A Tool to Strengthen the Older Patient-Companion Partnership in Primary Care: Results from a Pilot Study

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Abstract

Objectives—To determine the acceptability of a pre-consultation checklist for older patients who attend medical visits with an unpaid companion and to evaluate its effects on visit communication.

Design—Randomized controlled pilot study.

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Setting—Academic geriatrics ambulatory clinic.

Participants—Thirty-two patients age 65+ and their unpaid companion.

Intervention—A self-administered checklist was compared to usual care. The checklist was designed to: (1) elicit and align patient and companion perspectives regarding health concerns to discuss with the doctor, and (2) stimulate discussion about the companion's role in the visit.

Measurement—Primary outcome: ratio of patient-centered communication, coded from visit audiotapes. Secondary outcomes: checklist acceptability; visit duration; patient-companion verbal activity; patient- and physician- reported perspectives of the visit.

Results—All intervention patients and companions (n=17) completed the checklist, and all participants (n=32 dyads) completed the study. Patients and companions stated the checklist was easy to complete (88%), useful (91%), and they uniformly (100%) recommended it to other patients. Communication was significantly more patient-centered in intervention (versus control) group visits (ratio of 1.22 versus 0.71; p=0.03). Visit duration (35.0 and 30.6 minutes; p=0.34) and percent of total verbal activity contributed by patients and companions (58.2% and 56.3% of visit statements; p=0.50) were comparable in intervention and control groups, respectively. Physicians were more likely to indicate intervention (versus control) companions "helped them provide good care to the patient" (94% vs. 60%; p=0.02). Intervention (versus control) patients were more likely to indicate they "better understood their doctor's advice and explanations" because their companion was present (82% vs. 47%; p=0.03).

Conclusion—A checklist to elicit and align perspectives of older patients and their companions resulted in enhanced patient-centered medical visit communication.

Keywords

Family caregiver; primary health care; physician office; patient-provider communication

INTRODUCTION

With low levels of educational attainment[1] and a high prevalence of sensory and cognitive deficits,[2,3] many older adults are ill equipped to successfully function in today's complex health care environment. Patient-directed pre-consultation interventions have been developed to prompt patient engagement in their care.[4,5] Health literacy universal precautions have been developed to reduce health system demands.[6,7] No interventions to date specifically address the fact that 4 in 10 primary care patients – those who are older, less educated, and in worse physical health – regularly attend routine medical visits with an unpaid companion, usually a family member.[8,9] The companions who accompany older adults to medical visits participate in visit communication[8,9] and their attendance in medical visits persists over time.[10]

We developed a pre-consultation checklist to strengthen the existing but under-recognized older patient-companion partnership. The checklist was designed to:(1). elicit and align patient and companion perspectives regarding patient health concerns to discuss with the doctor, and (2). stimulate discussion about the patient's desires for assistance from the companion in the visit. In this paper we describe the checklist and present preliminary evidence of its acceptability and effect on medical visit communication in a pilot randomized study conducted in an academic geriatrics ambulatory clinic.

METHODS

Our intervention is guided by theory and informed by evidence from the patient-provider communication literature. We posit that previously described aspects of the patient-provider

relationship[11] and medical communication processes[12] may be extended to the older patient and their companion, when present. Prior studies find older patients are often unable or unwilling to articulate their desired preferences for communicating with medical providers[13,14] and that patient, family, and provider assessments of patient symptoms [15,16] and treatment priorities [17,18] commonly diverge. Medical communication that is aligned with patient information sharing and decision-making preferences is associated with varied end-points such as patient satisfaction, emotional well-being, treatment adherence, and physiologic measures such as lower symptom burden.[19] These favorable endpoints are thought to result at least in part from greater patient responsiveness when medical communication is tailored to their expectations, interpersonal behaviors, and autonomy beliefs.[19,20] We hypothesized that a pre-consultation checklist to: (1). elicit and align patient and companion perspectives regarding patient health concerns to discuss with the doctor, and (2). stimulate discussion about the role to be assumed by the companion in the visit would facilitate patient-centered communication by clarifying the visit agenda and specifying patient preferences for the companions' role in the encounter.

