago.

For each question in the IQCODE, the caregiver rates the recipient as "much better" (coded as 1) to "no change" (coded as 3) to "much worse" (coded as 5); the responses are then averaged (Jorm & Jacomb, 1989). Participants struggled to make sense of the design and were prone to reject the entire premise because:

> "Eso no existe, eso no existe. En 10 años eso no existe, el 'mucho mejor' . . . la palabra 'mejor' no existe en demencia. *[That doesn't exist, that doesn't exist. In 10 years that doesn't exist, 'much better' . . . the word 'better' doesn't exist in dementia.]*" (Group 2, Figure 7a)
> "It doesn't get better and that's what I tell them. It doesn't get better." (Group 5, Figure 7b)

The scaling was so counterintuitive to participants that some ignored the labeling that conflicted with their frame and instead saw 1.0 as representing the beginning of decline, as evidenced by the response of a participant who was asked to interpret the meaning of a score of 2.2 (i.e., "somewhat better"): "2.2 no está enfermo, pero tampoco está muy bien. *[2.2 means he isn't sick, but he's not very good either.]*" (Group 2, Figure 7a). Participants' preferred solution was to truncate the scale so as to only show 3.0–5.0. Although such a scale would serve for most cases, the full scale would be needed to display uncommonly low (i.e., favorable) scores.

In order for designs to be consistent with the frame of inevitable decline, participants requested that scales be presented consistently with "good" values on the left and "bad" values on the right leading us to flip the scaling for the Pearlin Self-Mastery for which high values originally indicated high self-mastery. The exception was overall health because numbers should logically increase from left to right and 100 is a better anchor for "best possible health" than 0.

It was clear when designs were consistent with participants' frames because they spontaneously identified with the images and made self-assessments:

> "Yo diría que la mía está en 90. Y no digo 100 porque tengo tantos problemas de dolores en la espalda y en mi cuerpo entero. *[I would say that mine is at 90. And I don't say 100 because I have so many problems with pains in my back and in my whole body.]*" (Group 4, Figure 1)
> "A veces yo también me he identificado con esta nube. *[At times I, too, have identified with this cloud]*" (Group 1, Figure 4)

The readiness with which participants assessed themselves in response to the infographics suggests that graphically enhanced survey questions would be useful and engaging for data collection:

> "Bueno, a mí me pareció más interesante así con gráfica que con cuestionario, porque se interactúa una y otra. *[Well, it seemed more interesting to me like this with*
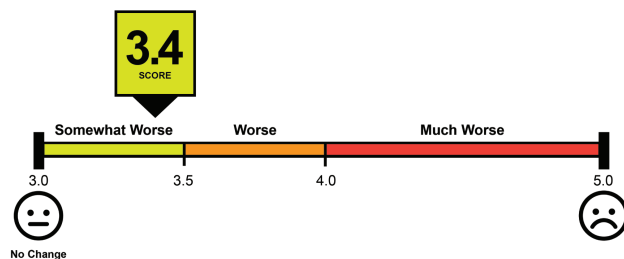
A

Change in Manuel's mental functioning compared to 10 years ago
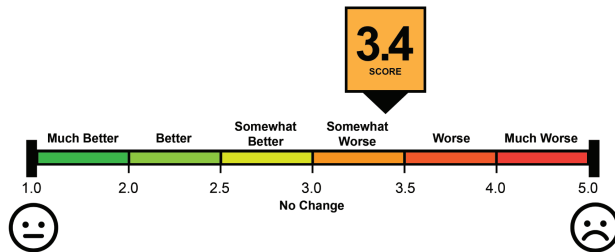
B

Change in Manuel's mental functioning compared to 10 years ago

Figures 7. (a, b) Scores on the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) can range from 1 ("much better") to 5 ("much worse") as shown in panel a but caregivers rejected the notion of improvement to the point of incorrectly interpreting values between 1 and 3 as signaling the beginning of inevitable decline. The truncated version shown in panel b was preferable and interpreted correctly despite the nonideal 3–5 scaling.

graphics than with a questionnaire, because they interact with one another.]" (Group 4, general comment)

Tailored Infographics as Cues to Action

Participants reacted to unfavorable results within an infographic by describing how the infographic would motivate them to engage in self-management. For example, one participant gave interpretations for different scores on the Geriatric Depression Scale:

"If you were to give this to me and say 26–27, I have issues. I need to really be able to get some help. If I come back with 5, I am glad that I am not . . . with all this burden that I have and all the responsibilities, and all

the whatever, I am still okay. I am 14: I have to have a concern that I need to do things probably differently in order to not get severe in my depression." (Group 6, Figure 5)

In particular, participants felt it was imperative to preserve their own health in order to meet the demands of caregiving: "Si tú estás más enfermo que ella, ¿cómo tú la vas a cuidar? *[If you're sicker than she is, how are you going to care for her?]*" (Group 2, Figure 1). Participants mentioned a variety of self-management approaches they might take to relieve stress including yoga, art, prayer, exercise, singing and dancing, spending time with loved ones, and getting caregiving help.

