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Bruce Ovbiagele

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‘Al Pie De La Letra’

Crafting a Report Card for Elderly Spanish-Only–Speaking Patients With Stroke

Bruce Ovbiagele, MD, MS

Background and Purpose—Ethnic minorities are at higher stroke risk than non-Hispanic whites yet are less likely to have optimal vascular risk factor control. There is a need to develop culturally sensitive strategies for enhancing vascular risk reduction in minority patients with stroke. This study aimed to develop a postdischarge report card to boost treatment adherence among elderly Spanish-speaking patients with stroke within an urban health system.

Methods—This study included a total of 13 Spanish-only speaking participants aged ≥60 years discharged from a local government hospital in Los Angeles within 18 months of an index ischemic stroke and 6 caregivers engaged in focus groups and interviews. Structured interviews were conducted with 11 care providers and 9 administrators at the hospital. Framework analysis examined the data and elicited themes to adapt a pre-existing patient report card tool.

Results—Spontaneously using the same phrase, “Al pie de la letra,” several participants expressed a need to follow medical instructions accurately to prevent recurrent stroke and identified barriers/facilitators for doing so. They made comments about the pre-existing report card, advising several changes, including the clarification of phrases, and written instructions to explain the need for the card and how to fill it out. The providers and administrators recommended avenues for successfully using the card at the hospital. A new report card was created that incorporated all major perspectives.

Conclusions—Crafting a culturally sensitive tool for promoting treatment adherence in elderly Spanish-only-speaking patients with stroke within an urban health system using a participatory methodology is feasible. The efficacy of this new report card should be tested in a randomized controlled trial. **(*Stroke*. 2010;41:771-777.)**

Key Words: adherence ■ elderly ■ focus groups ■ health services research ■ interviews ■ ischemic ■ outcomes ■ prevention ■ quality improvement ■ Spanish ■ stroke

There is a need to craft and validate effective poststroke hospitalization treatment adherence interventions to complement already existing successful inpatient quality improvement programs.[1] In particular, ethnic minorities who disproportionately shoulder the burden of stroke are also less likely than non-Hispanic whites to receive optimal stroke care or have their risk factors well controlled.[2]

Because Hispanics are now the largest US minority population, and continue to grow and age, optimal measures to target this population for stroke prevention and bridge the ethnic divide are critical.[3] Improving access to quality stroke care through ethnically sensitive strategies may enhance outcomes in these individuals.[4] Major barriers to stroke risk factor control in many elderly Hispanics include poor language comprehension, poor physician–patient communication, cultural differences, low educational level, multiple comorbid medical conditions, and lack of health insurance.[5]

Focus group methodology elicits responses to a standard set of topics in a group setting and is widely used to find out why people feel as they do.[6] With a skilled moderator, the group setting stimulates discussions that would not occur in dyadic interactions and encourages participants to explore similarities and differences of opinions and experiences.[7]

Using mainly focus group methodology, the objective of this qualitative study was 3-fold: (1) to assess the feasibility of conducting qualitative investigation in Spanish-only-speaking elderly patients with stroke; (2) to obtain information about barriers and facilitators of compliance to guideline-recommended biomarker goals for vascular risk reduction after stroke in this population; and (3) to modify an existing recurrent stroke prevention tool to ensure it is culturally appropriate for older Spanish-only-speaking Hispanics for potential future testing in a randomized controlled trial.

Methods

The Adaptation and Development in High-risk Hispanic Elderly patients of a Report card intervention to prevent vascular Events (ADHERE) project was implemented at the Olive View-UCLA

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From the Stroke Center and Department of Neurology, UCLA Medical Center, Los Angeles, Calif.

Correspondence to Bruce Ovbiagele, MD, MS, Stroke Center and Department of Neurology, University of California at Los Angeles, 710 Westwood Plaza, Los Angeles, CA 90095. E-mail Ovibes@mednet.ucla.edu

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Table 1. Adaptation and Development in High-Risk Hispanic Elderly Patients of a Report Card Intervention to Prevent Vascular Events (ADHERE) Project: Prespecified Target Groups and Issues