We sought to develop a checklist that was brief and appropriate for self-administration in a clinic waiting room. Careful attention was paid to considerations of the busy physician practice and the diverse older adult population. We reviewed a wide range of existing health-related quality of life, functional status, and needs assessment instruments to construct an item pool of common older patient concerns that were appropriate for discussion in primary care visits. To establish face and content validity, a panel of 3 geriatricians and 1 geriatric psychiatrist then reviewed and nominated candidate items for inclusion. We generated a final list of 23 common patient concerns that was balanced across physical, mental, and social role function domains.

The checklist (see Appendix) involves two activities that are completed by a patient and their companion before a scheduled appointment. The first activity involves completing the checklist of common geriatric health concerns using three steps. Instructions separately elicit patient and companion notation of concern ("not at all", "a little", and "a lot") for each health concern, and then together, to identify or negotiate which concerns to discuss with the doctor in the upcoming visit. Instructions to the patient state: "the patient may work independently or the companion may read the list and record the (patient's) answer." Instructions to the companion state: "it is fine if the companion has different concerns than the patient." In a **second** activity, patients are asked to identify ways they would like their companion to help them during their visit from a list of previously observed behaviors.[9] All text is in large (16-point) font.

Recruitment and Eligibility Criteria

We conducted a pilot study of the checklist at the Beacham Ambulatory Care Center, operated by the Johns Hopkins University Division of Geriatric Medicine and Gerontology between April and August 2012. Clinic staff mailed recruitment letters to established patients of 4 participating geriatricians with upcoming scheduled visits. Patients who did not "opt out" by mail were contacted by a member of the research team to discuss the study and administer a brief telephone screening interview. Inclusion criteria included: 65 years of age or older, English speaking, hears well enough to communicate by phone, sees well enough to read large print, typically accompanied to doctor visits by an unpaid companion, and provided contact information for their companion. As this study was designed as a proof of concept pilot study, we sought to recruit a more homogeneous clinical study sample that would be able to complete the checklist. Therefore, older adults with significant cognitive deficits on the basis of more than two incorrect answers on a 6-item cognitive screen[21] were

excluded. Comparable sensory and cognition exclusion criteria applied to companions who also completed screening calls.

Study Procedures

Eligible patient-companion dyads who expressed an interest in the study met a member of the research team 30 minutes before the patient's scheduled appointment in the physician office waiting room. After providing informed consent using an institutional review board approved form, each dyad was randomized to the checklist or to usual care using stratified, blocked randomization with alternating block sizes of 4 and 6 for each physician. Dyads assigned to the intervention received a clipboard, pen, and a copy of the checklist that they completed together in the clinic waiting room without research or office staff assistance. Dyads assigned to usual care waited for their visit as usual. All medical encounters were audio-recorded but otherwise proceeded as usual, without research or office staff involvement. Physicians, patients, and companions completed surveys immediately after the visit in the office suite. Patients and companions were contacted by telephone two weeks following the visit and were asked additional questions about the medical visit, as well as socio-demographic factors and health status. Patients and companions received a $20 gift card after the medical visit and again after the two-week telephone interview.

Study Measures

Patient attributes—Patient attributes included age, gender, living arrangement, educational attainment, self-rated health, and whether they received assistance with self-care and household activities. Patients were asked to respond to a single-item health literacy screen "how confident are you filling out medical forms by yourself,"[22] years under the care of the physician, and numbers of daily prescribed and over-the-counter medications.

Companion attributes—Companion attributes included age, gender, relationship to the patient, educational attainment, and employment. In post-visit surveys, patients, companions, and physicians were asked about visit communication. Intervention patients and companions were asked questions regarding checklist acceptability, including its utility, burden, and helpfulness.

Recordings of medical visit dialogue were coded using the Roter Interaction Analysis System (RIAS), a validated system for empirically describing medical visit communication.[23] A trained RIAS-coder who was blinded to group assignment coded visit recordings by assigning each complete statement to one of thirty-eight mutually exclusive and exhaustive communication categories. The large numbers of codes were collapsed to ten summary RIAS categories. For each RIAS summary category, we examined the proportion of visit statements contributed by the patient and companion, together, in relation to aggregate visit statements. Physician contribution to visit communication is not presented as the focus of this investigation is the patient-companion dyad. Three measures of visit processes were also examined:

1. Patient-centered communication is operationalized as a ratio of statements that encompass psychosocial and socio-emotional elements of exchange reflecting the lived experience of patients relative to statements that reflect a more biomedical and disease-focused perspective.[23,24] A value greater than 1 indicates a more patient-centered encounter, whereas a value less than 1 indicates a more physician-centered encounter.

