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Helpers help people with intellectual and developmental disabilities and hypertension to understand their condition and the need to adhere to anti-hypertensive medication

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Abstract

Background.—Recent evidence suggests that many adults with intellectual and developmental disabilities (IDD) do not adequately manage hypertension (HTN) medication. Known risk factors for insufficient prescription filling include age, residential placement, and lack of caregiver support. This is a first report of a randomized intervention trial designed to analyze the relationship of a brief educational intervention with increased knowledge about HTN and improvement in prescription filling for anti-hypertensive medication.

Objective/Hypothesis.—The objective was to test whether an educational flyer and regular messages about HTN and the importance of refilling medication would improve scores on knowledge surveys. Participants were Medicaid members with HTN and IDD (Member) or caregivers (Helpers) who chose to participate on behalf of a Member.

Methods.—Recruitment letters explained that either the Member or their Helper could participate (not both). Participants were randomly assigned to the Case or Comparison group, and both were comprised of Members and Helpers. Only Case participants received a flyer and monthly HTN education messages for one year, but all participants completed knowledge surveys at baseline, six, and 12 months. Linear regression and log-binomial models were used to compare responses between groups.

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The authors declare that there is no conflict of interest.

PREVIOUS PRESENTATIONS

Moran M and Davis B. *Recruiting Medicaid Members for a Randomized Intervention Trial.* Poster presented at 3rd Annual Health Data Symposium, “Data-Driven Approaches to Promote Equity.” February 1, 2019, jointly sponsored by the Arnold School of Public Health and SC Dept. of Health and Environmental Control.

Results.—Case Helpers had statistically significant improvements on HTN knowledge from baseline through the first year, compared to Comparison Members and Comparison Helpers. Regardless of group assignment, Helpers scored better on surveys than did Members.

Conclusions.—This study suggests that it is beneficial to explicitly include Helpers in health care instruction and in management of chronic disease for adults with IDD.

Keywords

Intellectual Disability; Hypertension; Randomized Intervention; Prescriptions; Caregivers

INTRODUCTION

It is estimated that 108 million US adults have HTN,¹ a known risk factor for the development of cardiovascular disease (CVD).^{2,3} Of these, approximately 76% do not have their HTN under control.¹ IDD originates before adulthood, is characterized by significant limitations in intellectual functioning, and impacts practical and social skills.⁴ The prevalence of HTN in adults with IDD has not been firmly established, but a study of 33,122 American adults who participated in Special Olympics found that the rate was similar to that of the general population.⁵ Although lifestyle modifications may help to lower blood pressure, anti-hypertensive medications are often needed for effective management and reduction in risk for CVD.^{3,6} Data about non-adherence to medication is inconsistent, but poorer adherence is reported for certain groups, such as African Americans and people with less income, especially those without private insurance.⁷⁻⁹ In our previous work, we noted that only about half of adult Medicaid members with IDD and HTN were adherent to anti-hypertensive medication during the study period of 2000–2014.¹⁰

In the US, approximately 71% of adults with IDD live with parents, other family members, and/or personal care assistants.¹¹ Since community living outside of professionally supervised settings is common among adults with IDD,¹² we focused on those who lived independently or with family or paid caregivers. Few studies about adults with IDD and HTN have exclusively focused on this more independent group. In fact, the Administration for Community Living has stated that families are the primary means of support for people with disabilities in the US; and numerous studies have investigated caregiver burden, including the health and social consequences of lifelong caregiving.¹³ There is substantial evidence that programs that provide emotional support and respite to caregivers of adults with IDD, reduces negative health outcomes for caregivers, and supports prolong their ability to keep their family member with IDD at home.¹⁴⁻¹⁷ There is less evidence in the literature about whether providing information about chronic health conditions to caregivers has direct or indirect effects on the health of the family member with IDD.¹⁸

A study of Kansas Medicaid data found that only 55% of those with IDD and HTN were adherent to anti-hypertensive medication, and hypothesized that better medication adherence was associated with community-based support.¹⁹ Proven strategies to improve adherence to HTN medications have involved combinations of patients, caregivers, and healthcare providers working together.²⁰ Most studies about adults with IDD and HTN have lacked data on residence type; and community living codes on medical records can imply a variety

of different scenarios, including independent living, staying with family or a caregiver, or living in supervised apartments or group homes. This study was designed to focus on adults with IDD, who either live alone or in family homes, since no randomized intervention trial had been previously conducted to examine effects of educational interventions in this population.

The current study is the first part of a randomized trial to test the effectiveness of an educational intervention, targeted to people with IDD and their Helpers, to improve anti-hypertensive medication adherence in adult South Carolina Medicaid Members with IDD and HTN. The focus of this initial analysis was to determine if the intervention increased participants' knowledge scores about HTN and the importance of medication adherence.

METHODS

We worked with the SC Department of Health and Human Services (SCDHHS) to produce a list of potential participants and randomized them into Case and Comparison groups using a random number generator. Recruiters worked onsite at SCDHHS offices to contact participants and administer the educational intervention.

Recruitment.