ADHERE Target Groups	ADHERE Target Issues
6 patient/caregiver focus groups with at least 5 participants each (including both bilingual caregivers)	Beliefs about stroke risk factor control and prevention; Existing self-management skills, strategies, experiences; Expectations/preferences; Literacy/reaction to/perceived use of written health information; Impressions of patient report card tool.
Approximately 10 healthcare provider interviewees, including neurologists, primary care physicians, nurses, dieticians, physiatrists, pharmacists, social workers (English-speaking only and bilingual)	Current approaches to vascular risk factor control and perceived gaps in care; Cultural competence/communication; Knowledge of treatment guidelines; Impressions of patient report card tool.
Approximately 10 healthcare administrator interviews (chiefs of hospital administration, nursing administration, neurology, ambulatory care, medicine, social work, information technology, pharmacy)	Existing care coordination personnel and models for other conditions/populations; Available risk factor control programs; Information technology systems support/assessment of accessibility/adequacy of administrative databases and systems for use in intervention; Impressions of patient report card tool.

Medical Center (OVMC) between January through June 2009. OVMC is a local government-run hospital affiliated with a university. Hispanic patients account for approximately 80% of the hospital's yearly census. The main study subjects were elderly Spanish-only-speaking Hispanic patients with stroke, but input was also obtained from caregivers of these patients as well as OVMC healthcare providers and administrators. An overview of the target groups and pertinent information to be obtained from these individuals is shown in Table 1.

Main Subject Eligibility Criteria

Inclusion criteria consisted of Hispanic ethnicity; Spanish-speaking only; age ≥60 years; ischemic stroke within 2 years; and atherogenic index stroke mechanism or Framingham coronary risk score >20%.

Main subject exclusion criteria consisted of any medical condition that would limit participation in follow-up assessments; severe cognitive impairment/dementia (Mini-Mental State Examination score ≤24); and severe global disability (modified Rankin Score ≥3).

These exclusionary criteria applied only to participation in the patient focus groups. Caregivers of excluded patients were permitted to participate in the caregiver focus group.

Patients were recruited from the OVMC inpatient stroke service or outpatient stroke clinic. To ensure the inclusion of stroke survivors along the continuum of postdischarge stroke care, patients were recruited at the time of hospital discharge, 3 to 6 months after the index stroke and approximately 1 year after the index stroke. To gain as broad a perspective as possible, subjects were recruited with a wide range of disease severity and stage, roughly equal proportions by sex, and a range of ages >60 years. An ADHERE research coordinator identified subjects through emergency department, inpatient neurology service, and stroke clinic screening logs. All recruitment materials were in Spanish and English.[8] All subjects provided written informed consent. The local Institutional Review Board approved the study.

Providers were interviewed about systems currently in place for enhancing stroke patient follow-up adherence behavior as well as suggestions for avenues for improvement. Recruitment of providers and administrators was done by phone, e-mail, or verbal invitation.

Tool for Adaptation

The patient report card tool to be adapted (at www.strokeprotect.mednet.ucla.edu), available in English, was based on expert consensus guideline recommendations and incorporates 9 program goals, each of which a patient receives 1 point if they are in compliance with the goal. Patients are then scored with a letter grade based on their level of compliance. There are 3 medication goals, 3 lifestyle modification goals, and 3 target biomarker goals. Before study initiation, we created a Spanish version of the Preventing Recurrence of Thromboembolic Events through Coordinated Treatment (PROTECT) Report Card to be used for the focus groups.

Focus Groups

Representatives of a communications company conducted the focus groups and interviews in Spanish and moderated/transcribed. No care providers were present during the focus group sessions or interviews. To facilitate patient and caregiver discussion guides, demographic surveys were also used during the meetings. The guides, which contained open-ended questions, were used by the focus group moderator/interviewer to elicit comments and opinions from respondents. Themes in the guides as well as other related issues brought up spontaneously by the participants were explored during the focus groups and interviews. Demographic surveys probed characteristics like age, schooling, and medical insurance category, among other information. The focus groups and interviews were audiotaped and the tapes were later transcribed.

Provider and Administrator Interviews

These in-person interviews probed information on current OVMC stroke risk factor control programs and the use/feasibility of adopting a new program for patients with stroke within the health system. Questionnaires were developed for the interviews that contained open-ended items.