2. Medical visit duration, expressed in minutes.

3. Patient and companion verbal activity, reflecting the proportion of total visit statements contributed by patient and companion.

Data Analysis

Analyses were performed in SAS statistical software, version 9.3 (SAS, Cary, NC), with each patient-companion dyad and their recorded medical encounter as the unit of analysis. Simple descriptive statistics (frequency distributions, group means) were used to evaluate between-group differences in patient and companion attributes and patient, companion and physician post-visit responses to questions about visit communication and the role of the companion.

RESULTS

Study Sample Characteristics

Recruitment letters were mailed to 263 established patients of four participating geriatricians with upcoming scheduled visits. Of these patients, 20 (7.6%) returned cards indicating they were not accompanied, 42 (16.0%) refused participation by mail, and 42 (16.0%) patients could not be reached. Screening calls were made to 159 (60.5%) patients: 70 (26.6%) were not eligible, 53 (20.2%) refused participation, 4 (1.5%) were not available due to rescheduled appointments. A total of 32 patients and companions were eligible and consented to participate. These 32 dyads were randomized to usual care (n=15) or to the checklist (n=17); all 32 patients and companions (100%) completed follow-up interviews (Figure 1).

Enrolled patients (n=32) were on average 81.8 years, female (59.4%), lived alone (61.3%), and completed high school (41.9%) or some college (41.9%; Table 1). Approximately one-third (34.4%) of patients were suspected of low or marginal health literacy.[22] Patients rated their health as excellent/very good (28.1%), good (31.3%), or fair/poor (40.6%). They were taking an average of 8.9 prescribed and over-the-counter medications daily. Patients received assistance with dressing or bathing (15.6%), coordination of services (34.4%), managing medications (43.8%), scheduling physician appointments (46.9%), medical bills and paperwork (50.0%), coordination of health information (53.1%), and transportation (75.0%). Patients overwhelmingly indicated their companion was the person who helped the most with these activities (87.5%). Companions were mostly spouses (31.3%) and adult children (53.1%). Nearly half (45.2%) of companions were employed for pay and they worked an average of 30 hours per week. No group differences in patient characteristics were statistically significant. Companions in the control (versus intervention) group were more likely to be female (86.7% versus 52.9%; p=0.04).

Acceptability of Checklist

Intervention participants responded to questions regarding checklist burden, utility, and helpfulness. All patients (100%) and most companions (81.3%) indicated that the amount of time it took to complete the checklist was "just right." The vast majority of patients (94.1%) and companions (87.5%) agreed or strongly agreed that completing the checklist was useful, and easy to complete (88.2% for patients and companions). Most patients agreed or strongly agreed that completing the checklist improved their companion's understanding of their most important concerns (82.4%) and discussions with the doctor (88.2%). Patients and companions unanimously (100%) stated that they would recommend completing the checklist to other patients and nearly all (94.1% of patients and 100% of companions) indicated they would like to continue responding to the checklist in the future.

Group Differences in Communication—Communication was significantly more patient-centered in intervention (versus control) group visits (patient-centered communication ratio of 1.22 versus 0.71; p=0.03). Intervention patients and companions engaged in significantly less biomedical information exchange than patients and companions in the control group (34.0% versus 47.8% of visit statements, respectively; p<0.01)but asked more lifestyle and psychosocial questions (0.9% versus 0.3% of visit statements, respectively; p=0.03) and provided more lifestyle and psychosocial information (22.8% versus 15.9% of visit statements, respectively; p=0.05). Visits for patients in the intervention group were 4.4 minutes longer than control group visits (35.0 versus 30.6 minutes; p=0.34; see Table 2). Percent of total verbal activity contributed by patients and companions was comparable for intervention and control group dyads (58.2% versus 56.3% of visit statements, respectively; p=0.49).