The study protocol and informed consent procedures were approved by the University of South Carolina's Internal Review Board (IRB) prior to study commencement. A list of adult Medicaid members, ages 18–64 years, with diagnoses of both IDD and HTN (Members) was generated by SCDHHS in May of 2018. Recruitment letters were mailed to 2393 potential Members to explain the study with instructions for declining participation, indicating that either the Member or a person who helps them with their medication could participate. Recruiters telephoned Members' homes to seek verbal informed consent to participate, either from the Members or from a family member or caregiver (Helper) who claimed to be responsible for obtaining prescription medication for the person with IDD and HTN. If a Member lived independently and took care of their own medications, then the Member was recruited to participate. If a Member lived with family or had a regular caregiver, then the Member had the option of participating, if they were able to do so, or their Helper could participate. When Members participated, regardless of whether they had a Helper; all subsequent phone calls and text messages for surveys and other study communications were directed to the Member only, to try to ensure that Helpers did not assist Members with answering questionnaires.

A new contact list was provided by SCDHHS about six months after study initiation, which included 216 additional, newly enrolled Medicaid members who met the recruitment criteria; thereby increasing the potential pool to 2609 individuals. Recruiters kept logs of all contact attempts, and left voicemails when possible. If a household was contacted at least three times with no response, a second letter was sent, requesting callback to sign up for participation. Recruiters tried to reach people at different times to account for varying schedules.

Exclusion Criteria.—Members were excluded if it was self-reported or reported by their Helper that the Member had not been prescribed blood pressure medication within the last two years. Staff at group homes consistently refused to allow study personnel to talk to residents due to privacy issues; thus, 646 potential participants who were Medicaid members from group homes and/or professionally managed living situations had to be excluded.

Summary of Recruitment Efforts (see Figure 1):

- 2609 people initially thought to be eligible
- 646 (25%) excluded due to residence in professionally managed living situations, leaving 1963 eligible Members
- 412 (21%) agreed to participate, represented by 116 Members and 296 Helpers

Case/Comparison Assignment.

Equal numbers of participants were randomly assigned within age group strata for Members (below and above 45 years) to the Case and Comparison group. Randomization was made irrespective of whether a Member was self-represented or chose to be represented by their Helper. The age cutoff was used to try to ensure that the case and comparison groups were comparable.

Intervention.

The educational intervention was delivered to Case participants (Case Members and Case Helpers) by recruiters who were psychology and social work graduate assistants, with supervision from the Study Manager. An informational flyer about blood pressure (see Appendix A for a text-only version) was provided, along with monthly educational messages for one year. Two sets of messages were developed, one for Case Members and the other for Case Helpers (see Table 1 for examples). Messages for Members were direct (e.g., “take your blood pressure pills just like your doctor advised”); whereas messages for Case Helpers were indirect (e.g., “be sure that the person you help takes blood pressure medicine as the doctor advised”). Assessment for readability was performed using Microsoft Word software; and messages were determined to be at grade level six for Case Members and seven for Case Helpers. Case participants could choose to receive messages by text, phone, or email. Comparison participants did not receive the educational flyer or the monthly messages during the intervention period, but they will receive the flyer at the conclusion of participation.

Surveys.

Each Case and Comparison participant completed a knowledge-based survey at baseline (Survey 1), and then every six months for two years, for a total of five surveys. The surveys were constructed for readability for people with lower literacy, and the entire body of survey questions was found to be at grade level 4.7. The educational intervention only occurred for the first 12 months; thus, Survey 3 was administered just after the intervention portion was concluded. The focus of this manuscript is on Surveys 1–3, as Surveys 4–5 have not concluded. The surveys were designed to assess the same knowledge. For example,

the question related to symptoms of HTN was posed as follows in Surveys 1, 2, and 3, respectively: *people with high blood pressure are most likely to have which of the following signs and symptom; what is the most common symptom of high blood pressure, which is a common symptom of high blood pressure.* (In all cases, the correct answer was that there are no common signs and symptoms.)

Incentives.

Participants received a \$25 incentive for signing up and completing Survey 1. They were also given \$10 for completing each subsequent survey. Participant incentives were sent in cash by U.S. Mail. Rarely (<7 times), a participant reported not receiving an incentive, and was mailed a replacement payment.

Lost to Follow-up.

If a telephone number was disconnected or blocked, or if multiple voicemails did not result in a response, a letter was sent to the home to request a callback to continue participation. If there was no response, the participant was marked “lost to follow-up” (LTFU). We received new contact information for the cohort from SCDHHS every few months. If someone had a new number or address, even if they had been marked as LTFU, we attempted re-contact and allowed them to rejoin the study. We analyzed the retained cohorts at 6-months and 12-months, after removing LTFU, to determine whether any of the groups (Case Members, Case Helpers, Comparison Members, Comparison Helpers) had significantly changed with regards to percentages of Helpers vs. Members or demographics (sex, race, age), when compared to the groups in the originally recruited cohort.

Prescription Data.

Prescription filling behavior for all participating Members as well as the Members represented by the participating Helpers will be calculated based on collection of data from Medicaid pharmacy files. These data will be used in the final report of the randomized intervention trial, but it is not part of the analysis of the knowledge gain for this report. For the final report, knowledge scores will be considered as a possible mediator between case assignment and the outcome of HTN filling behavior, and it therefore was considered important to briefly summarize here.

Statistical Methods:

Baseline characteristics were summarized for Case and Comparison groups. Means (standard errors) were calculated for knowledge scores from Surveys 1–3.