Analyses

A priori, we identified distinct themes potentially affecting a range of elderly Spanish-speaking persons with vascular disease.[5,9,10] We then examined expressions found in the actual focus group transcripts (the "texts").[11] To deduce themes from focus group texts, audiotapes of all groups and interviews were transcribed, deidentified, and translated and responses to the structured questionnaire documented. After each focus group session, 2 individuals independently read transcript samples and themes identified through techniques, including repetition, linguistic connectors, transitions or naturally occurring shifts in content, and metaphors and analogies.[11] After examining portions of transcripts, consensus was reached through mutual agreement about themes to examine in detail. The aforementioned processes were conducted after the first 2 patient and caregiver focus group sessions and 5 provider interviews; modifications were then made to the report card tool based on themes derived from views and opinions of the respondents, and the updated report card was then pilot-tested during the final patient and caregiver focus group sessions as well as remaining provider/administrator interview-

Table 2. Overview of Focus Group Sessions Among Elderly Spanish-Only-Speaking Patients With Stroke Geared at Adapting a Report Card to Enhance Patient Adherence to Stroke Preventive Strategies

Issues	Barriers	Facilitators	Recommendations/Themes
Optimizing postdischarge adherence	Too much information at hospital discharge	Dedicated personnel	Streamline discharge stroke information
	Spanish translation inadequate		Increase availability of official Spanish translators
	Reluctant to ask for clarifications from doctor		Repeatedly ask if instructions are clear
Initial version of report card	Font too small, "what is that (asterisk)?"	Empowering	Enlarge font, remove asterisk
	Purpose not sufficiently apparent	Educational	Separate written instructions to explain card purpose and how to use it
	"How does it work?" "What is the purpose of it?"		
	Some phrases incomprehensible, wrong accents	Motivational	Translate phrases better
	Thought responses were to be answered yes or no (not scored)		
	Difficulty understanding exercise and biomarker goals (ie, items requiring the choice of >1 scoring option)		
Updated version of report card	Slight difficulty understanding exercise and biomarker goals	Good flow	Most understood explanation of lifestyle and biomarker goals
		Easily legible	Brief explanation of lifestyle/biomarker goals will still be needed (in addition to written explanation)
		Instructions easy to follow	

ees. Subsequently, TACT software (http://www.chass.utoronto.ca) was used to scan final transcript texts to generate word frequency lists, and text management software (ATLAS.ti 6.0) was used to mark where each theme occurred.[12] A final version of the report card was then created.

Results

The recruitment process was a time-consuming and challenging task, and many of the "confirmed" patients and caregivers (at least 8 for each scheduled session) never showed up the day of the scheduled session. Overall, 11 women and 8 men participated in the patient and caregiver focus groups. Although the aim was for at least 5 persons per focus group session, despite multiple follow-up reminders, some focus group sessions comprised <5 persons due to poor attendance. This was particularly the case with regard to the caregiver focus groups. The focus groups were held on weekend days to accommodate the work schedules of caregivers, but attendance of these sessions remained suboptimal. Ultimately, patient focus Groups 1 and 3 had 5 participants each, patient focus Group 2 had 3 participants, whereas caregiver focus Groups 1 and 3 had 2 participants each and caregiver focus Group 2 had only 1 participant. As such, the intended caregiver focus groups were generally individual or group interview sessions.

Of the 13 stroke survivors who participated in the patient focus groups, ages ranged from 62 to 75 years, 7 were women, 11 were married (2 were widowers), all were first-generation immigrants who came to the United States from Latin America, 8 were from originally from Mexico, 4 from Central America, and 1 from Puerto Rico. Most (12 of 13) had <8 years of formal education, whereas 1 person had 9 years of education. Most (10 of 13) used Medicare and/or Medicaid. All patients lived in multigeneration households and to varying degrees depended on their primary caregivers or other family members for their transportation and other everyday life necessities. All had a stroke within 18 months of focus group participation, 2 within 1 month, 2 within 3 months, 3 within 6 months, 2 within 1 year, and the rest beyond 1 year of participation. Twelve of the 13 patients indicated that they still experienced some form of physical or emotional impairments associated with their index stroke.

The majority believed that they could help themselves to prevent another stroke and that following the doctor's orders would greatly increase their chances of preventing another stroke. A frequently and spontaneously mentioned phrase by several participants at different times during all focus groups regarding optimal treatment adherence was "Al pie de la letra" ("literally" or "to the letter").