Group Differences in Patient, Companion, and Physician Perspectives on Communication—Physician, patient, and companion responses to questions about medical visit communication suggest that intervention (versus control) group companions were more active in facilitating information exchange. Physicians were 34% more likely to agree or strongly agree that intervention (versus control) group companions "helped them provide good care to the patient" (94.1% vs. 60.0%; p=0.02). Intervention patients were more likely to agree or strongly agree that because their companion was present they "better understood their doctor's advice and explanations" (82.4% vs. 46.7%; p=0.03) and that "their doctor understood their concerns more fully" (64.7% vs. 40.0%; p=0.31) than their control group counterparts.

CONCLUSION

Our study indicates that a pre-consultation checklist to strengthen the partnership between the older patient and their unpaid visit companion is acceptable and may confer benefit to medical visit communication. Patient-companion dyads successfully self-administered the checklist in a clinic waiting room immediately prior to a scheduled visit. Nearly all intervention participants reported the checklist was helpful to visit discussions and expressed a willingness to continue responding to it in the future. Our most notable findings relate to the consistency across both post-visit survey responses and audio taped dialogue suggesting that intervention group companions were more actively engaged in the medical visit in a manner that was beneficial to patient-centered communication. Intervention patients and companions engaged in significantly more lifestyle and psychosocial dialogue and less biomedical discussion, differences that are indicative of more patient-centered care.[24]

Study participants are drawn from a complex older patient population for whom evidence-based guidelines are less applicable and quality of care is poor.[25,26] Enrolled patients were on average 82 years of age, taking nearly ten daily prescribed and over-the-counter medications and they were overwhelmingly accompanied by the spouse or the adult child they reported helped them "the most" with health-related activities. That patients' companions were generally more highly educated and in better health, and that their role was endorsed as influential to information exchange and understanding is consistent with foundational frameworks[27] and qualitative studies[28] suggesting that social support may bridge communication barriers and health literacy deficits for vulnerable patients. Companions were generally younger than patients; cohort differences may exist in regard to patient and companion preferences and expectations for interactions with medical providers.

Our intervention acknowledges the independent perspective and role of companions in older patients' health care encounters. By striving to engage the companion as desired by the patient, our intervention is consistent with ethical guidance recently set forth by physician

organizations in emphasizing respect for patient dignity, rights, and values, the use of physician communication to support accurate and shared understanding of the patient's condition and treatment goals, and the value of family involvement in continuity of care.[29] Although patient privacy has been raised as an impediment to health care strategies that formally recognize and partner with patients' broader social support networks, concerns regarding patient privacy did not emerge as a problem in this study. Potential unintended consequences of the intervention that pertain to privacy, interpersonal conflict, as well as provider practice-based implications (e.g. patient flow, visit duration)will be carefully monitored in future work.

Several limitations of this study merit comment. Most notably, this was a pilot study to evaluate acceptability of a patient-companion pre-consultation checklist and establish proof of concept. Our findings suggest that a Phase III efficacy trial with a larger sample and diverse clinical settings is warranted. As a pilot, the study was not powered to detect between-group differences, or to perform multivariate analyses to account for differences in patient or companion characteristics. Given that the study was conducted in a single academic ambulatory geriatrics clinic, results cannot be extrapolated to mainstream primary care practice. Patients with severe cognitive and sensory impairments were excluded from the study, as were patients who were accompanied to their medical visit by a paid companion.

Health care delivery interventions for complex older adults have targeted patient, provider, and health system-level factors. In contrast, this intervention targeted the existing but under-recognized patient-companion partnership. The approach has several attractive and practical features. The approach is directed to a population that has been shown to be both high-risk and costly[8] and to a partnership that is enduring.[10] The strategy is practical in that it seeks to optimize a naturally occurring partnership between patients and their existing social supports. The approach that we have developed involves minimal cost and does not require restructuring of provider practice. Further research is needed to evaluate this intervention in a larger sample with longer duration of follow-up.

Acknowledgments

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Appendix. Patient-Companion Preconsultation Checklist

Instructions

The next page lists some common patient concerns. Use the following three steps to work together to review and discuss this list.