To identify risk factors associated with patterns of numeric scores from Survey 2 and Survey 3, two statistical models were considered: (1) linear regression and (2) log-binomial model. Both models used the outcome as 100 times the number of questions correctly answered on Survey 2 and Survey 3 out of the total number of questions answered.

The linear regression model can be delineated as:

$$y_i = \beta_0 + \beta_1 x_i + \beta_2 \text{case}_i + \beta_3 \text{helper}_i + \beta_4 \text{case} * \text{helper}_i$$

Where the outcome y_i represents 100 times the number of questions answered correctly, divided by number of questions answered on Survey 2 (or Survey 3) for participant i ; and x_i is defined as 10 times the number of questions answered correctly on Survey 1, divided by the number of questions answered on Survey 1 for participant i . A single unit increase of x is associated with a 10% higher score on the first exam. Variables for Case or Comparison, Helper or Member, and an interaction term between Case and Helper were also included as covariates, given their potential contribution in predicting knowledge scores for Surveys 2 and 3.

In the log-binomial model the questions in subsequent surveys are treated as a series of Bernoulli trials. We modeled the likelihood of correctly answering a question on a subsequent survey after adjusting for the score from baseline (Survey 1), Case group, Helper group, and an interaction term between Case and Helper (to investigate whether Helpers had a differential impact on Case and Comparison participants). The same covariates were used in the linear regression model. The log-binomial model was used to obtain risk ratios (RRs) for Surveys 2 and 3. Linear regression model results were summarized with coefficient estimates, standard errors, and p-values; whereas, log-binomial model results included coefficient estimates, RRs, standard errors and 5% confidence intervals of RRs and p-values.

To examine the interactive effects among variables, indicator variables were separately coded for: Case Members, Case Helpers, Comparison Members, with Comparison Helpers who served as the reference. We also evaluated the overall effect of the intervention by comparing Case vs. Comparison scores, and scores of Helpers vs. Members.

Data management and modelling was performed using SAS 9.4 (SAS Institute Inc., Cary, NC, USA), and statistical significance was set at 0.05.

RESULTS

The ultimate goal of the randomized intervention trial is to improve prescription days covered in the Medicaid population of people with IDD and HTN. Therefore, the demographics and health data reported below describe the 412 Medicaid Members who either participated in the study directly or were represented by their Helper.

Demographics.

The average age of the 412 Members with IDD and HTN who comprised the cohort was 45.0 years (min=18, max=64; S.D.=12.8); and 57.5% were male (Table 2). Also, 58% were Black, 21% were white, and the remaining 21% were of another or unknown race. When compared to the remaining 2197 Members who were initially eligible, there was no statistically significant difference in sex ($p=0.32$); but the recruited cohort had statistically significantly more Black people (58.2% vs. 50.7%), fewer whites (20.9% vs. 33.2%), and, on average, they were 3.1 years younger.

Healthcare Coverage.

At the time of enrollment, Table 2 shows that 145 of the 412 Members (35.19%) were Medicaid only (i.e., not enrolled in any other healthcare coverage). Among the rest, 225 (54.6%) were eligible for Medicare, 20 participants (4.85%) had 3rd party coverage, and 5 (1.21%) had all three types of coverage. Of the those with Medicaid only, 80 were in the Case group and 65 were in the Comparison group.

We found no significant differences between Case and Comparison groups in terms of race, sex, age, percent of Members vs. Helpers who were receiving the intervention, or number of medication types per Member (Table 2).

Surveys.

Table 3 shows the comparison in baseline survey responses of Case vs. Comparison groups (without regard to the Member vs. Helper variable). Knowledge about HTN and its management was found to be similar, except for the question about how to control HTN (which is to take medication as prescribed), for which the Case group did significantly better in answering correctly (87.4% vs 76.3%, $p < 0.01$). Notably, the greatest lack of knowledge among all participants was that there are no common symptoms of HTN. Further, at baseline, about half of all participants did not know that a blood pressure of 140/90 is hypertensive, and that the recommended level of exercise is 30 minutes on most days.

Survey 2 was completed by 333 people (176 Case and 157 Comparison) with 79 LTFU. Survey 3 was completed by 306 people (160 Case and 146 Comparison), with an additional 27 LTFU.

For Survey 2, there continued to be a statistically significant difference between Case and Comparison groups in knowledge regarding the most important way to control HTN (taking medication as prescribed). This was answered correctly by 88.6% of the Case group and 79.6% of the Comparison group, with $p = 0.02$. There were no statistically significant differences in rates of correct responses for other questions. In general, the two groups continued to perform poorly on the question about symptoms, but the Case group improved from 16.8% answering correctly on Survey 1, to 29.5% on Survey 2. The Comparison group was less changed, falling from 23.7% correct to 22.2% correct for that question. There was no question about exercise on Survey 2.

In Survey 3, two questions were answered correctly by a significantly greater percentage of Case participants: a) *People with hypertension who don't take their medicine are more likely to get which of these?* (Stroke) - answered correctly by 86.2% of Cases vs. 76.7% of Comparisons, with $p = 0.03$, and b) *Hypertension is another word for ___?* (High Blood Pressure) - 75.6% of Cases got it right, but only 65.1% of the Comparisons were correct, $p = 0.04$. Also, in Survey 3, only 17.5% of the Cases and 17.8% of the Comparisons answered the question about symptoms correctly, but the majority in both groups answered the exercise question correctly (Case = 60.6% and Comparison = 56.8% correct).