Participants saw value in a hypothetical online system where they could self-administer instruments and see their result as a tailored infographic. However, participants pointed out that additional information would be needed to supplement the infographics such as suggestions for self-management and linkage to caregiving resources. Participants also wanted guidance on which results are actionable. For example, there are no cutpoints associated with the EQ-5D (overall health), so it is not clear when scores become worrisome: "So the question that I have for you is at what point does it become a problem? Is this 70%? Is that where it falls?" (Group 6, Figure 1). One potential pitfall participants noted is that unfavorable results have the potential to alienate the people who need support the most: "The worse [the caregiving burden] gets the less I would check in because I don't want to face it [laughter]" (Group 3, Figure 2).

Discussion and Implications

In this study, we demonstrated that tailored infographics helped caregivers make sense of their health status by supporting comprehension. As predicted by the HBM, they also served as cues to action by motivating caregivers to consider the self-management steps they would take in a given situation. Key findings to inform best practices are that infographics should use intuitive scaling that is consistent with viewers' frames and be presented in a context that supports self-management processes.

Participants preferred scaling that was intuitive for them—most seemed to be very comfortable with percentages—and, whenever possible, consistent across variables/topics. This finding is consistent with studies that evaluated various graphical formats for displaying a variety of laboratory values and patient-reported outcomes (Nystrom et al., 2018). One set of studies found that participants made more accurate interpretations of trends over time when high values were associated with positive value judgments ("higher = better," e.g., a rising physical function score is good) rather than negative ones ("higher = more," e.g., a rising fatigue score is bad) (Brundage, Smith, Little, Bantug, & Snyder, 2015; Snyder et al., 2017). By contrast, our participants preferred that data

consistently be displayed with favorable (low) values on the left and unfavorable (high) values on the right, to match their frame of inevitable decline. Taken together, these results suggest that the direction of the scaling should, whenever possible, be matched to the likely frame of the viewer in regards to the topic at hand. For example, a caregiver who also happens to wear a fitness tracker may apply a frame of inevitable decline to displays related to dementia, but a frame of striving for improvement for displays related to their own level of fitness. Of course, it is not always possible to manipulate scaling or make displays consistent across variables as is the case in HIV care when comparing CD4 counts to viral load because these are absolute counts that trend in opposition to one another. For psychometric instruments, any changes to scaling must be weighed against the possibility of confusion if the original scaling is in wide use among clinicians or in patient-facing displays.

Our finding that caregivers saw tailored infographics as cues to health-promoting actions highlights the importance of presenting the infographics in a context in which additional supports are available for selecting those actions. This conclusion is similar to that of Giardina, Baldwin, Nystrom, Sittig, and Singh (2018) who found that patients viewing test results via online portals needed additional supports, such as linkages to educational websites, to contextualize the information and identify appropriate next steps. Online, tailored infographics can be presented alongside infobuttons that link to more in-depth explanations of the topics/results, caregiving tips, community resources, and more (Long, Hulse, & Tao, 2015). Offline supportive contexts could include encounters with clinicians or community health workers in which additional information is given face-to-face on an as-needed basis. Tailored infographics present an opportunity to promote awareness of health issues, increase knowledge competencies, enhance client engagement, and establish or strengthen linkages to care.

Caregivers were amenable to the idea of using an online system that would allow them to self-administer instruments and receive tailored infographics with their results. They even raised the possibility of using graphical enhancements not just in the delivery of results but also as part of the data collection process. Graphical enhancement could be as simple as adding color coding to response options or more complex as in the Dartmouth COOP Functional Assessment Charts where every response option for each item is illustrated (Nelson et al., 1987). Few studies have explored the effect graphical enhancements on data quality or on instruments' psychometric properties (Jenkinson, Mayou, Day, Garratt, & Juszczak, 2002), so further research is warranted prior to implementation.

Clinical Implications

On the basis of prior research on interventions for caregivers, we know that the information caregivers appreciate most is about dementia and its impact, alongside resources to manage and cope with the burden of the disease (Luchsinger et al., 2018). Most existing caregiver information includes these types of educational components, but our study shows that well-designed tailored infographics can facilitate the delivery of the information, to ultimately benefit caregivers' coping abilities, and mental and physical well-being.

Limitations

One limitation of this study is the possibility that social desirability bias constrained negative feedback. We minimized this limitation by asking open-ended questions and encouraging constructive criticism. Another is that we used simulated data to tailor the infographics. We do not know if participants might react differently when faced with their own data, especially if the topic is stigmatized, such as psychological distress. Further research is needed on this topic. A third limitation is that it is not clear to what extent our findings will be transferable to other groups of caregivers. Acceptable labeling, colors, and imagery can be expected to vary based on the cultural context of the viewer. That said, we do not consider any aspects of the successful English-language designs from this study to be specific enough to Hispanic culture as to preclude acceptability to a broader range of caregivers. For example, the acceptability of weather-in-the-head as a representation of psychological distress is consistent with English- and Spanish-language Google image search results which presumably reflect the prevailing cultural associations.

Conclusions

The findings from this study advance knowledge by identifying specific graphical elements that contribute to the comprehensibility of infographics used to convey health status. Further, they highlight the critical importance of presenting information in ways that match the frames viewers are likely to bring to a topic. These advances are important because adequate comprehension is a prerequisite to caregivers' recognition that a specific cause of a potential health issue, such as a high level of caregiving burden, should be addressed. Given appropriate informational supports, caregivers will be in a better position to recognize threats to their health status and take appropriate preventive self-management actions to avoid or diminish negative health consequences of caregiving.

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Conflict of Interest

None reported.

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