First, the *patient* should identify their level of concern ("not at all", "a little", or "a lot) for each topic. The patient may work independently, or the companion may read the list and record the patient's answer. Circle the number that reflects the patient's stated level of concern.

Next, the *companion* should identify their level of concern ("not at all", "a little", or "a lot) for each topic in regard to the patient's health. Draw an "X" through the number that reflects the companion's level of concern. It is fine if the companion's concerns are different than those of the patient.

Together decide which identified concern or concerns are most important to discuss with the doctor. Use the right column to check at least three topics to discuss with your doctor today.

It is important to remember that doctors are used to talking about all kinds of health and personal matters, including topics that may be sensitive, like memory problems, depression, or sexual function. Talking honestly with your doctor about your concerns is the first step in an effective partnership.

Concerns to Discuss with Your Doctor Today

Common Concerns	Level of Concern			Discuss with Doctor
	Not at All	A Little	A Lot	
Shortness of breath	1	2	3	
Pain	1	2	3	
Falling or fear of falling	1	2	3	
Dizziness or balance	1	2	3	
Hearing or vision	1	2	3	
Trouble with sleep	1	2	3	
Lack of energy	1	2	3	

Common Concerns	Level of Concern			Discuss with Doctor
	Not at All	A Little	A Lot	
Incontinence/bladder problems	1	2	3	
Constipation or bowel problems	1	2	3	
Poor appetite or weight loss	1	2	3	
Concerns about driving	1	2	3	
Difficulty bathing, dressing, or walking	1	2	3	
Receiving the help I need	1	2	3	
Getting out to do the things I enjoy	1	2	3	
Regular exercise	1	2	3	
Stress or worry	1	2	3	
Feeling sad or blue	1	2	3	
Trouble concentrating or remembering	1	2	3	
Sexual function or sexuality	1	2	3	
Smoking or alcohol use	1	2	3	
Medication issues side effects	1	2	3	
Results from a lab test or consultation	1	2	3	
Keeping up with appointments	1	2	3	
Other issues/concerns	1	2	3	
	1	2	3	

Help from Your Companion

Having a companion attend a doctor visit can be useful, particularly when they know *how* to help. Listed below are several ways a companion might support a patient during their doctor visit. Read through this list together. Then, the *patient* should identify what help they would like from their companion during today's visit.

There may be some visits where a patient would like the help of their companion and other visits they prefer to attend alone. This is fine too. Often, it is just a matter of talking about your wishes. Take a few minutes to talk about the visit today.

I would like my companion to (check all that apply)
Listen to what the doctor says.
Take notes (for example, about your diagnosis, medications, diet, or referrals).
Remind me to ask my questions.
Ask the doctor questions directly, on my behalf.
Remind me to tell the doctor about my symptoms.
Provide information about my health to the doctor.
Make sure I understand what the doctor says.
Stay in the waiting room for part of the visit.

I would like my companion to (check all that apply)
Stay in the waiting room for the entire visit so that I may talk to the doctor alone.
List other help you would like from your companion below:

There may be some visits where a patient would like the help of their companion and other visits they prefer to attend alone. This is fine too. Often, it is just a matter of talking about your wishes. Take a few minutes to talk about the visit today.

Stage One: Mailed Letter from Clinic Medical Director to Established Patients with Scheduled Visit in 4-Month Period; n= 263

Card returned by mail to study:
Not Eligible: n=20 (8%)
 --not accompanied, n=20
Refuse: n=42 (16%)
--too sick/tired, n=12
--do not want visit taped, n=10
--too busy, n=5
--too much trouble, n=2
--other/unspecified, n=13

Unable to Contact: n=42

Not Eligible: n= 70 (27%)
--<65 years, n=1
--hearing/vision, n=7
--English language, n=1
--demented, n=19
--not accompanied, n=37
--paid companion, n=1
--NH/hospital, n=3
--deceased, n=1
Refuse: n= 53 (20%)
--time, n=12
--do not want visit taped, n=2
--not interested, n=35
--other, n=4
Reschedule Appt: n= 4 (2%)
Eligible: n= 32 (12%)

Stage Two:
Patient and Companion Screen
n=159 (61%)