We present the means and standard deviation of the scores on all surveys in Appendix B, which shows the means for Cases vs. Comparisons and Helpers vs. Members.

Lost to Follow-up.

By the conclusion of administration of Survey 3, 106 people (26.5% of the cohort) were LTFU, after accounting for five who failed to complete Survey 2, but who were re-contacted and completed Survey 3. The reasons for the 106 LTFU included:

- 19 (18%) – Death of Member or Helper
- 11 (10%) – Declined participation, including 1 Helper no longer working with Member
- 76 (72%) – Unable to contact by phone, mail, or email

Appendix C, Table C.1., shows that at each stage, 6-months and 12-months after recruitment, the LTFU did not have a statistically significant effect (p-values are all >0.05) on the overall make-up of the Case and Comparison groups in terms of percentages of Members vs. Helpers who were continuing to participate. Similarly, when considering the demographics of the retained participants at each stage, there were no statistically significant changes in the make-up of the Case group vs. the Comparison group regarding sex, race, or age as compared to the original cohort (Appendix C, Tables C.2. and C.3.).

Statistical Models.

Regression results are shown in Table 4. The results for Survey 2 (n=333) and Survey 3 (n=306) were similar. The proportion of correct answers (score) on Survey 2 was statistically significantly higher for participants with a higher score on Survey 1; similarly, higher scores on Survey 1 were significantly associated with higher scores on Survey 3. Case Helpers had statistically significantly higher scores than Comparison Members for Surveys 2 and 3; however, for Survey 2, Case Helpers had higher scores compared to Comparison Helpers, but this did not reach statistical significance (p=0.06). For Survey 3, Case Helpers did have significantly higher scores than Comparison Helpers. In both surveys the scores of Helpers were statistically significantly higher than those of Members, regardless of group assignment. Case Members did not have statistically significant improvement in scores from baseline to either six months or one year, as compared to Comparison Members.

We identified significant RRs for the correct response rates using log-binomial models; and the results are in Table 5. In this model, again, scores on Survey 1 were statistically significant predictors for scores on both Survey 2 and Survey 3. For Survey 2, Comparison Helpers were 1.18 (p=0.03) times more likely than Comparison Members to answer questions correctly, and Case Helpers were 1.26 (p<0.01) times more likely than Comparison Members to answer correctly. Similarly for Survey 3, when compared to Comparison Members, the Comparison Helpers were 1.15 times (p=0.02) more likely, and Case Helpers were 1.22 times (p<0.01) more likely to answer the questions correctly. Helpers were more likely to answer questions in Survey 2 correctly (RR=1.17, 95% CI: 1.06,1.30 with p<0.01), compared to Members, regardless of assignment to Case or Comparison. In Survey 3 we had similar results, with Helpers 1.15 times (p<0.01) more likely than Members to correctly answer questions.

DISCUSSION

This randomized intervention trial is the first, to our knowledge, to test the effectiveness of an educational intervention designed to inform adults with IDD and HTN and their Helpers about the importance of adherence to anti-hypertensive medication. Case Helpers had statistically significant improvements on HTN knowledge from baseline to 6 months of the intervention, compared with Comparison Members, and they also improved more than Comparison Helpers at 6 months, but the improvement did not quite reach statistical significance ($p=0.06$). Case Helpers also had statistically significant improvements in scores from baseline to 12 months, when compared to both Comparison Members and Comparison Helpers. Regardless of group assignment, Helpers scored better on surveys overall than did Members, as may be expected; since, presumably, Helpers did not have IDD. Unlike the Case Helpers, the Case Members did not fare better on surveys following the intervention, compared to Comparison Members.

For adults with IDD, proper management of HTN requires coordinated care and supports, including access and receipt of healthcare services, and filling of anti-hypertensive prescriptions. Education with the goal of improvement in health literacy for caregivers to people with IDD is important. One study found that such caregivers often lacked support in the form of reliable sources of information about medications for the person that they help,²¹ and another study indicated that caregivers of adults with IDD felt that managing medication was stressful.²² While we did not address stress in this study, we did provide some reliable information about the importance of taking prescribed HTN medication daily, and the consequences of not doing so. These studies strengthen the idea that there is value in providing simple low-cost educational programs through Medicaid or other insurance providers to Helpers of people with IDD, to improve understanding about the importance of medication adherence, especially for chronic conditions like HTN.

The study has a few limitations. First the results only apply to adult Medicaid members with IDD and HTN who lived in community settings that were not managed by a disability provider organization. Therefore 25% of possible participants who lived in group homes had to be excluded. Second, recruited participants were statistically more likely to be Black or non-white, and younger (~3 years) compared to the underlying population of Medicaid Members with HTN and IDD. The exclusion of supervised settings could have contributed to this difference, but it could also be reflective of racial disparities in access to care or cultural differences about residential preferences. Third, 25.7% were LTFU, so Surveys 2 and 3 could not be administered to the entire cohort; thus, those who remained in the study might not have been entirely representative of the initially recruited population. Fourth, while the study team was sensitive to the issue of readability in all materials, some participants likely struggled to understand both the educational messages and the survey questions. To some extent, this problem is unavoidable when trying to remotely educate people with IDD about a particular health condition. The target group for this study has traditionally been a hard-to-reach population, in part due to frequent residential relocations and changing telephone numbers, which was also notable in our cohort. We believe that these findings for people who live independently, without placement through a disability service organization, and for those who have a Helper, are represented by this study. In addition, these results

may not be generalizable to other states due to differences in individual and population level characteristics, Medicaid policy, and health and disability system resources.