In the first 2 sessions with patients, none of the respondents was able to score the card without some initial basic instructions from the focus group moderator and 2 respondents were unable to complete the task successfully

Table 3. Overview of Focus Group Sessions Among Caregivers of Elderly Spanish-Only-Speaking Patients With Stroke Geared at Adapting a Report Card to Enhance Patient Adherence to Stroke Preventive Strategies

Issues	Barriers	Facilitators	Recommendations/Themes
Optimizing postdischarge adherence	Different caregivers accompany patient	Dedicated personnel	Caregivers play central role
			Speak to as many family members as possible and ask information to be passed along to others
	Lifestyle changes more difficult than medication compliance due to patients' set ways		Put most emphasis on lifestyle changes
Initial version of report card	Purpose not clear enough; only one caregiver [daughter] filled card out without explanation	Empowering	Separate written instructions needed especially for lifestyle and biomarker goals
	Greatest difficulty understanding lifestyle and biomarker goals		Have backup card copy in hospital
	Patients/family may lose card or forget to bring it to hospital		Make sure every doctor is aware of card"they change all the time!"
Updated version of report card	A few phrases not well translated	Generally easy to understand	Change some sentences for better clarity

even after a full explanation as to what was required of them. A summary of the main themes of the patient focus groups is shown in Table 2.

The 6 participating caregivers were either female spouses or daughters of a stroke survivor. Two of the caregivers (daughters) were bilingual. A summary of the main themes of the caregiver focus groups/interviews is shown in Table 3.

Of 20 interviews conducted, 9 were with administrators and 11 with providers. The length of experience at OVMC ranged from 15 months to 30 years. Administrators included both nurses and doctors overseeing the medical center, nursing center, quality control, pharmacy, and clinical programs (including neurology and primary care). Providers included neurologists, generalists, pharmacists, nutritionists, nurses, social worker, and physical therapists. Four of the providers were fluent in Spanish. Summaries of the main themes of the provider and administrator interviews are shown in Tables 4 and 5. The final version of the new report card and instructions are shown in the Supplemental Appendix, available online at http://stroke.ahajournals.org.

Discussion

This study shows that it is feasible to conduct qualitative investigation to improve care among Spanish-speaking-only elderly patients with stroke seen and their caregivers encountered within an underresourced local government healthcare system. The study also successfully obtained the opinions and recommendations of healthcare providers and administrators within the same system about optimizing stroke treatment adherence in these patients. However, the number of focus group participants did not meet prespecified goals, particularly for the caregivers, and given their central role in the continuing medical care of these patients, future qualitative studies will need to implement strategies to better promote the full participation of caregivers of this patient population. Still, there are relatively few studies that have explored patient and caregiver views in developing secondary stroke prevention tools,[13] and no published studies were found incorporating the views and recommendations of Spanish-only-speaking patients with stroke in the crafting of a tool to promote treatment adherence.

Patients and caregivers were fully aware that correctly adhering to medical instructions could help them prevent another stroke but were much less aware of the link between complying with drug prescriptions/lifestyle habits/biomarker control and stroke risk. Many of the thematic contributors to this knowledge-implementation gap, including information overload at hospital discharge, language barriers, cultural reluctance to query providers, inadequate financial resources, and difficulty changing traditional habits, have been observed in prior studies of patients with stroke in general or Hispanic patients in particular.[1,5,13] Most of the potential challenges noted by the providers and administrators related to inadequate resources (mostly financial), which are not readily amenable to prompt solutions, in this healthcare setting. However, issues like insufficient provider knowledge could be addressed through educational in-services and program feedback, whereas time constraints and some cost issues may be mitigated through cost-neutral tools that work within the pre-existent hospital framework.

Beyond feasibility, a major study goal was to arrive at a culturally acceptable patient report card that can improve

Table 4. Overview of Healthcare Provider Interviews Geared at Adapting a Report Card to Enhance Adherence to Stroke Preventive Strategies Among Elderly Spanish-Only-Speaking Patients With Stroke