Stage Three: Randomized n= 32

Experimental Group
N= 17   Allocated (53%)
 0   Rescinded consent

Control Group
N= 15   Allocated (47%)
 0   Rescinded consent

Two-week interview
N=17   Interview completed (100%)
 0   Rescinded consent
 0   Unable to contact

Two-week interview
N=15 Interview completed (100%)
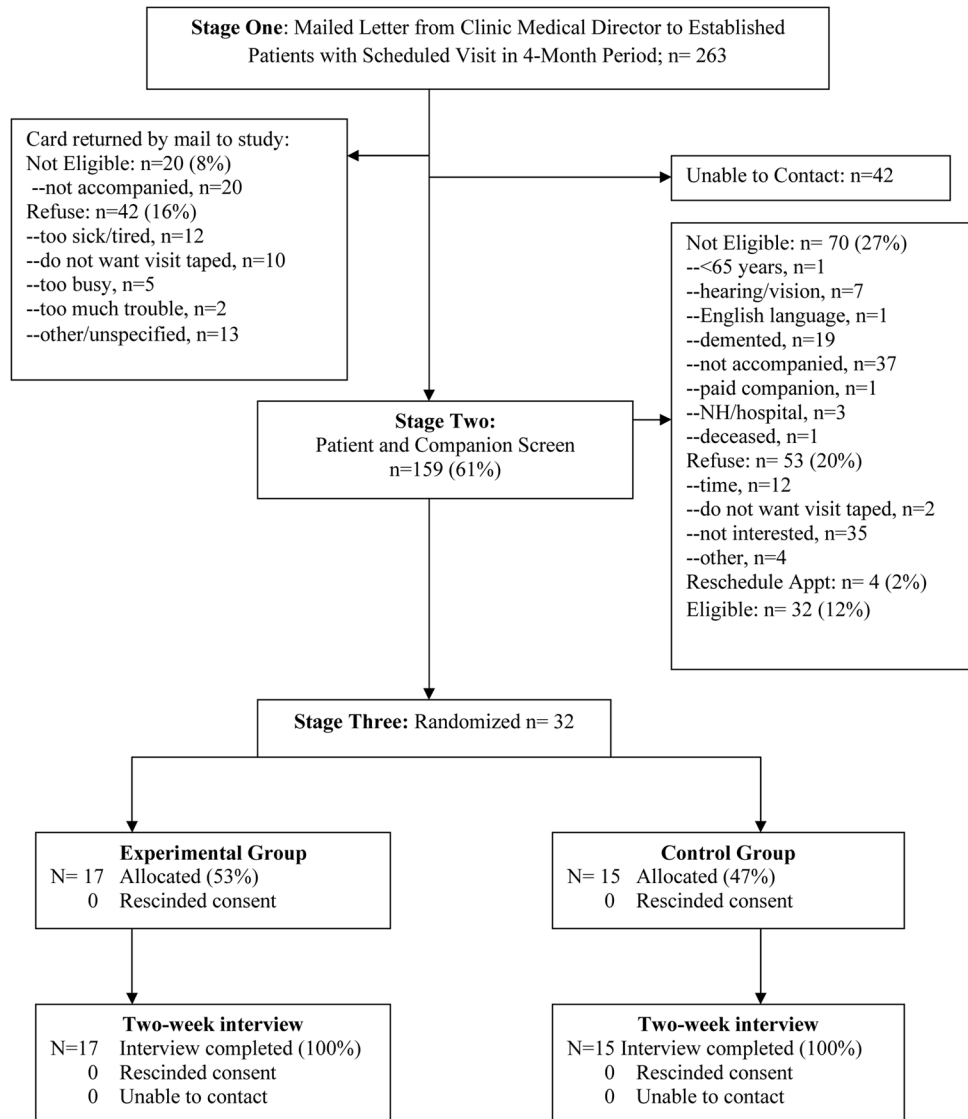 0   Rescinded consent
 0   Unable to contact

Figure 1.
Study Participant Recruitment and Randomization.