The findings here are modest and limited to knowledge scores, but they are the first part of the bigger picture that the study seeks to address. The larger question is whether the educational intervention contributed to more prescription days covered, fewer emergency department visits, and fewer inpatient days for adults with IDD and HTN. This initial analysis addressed the question of HTN knowledge gain among those with IDD and their Helpers, using a powerful study design that reduced risk of internal bias and allows for confidence in the findings. The study was done from the setting of the SC Medicaid program, and it demonstrates the utility of an embedded educational intervention in a public healthcare coverage program.

CONCLUSIONS

We demonstrated that a simple and low-cost educational intervention can help family members or others who assist Members with IDD and HTN, who live in family homes or community settings, to learn about the importance of adherence to anti-hypertensive medication. Previous research found that adults with IDD and HTN have greater adherence to anti-hypertensive medication in settings with professionally managed medication or in community settings with greater supports.¹⁹ While this preliminary study did not report about medication uptake or refills, it did focus on improving knowledge about the need for HTN medication adherence.

Overall, the usefulness of inclusion of Helpers in management of HTN might appear intuitive; but it is important to demonstrate that collaborations between adults with IDD and their Helpers is associated with increased knowledge about the underlying condition and the reasons that medication adherence is important. This was shown in comparison to both adults with IDD without a self-identified Helper (regardless of whether they received the intervention) and to the Helpers who did not receive the intervention.

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DISCLOSURES

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Appendix A.: Information contained in “Living with Hypertension” study flyer (text-only).

What is blood pressure?

Blood pressure has two measurements:

- The **top number** is pressure of blood being pumped out of the heart.
- The **bottom number** is pressure that is made every time the heart beats.
- Doctors should check blood pressure 2 times or more during every visit.
- Another word for high blood pressure is hypertension.

What is a healthy blood pressure?

HEALTHY BLOOD PRESSURE:	
Top Number (Systolic)	Less than 120
Bottom Number (Diastolic)	Less than 80

How does someone control high blood pressure?

- Take your medicine as your doctor directed!
- Lose weight if you need to, by eating more fruits, vegetables, and lean meats and less dessert
- Exercise for 30 minutes or more on most days by:
 - Walking fast
 - Riding a bike
 - Participating in sports like Special Olympics

What does high blood pressure feel like?

- Most people can't tell if their blood pressure is high
- It is a "silent killer"
- Some people have headaches, dizziness, or a very red face, but most people do not have any of these.

What happens if you stop taking your medication?

- You could have:
- A Stroke
 - Heart Disease
 - A Heart Attack
 - Kidney Disease
 - Or you could DIE!

What can happen if I do not keep my blood pressure under control?

- Bleeding in your brain (strokes)
- Heart attack
- Kidney failure

Why is taking your medication as directed by your doctor important?

- It will reduce the chance of having a stroke or heart attack
- There are no common signs of high blood pressure, so it is important to take your medicine as directed even when you feel good!

Other tips to manage high blood pressure:

- You can check your blood pressure in between doctor visits at home, at the drug store, or at some grocery stores
- You will probably need to take blood pressure pills for the rest of your life

Appendix B.: Mean and Standard Deviation of Scores on HTN knowledge Surveys at baseline (Survey 1) and 6- and 12-months following recruitment (Surveys 2 & 3, respectively), by Case or Comparison adults with IDD and HTN and their Helpers, in randomized education trial.

	Helper					Member				
	N	Mean	Std Dev	Survey	Total	N	Mean	Std Dev	Survey	Total
Case	160	73.39	17.11	Survey1	412	54	53.06	23.40	Survey1	412
	133	66.42	25.79	Survey2	333	43	44.96	25.60	Survey2	333
	116	72.52	17.85	Survey3	306	44	53.13	23.05	Survey3	306
Comparison	136	74.52	15.90	Survey1	412	62	49.40	22.34	Survey1	412
	108	62.65	25.56	Survey2	333	49	40.82	23.09	Survey2	333
	99	68.81	23.10	Survey3	306	47	49.73	21.41	Survey3	306

Appendix C: Analysis of Lost to Follow-Up to Determine if Statistically Significant Changes Occurred in Demographics (Race or Age) or in the Percentage of Helpers vs. Members in the Case and Comparison.

Table C.1.

Counts of Case and Comparison Helpers and Members at Baseline, and after removing those Lost to Follow-Up (LTFU) at two other time periods, 6- and 12-months following recruitment.

	Case-Helper N (% of Baseline)	Case-Member N (% of Baseline)	Comparison-Helper N (% of Baseline)	Comparison-Member N (% of Baseline)	p-value ¹
Baseline (n=412)	160	54	136	62	
6-months (n=333)	133 (83.13)	43 (79.63)	108 (79.41)	49 (79.03)	0.1673
LTFU	27 (16.88)	11 (20.37)	28 (20.59)	13 (20.97)	0.7898
12-months (n=306)	116 (72.50)	44 (81.48)	99 (72.79)	47 (75.81)	0.3698
LTFU	44 (27.50)	10 (18.52)	37 (27.21)	15 (24.19)	0.2105

¹ p-value determined using chi-squared 2x2 test with 0.05 as significance level

Table C.2.