Issues	Barriers	Facilitators	Recommendations/Themes
Optimizing postdischarge adherence	Poor inpatient–outpatient care transition	Dedicated personnel	Project must be properly translated and culturally acceptable
	Widespread electronic chart access not available	Prominent support system (caregivers)	Educate providers frequently
	Time constraints		
	Inadequate financial resources (hospital and patients)		
	Patients not used to preventive health care (some interviewees estimated that only approximately 10% of their patients comply with instructions		
	Many providers unfamiliar with prevailing stroke prevention guidelines		
	Immigration status concerns may influence limit compliance		
	Patients very used to their traditional diets (also healthy foods expensive)		
	Insufficient availability of proper in-person Spanish translators		
	High prevalence of untreated hearing and vision problems		
	Attitude of fatalism (may believe poor outcomes inevitable)		
	Transportation challenges (may travel by public transportation)		
Initial version of report card	A little too sophisticated	Empowering and educational	Get caregivers centrally involved
	Not intuitive enough; approximately 20 minutes will be needed to explain it	Medical terminology generally limited	Simplify as much as possible
	Smoking should not treated equally with fruit/vegetable consumption	Hospital already has successful diabetes clinic tool: booklet with blood pressure and blood sugar values entered at each visit (by nurse) and discussed with patient	Better for time savings and reinforcement if patient fills out card before seeing doctor
	Self-report may unreliable because patient eager to please doctor	May also remind or inform providers about discussing lifestyle goals	If patient genuinely unable to obtain relevant drugs due to bureaucratic issues should be given credit
	Patients may be unable to obtain relevant drugs regularly due to bureaucratic issues	Biomarker inclusion provides objective evidence of adherence/improvement	
		Consistency: “they don’t always see same doctor”	
Updated version of report card	Will still require brief verbal instructions	Good written explanation of card	Allow for brief additional verbal instruction
		Seventh grade readability	Make card sturdy and foldable
			Include boxes with dates so patient can see change patterns

care in this population. Although information interventions improve patient and caregiver knowledge of stroke and satisfaction,[14] they have not been linked to enhancements in harder outcomes. It is increasingly clear that traditional patient education not only provides information, but that self-management education imparts a level of self-efficacy, that is, ability to carry out a behavior required to reach a desired goal.[15] Controlled clinical trial data indicate that tools that incorporate self-management skills are more effective than information-only patient education in

Table 5. Overview of Healthcare Administrator Interviews Geared at Adapting a Report Card to Enhance Adherence to Stroke Preventive Strategies Among Elderly Spanish-Only-Speaking Patients With Stroke

Issues	Barriers	Facilitators	Recommendations/Themes
Optimizing postdischarge adherence	No money	"Clinical directors are always looking for ways to improve patient carewe are very proactive"	Get support from administration
	No integrated pharmacy database to track refills	Dedicated personnel	Use outpatient case managers
	Space limitations	Virtually all social workers are bilingual	Communicate and coordinate: hospital QI committee, and nursing best practice committees
	Language, culture, lack of understanding of OVMC health system		Update IT systems (electronic outpatient records and pharmacy refill tracking)
	Majority of provider do not speak Spanish		
Initial version of patient report card tool	"Yes and no responses would be better . . . but may remove reinforcement benefits of numerical scores"	Educational	Simplify language further
		Similar tool already used in diabetes clinic	
Modified version of patient report card tool	Will likely still need additional brief verbal explanation by providers		Get okay from "above"
			Ensure it is cost- and time-neutral for sustainability
			Involve all key personnel and communicate frequently
			Pilot project first

QI indicates quality improvement; IT, information technology.

improving clinical outcomes and reducing costs.[15] Indeed, it has been suggested that self-management education should play a central role in high-quality chronic care. It is with this backdrop that this study created a simple, culturally acceptable patient report card, which contains information on major secondary stroke prevention goals that the patient/caregiver has to be aware of, fill-in, update, be reminded about (with positive scoring reinforcement), and bring to each stroke or primary care clinic visit.

The study has limitations. The focus groups participants may not be fully representative of the target patient/caregiver population and provider/administrators were from a single hospital, so a complete range of views may not have been captured. As such, there is no guarantee that the report card will necessarily be applicable to all Spanish-only-speaking elderly patients with stroke encountered in an urban underresourced setting. It is also conceivable that the relatively small sample may have been biased to more compliant and more literate patients and caregivers. Still, the themes discussed in this article were dominant throughout the focus group discussions and interviews and were in accord with some prior themes reported in the literature. Given the aforementioned limitations, focus groups and structured interviews are used to generate hypotheses rather than test them. The efficacy of the card in promoting treatment adherence and perhaps lowering vascular risk in this population will need to be rigorously evaluated in a future randomized controlled trial.

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