Table 1

Enrolled Study Sample by Group Assignment

Patient Characteristics	Total Sample (n=32)	Group Assignment		P-value
		Checklist n=17 (53.1%)	Usual Care n=15 (46.9%)	
Age; mean (range)	81.8 (65–99)	80.7 (65–99)	82.9 (69–96)	0.471
Female; n (%)	19 (59.4%)	9 (52.9%)	10 (66.7%)	0.446
Lives alone; n (%)	19 (59.4%)	10 (58.8%)	9 (60.0%)	0.660
Educational attainment; n (%)				0.706
Elementary	5 (16.1%)	2 (11.8%)	3 (20.0%)	
High school	13 (41.9%)	7 (41.2%)	6 (40.0%)	
College or beyond	13 (41.9%)	7 (41.2%)	6 (40.0%)	
Self-rated health; n (%)				0.626
Excellent/Very Good	9 (28.1%)	6 (35.3%)	3 (20.0%)	
Good	10 (31.3%)	6 (35.3%)	4 (26.7%)	
Fair/Poor	12 (38.7%)	5 (29.4%)	8 (53.3%)	
Lower literacy; n (%)	11 (34.4%)	4 (23.5%)	7 (46.7%)	0.169
Years under physician care; mean (range)	3.9 (1–15)	3.9 (1–15)	3.9 (1–10)	0.954
Daily medications; mean (range)	8.9 (4–22)	9.9 (4–22)	7.8 (4–17)	0.232
Companion Characteristics				
Age; mean (range)	62.4 (35–81)	60.6 (35–79)	64.6 (48–81)	0.329
Female; n (%)	22 (68.8%)	9 (52.9%)	13 (86.7%)	0.040
Relationship to Patient; n (%)				0.604
Spouse	10 (31.3%)	4 (23.5%)	6 (40.0%)	
Adult Child	17 (53.1%)	10 (58.8%)	7 (46.7%)	
Other (friend, partner, other relative)	5 (16.1%)	3 (17.6%)	2 (13.3%)	
Educational attainment; n (%)				0.762
High school	6 (18.8%)	4 (23.5%)	2 (13.3%)	
College or beyond	26 (81.3%)	13 (76.5%)	13 (86.7%)	
Employed for Pay; n (%)	14 (43.8%)	9 (52.9%)	5 (33.3%)	0.265

Table 2

Group Differences in Communication

	Group Assignment		
	Checklist	**Usual Care**	**P-value**
Patient-Centered Communication [*]	1.22	0.71	0.034
Visit Duration (in minutes)	35.0	30.6	0.338
Verbal Activity [†]			
Patient Verbal Activity	37.7%	38.4%	0.876
Companion Verbal Activity	20.5%	17.9%	0.630
Patient & Companion Verbal Activity	58.2%	56.3%	0.498
Categories of Patient and Companion Talk[‡]			
Biomedical Data Gathering	3.2%	3.4%	0.747
Biomedical Information Giving	34.0%	47.8%	0.001
Lifestyle and Psychosocial Data Gathering	0.9%	0.3%	0.033
Lifestyle and Psychosocial Information Giving	22.8%	15.9%	0.048
Facilitation and Patient Activation	10.9%	8.3%	0.199
Positive Talk	12.8%	10.7%	0.178
Emotional Talk	9.7%	8.3%	0.720
Negative Talk	0.7%	0.6%	0.751
Social Talk	1.8%	1.6%	0.857
Procedural Talk	3.0%	2.6%	0.317

[*] Patient-Centered Communication refers broadly to the ratio of psychosocial and socio-emotional statements contributed by the patient, companion, and physician ((physician psychosocial questions, lifestyle and psychosocial information and counseling; facilitation and patient activation; positive, emotional talk) and patient and companion biomedical and psychosocial questions, psychosocial and lifestyle disclosure, and emotional talk)) relative to biomedical talk and orientations (physician biomedical questions, biomedical information and counseling; procedural talk and patient and companion biomedical disclosure).

[†] Verbal Activity reflects the proportion of statements contributed by the patient alone, the companion alone, and the patient and companion together, in relation to overall visit statements (including statements by the physician).

[‡] Categories of Patient and Companion Talk refer to the proportion of statements contributed by the patient and companion with in each RIAS summary category relative to total patient and companion visit statements (see Roter and Larson, 2002 or www.riasworks.com for more information).