Comparison of Retained Case and Comparison participants after LTFU, in terms of Race and Age at 6 months following recruitment.

	N (%) ² (%) ³ Female Members	N (%) ² (%) ³ Black Members	Age of Member
Case Helper - retained	54 (87.10) (40.60)	72 (83.72) (54.14)	44.20
Case Helper - LTFU	8 (12.90) (29.63)	14 (16.28) (51.85)	44.07
p-value¹	0.2860	0.9393	
Case Member - retained	20 (74.07) (46.51)	24 (82.76) (55.81)	47.88
Case Member - LTFU	7 (25.93) (63.64)	5 (17.24) (45.45)	49.73
p-value¹	0.3108	0.4454	
Comparison Helper - retained	36 (73.47) (33.33)	67 (77.91) (62.04)	43.76
Comparison Helper - LTFU	13 (26.53) (46.43)	19 (22.09) (67.86)	48.36
p-value¹	0.1984	0.8402	
Comparison Member - retained	30 (81.08) (61.22)	28 (71.79) (57.14)	43.67
Comparison Member - LTFU	7 (18.92) (53.85)	11 (28.21) (84.62)	50.92
p-value¹	0.6297	0.1509	

¹ p-value determined using chi-squared test by each category; for example, gender with category 'Case Helper'

² the first % shown is the number of retained or LTFU over the total number in the category

³ the second % shown is the number of female or black over total number in each category

Table C.3.

Comparison of Retained Case and Comparison participants after LTFU, in terms of Race and Age at 12 months following recruitment.

	N (%) ² (%) ³ Female Members	N (%) ² (%) ³ Black Members	Age of Member
Case Helper - retained	50 (80.65) (43.10)	64 (74.42) (55.17)	44.34
Case Helper - LTFU	12 (19.35) (27.27)	22 (25.58) (50.00)	43.75
p-value ¹	0.0665	0.4764	
Case Member -retained	23 (85.19) (52.27)	23 (79.31) (52.27)	48.64
Case Member - LTFU	4 (14.81) (40.00)	6 (20.69) (60.00)	46.60
p-value ¹	0.4835	0.4881	
Comparison Helper - retained	34 (69.39) (34.34)	59 (68.60) (59.60)	43.21
Comparison Helper - LTFU	15 (30.61) (40.54)	27 (31.40) (72.97)	48.70
p-value ¹	0.5029	0.3106	
Comparison Member - retained	28 (75.68) (59.57)	28 (71.79) (59.57)	44.11
Comparison Member - LTFU	9 (24.32) (60.00)	11 (28.21) (73.33)	48.60
p-value ¹	0.9767	0.2750	

¹ p-value determined using chi-squared test by each category; for example, gender with category 'Case Helper'

² the first % shown the number of retained or LTFU over the total number in the category

³ the second % shown is the number of female or black over total number in each category

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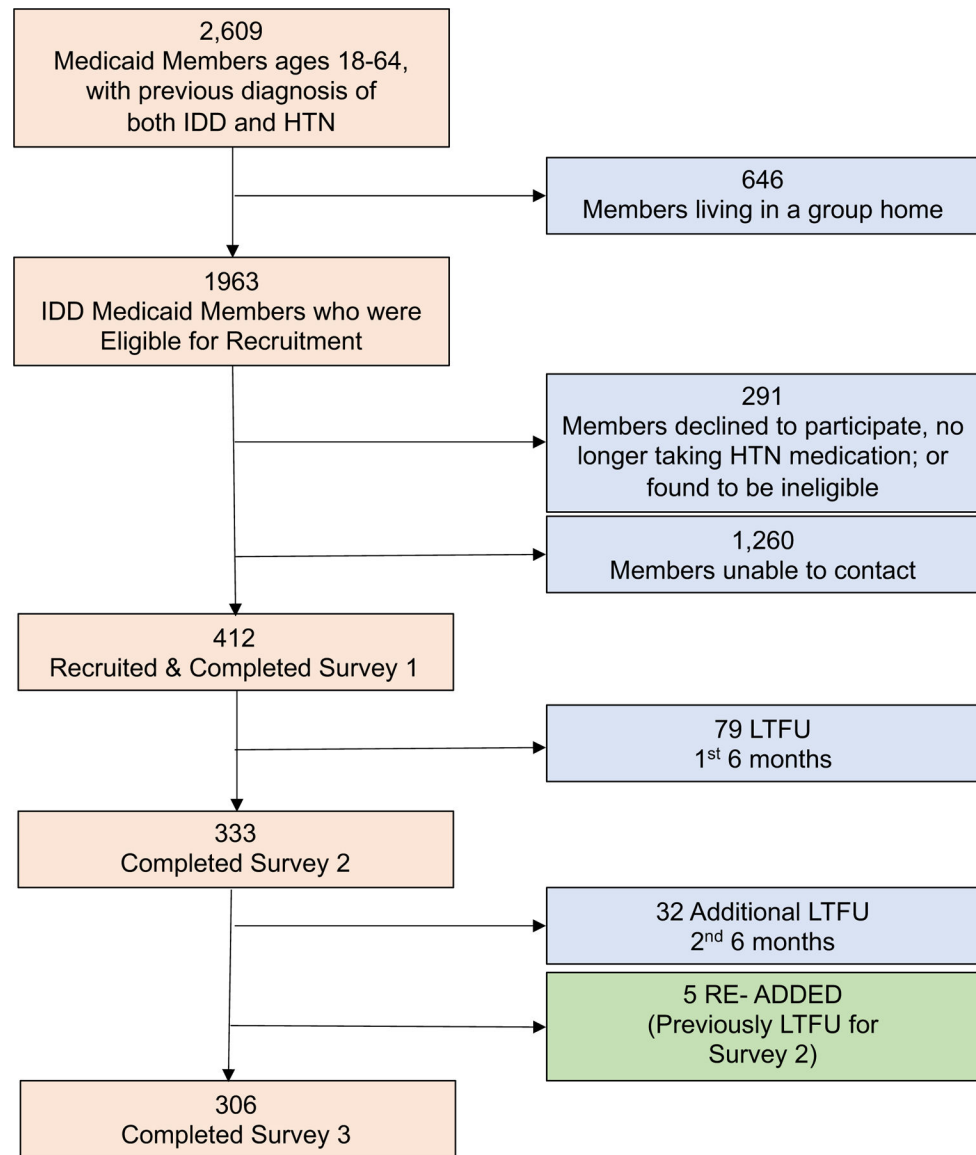


Figure 1.
Flow chart of recruitment and lost to follow-up for Medicaid members with IDD and Hypertension, in a randomized education trial

Table 1.

Examples of monthly educational messages provided to Case group in randomized trial of adult Medicaid Members with IDD and HTN and their Helpers.

Participants with IDD	Participants who are Helpers
<ul style="list-style-type: none"> You can't always tell if your blood pressure is high, so you need to take your blood pressure pills as instructed - even if you feel fine. 	<ul style="list-style-type: none"> Be sure that the person you help takes blood pressure medicine as the doctor advised. They need to take their pills even if they feel fine.
<ul style="list-style-type: none"> Did you know that high blood pressure is also called Hypertension? If you don't take your medicine like your doctor said, your hypertension could cause a stroke or heart attack! 	<ul style="list-style-type: none"> Did you know that high blood pressure is also called Hypertension? If the person that you help doesn't take their medicine as instructed, their hypertension could cause a stroke or heart attack!
<ul style="list-style-type: none"> Take your blood pressure pills just like your doctor advises! People who take their pills, eat healthy and exercise almost every day live longer and have fewer health problems. 	<ul style="list-style-type: none"> Does the person that you help take their blood pressure pills like their doctor prescribed? Taking blood pressure medication, eating healthy, and exercising are important for good health!
<ul style="list-style-type: none"> Do you take your blood pressure pills just like your doctor told you? A good blood pressure is less than 120 over 80. 	<ul style="list-style-type: none"> Did the person in your care take their hypertension pills today? Following the label about these meds can lower the risk for heart disease. A healthy blood pressure reading is less than 120 over 80.

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Table 2:

Demographic characteristics, and prescription fills of specific types and numbers of medication types between case and comparison adult Medicaid Members with IDD and HTN.

	Cases (n = 214) N (%)	Comparisons (n=198) N (%)	p-value
Person receiving Intervention			0.21
Person with IDD	54 (25.2)	62 (31.3)	
Helper/Family Member	160 (74.8)	136 (68.7)	
Sex *			0.78
Male	125 (58.4)	112 (56.6)	
Female	89 (41.6)	86 (43.4)	
Race *			0.15
Black	115 (53.7)	125 (63.1)	
White	50 (23.4)	36 (18.2)	
Unknown/Other	49 (22.9)	37 (18.7)	
Age (years) *	mean (sd): 45.2 (13.2)	mean (sd): 44.9 (12.5)	0.81
Types of Healthcare Coverage			0.39
Medicaid Only	80 (37.4)	65 (32.8)	
Medicaid & Medicare and/or 3 rd Party Insurance	134 (62.6)	133 (67.2)	
Types of Medication^a (within 6 months before recruitment, for participants with Medicaid Only)			
Beta blockers (BB) and diuretic	30 (13.9)	18 (9.1)	0.13
Diuretics	16 (7.4)	22 (11.1)	0.19
ARB and ACE	23 (10.7)	16 (8.1)	0.37
Alpha-1 blockers	2 (0.9)	0 (0.0)	0.18
Calcium channel blockers (CCB)	26 (12.0)	22 (11.1)	0.77
Alpha-2 receptor agonists	8 (3.7)	3 (1.5)	0.17
Vasodilators	2(0.9)	2 (1.0)	0.93
CCB and ACE	2 (0.9)	1 (0.5)	0.61
ARB, ACE and diuretic	15 (6.9)	8 (4.0)	0.20
Number of Medication Types			0.51
0	135 (63.1)	135 (68.2)	
1	50 (23.3)	40 (20.2)	
2	16 (7.5)	16 (8.1)	
3	13 (6.1)	7 (3.5)	

* Sex, age and race are reported for the people with IDD and HTN who are considered to be the participants in this study.

^aTypes of medication are not mutually exclusive. ARB = Angiotensin II receptor blockers, ACE = Angiotensin converting enzyme inhibitors.

Table 3:

Comparison of baseline HTN knowledge responses (SURVEY 1) between case and comparison adult Medicaid Members with IDD and HTN and their Helpers.

Baseline knowledge (N = 412, response rate = 100%)	Case (n = 214) N (%)	Comparison (n = 198) N (%)	p-value
People with high blood pressure are most likely to have which of the following signs and symptoms?			
No Symptoms	36 (16.8)	47 (23.7)	p = 0.08
Wrong Answer	178 (83.2)	151 (76.3)	
When should blood pressure pills be taken?			
Exactly as your doctor prescribed	201 (93.9)	188 (95.0)	p = 0.65
Wrong Answer	13 (6.1)	10 (5.0)	
Which of the following is a healthy blood pressure reading?			
115/70	140 (66.7)	127 (64.5)	p = 0.64
Wrong Answer	74 (33.3)	71 (35.5)	
Untreated high blood pressure could lead to which of the following?			
Stroke	189 (88.3)	168 (84.9)	p = 0.30
Wrong Answer	25 (11.7)	30 (15.1)	
What can you do to control high blood pressure?			
All of the above	187 (87.4)	151 (76.3)	p < 0.01
Wrong Answer	27 (12.6)	47 (23.7)	
*A blood pressure reading of 140/90 is considered:			
High	48 (47.1)	52 (53.1)	p = 0.40
Wrong Answer	54 (52.9)	46 (46.9)	
*Another way to say high blood pressure is:			
Hypertension	74 (72.6)	65 (66.3)	p = 0.34
Wrong Answer	28 (27.4)	33 (33.7)	
*What is the recommended amount of exercise for someone with high blood pressure?			
30 minutes on most days per week	48 (47.1)	40 (40.8)	p = 0.37
Wrong Answer	54 (52.9)	58 (59.2)	

*These three questions were added after approximately half of the participants were recruited, because they were needed for more clarity of the baseline understanding of participants. Therefore, they were only answered by 201 participants.

Table 4.

Results from linear regression modeling of risk factors associated with knowledge score at 6- and 12-months following recruitment (Survey 2 and Survey 3), for adult Medicaid Members with IDD and HTN and their Helpers.

Variable	Estimate	Std Error	p-value	Estimate	Std Error	p-value
Outcome was score on SURVEY 2 (N=333; response rate = 81%)			Outcome was score on SURVEY 3 (N=306; response rate = 74%)			
Reference: Comparison Member						
Intercept	7.10	4.50	0.12	25.23	3.94	<.01
Score on Survey 1	6.74	0.64	<.01	5.06	0.58	<.01
Case Member	1.87	4.59	0.68	1.06	3.95	0.79
Comparison Helper	4.56	4.13	0.27	5.17	3.70	0.16
Case Helper	9.92	3.96	0.01	10.48	3.55	< 0.01
Reference: Comparison Helper						
Intercept	11.66	5.32	0.03	30.41	4.82	<.01
Score on Survey 1	6.74	0.64	<.01	5.06	0.58	<.01
Case Helper	5.36	2.85	0.06	5.31	2.58	0.04
Comparison Member	-4.56	4.13	0.27	-5.17	3.70	0.16
Case Member	-2.69	4.21	0.52	-4.11	3.66	0.26
Overall						
Case vs Comparison (Reference)	3.61	2.70	0.18	3.18	2.35	0.18
Helper vs Member (Reference)	6.31	3.07	0.04	7.30	2.73	< 0.01

Note: Score on Survey 1 is defined as 10 times the # questions answered correctly on Survey 1 divided by the # questions answered on Survey 1. A single unit increase in score on Survey 1 is associated with a 10% higher score.

Table 5.

Results from Log-Binomial modeling of risk factors associated with knowledge score at 6- and 12-months following recruitment (Survey 2 and Survey 3), for adult Medicaid Members with IDD and HTN and their Helpers.

Label	Estimate	RR	Std Error	Confidence Interval		P-value
Outcome = Score on Survey 2 (Total=333)						
Reference: Comparison Member						
Intercept	-1.39	0.25	0.02	0.22	0.29	<0.01
Score from Survey 1	0.11	1.12	0.01	1.10	1.14	<0.01
Case Member	0.07	1.07	0.10	0.90	1.29	0.44
Comparison Helper	0.16	1.18	0.09	1.01	1.36	0.03
Case Helper	0.23	1.26	0.09	1.09	1.45	<0.01
Reference: Comparison Helper						
Case Helper	0.07	1.07	0.04	1.00	1.15	0.06
Case Member	-0.09	0.91	0.07	0.79	1.05	0.21
Overall						
Case vs Comparison (Reference)	0.07	1.07	0.05	0.97	1.18	0.16
Helper vs Member (Reference)	0.16	1.17	0.06	1.06	1.30	<0.01
Outcome = Score on Survey 3 (Total=306)						
Reference: Comparison Member						
Intercept	-0.98	0.38	0.02	0.34	0.42	<0.01
Score from Survey 1	0.07	1.08	0.01	1.06	1.09	<0.01
Case Member	0.06	1.06	0.07	0.92	1.21	0.41
Comparison Helper	0.14	1.15	0.07	1.03	1.29	0.02
Case Helper	0.20	1.22	0.07	1.09	1.36	<0.01
Reference: Comparison Helper						
Case Helper	0.06	1.06	0.03	1.00	1.12	0.06
Case Member	-0.08	0.92	0.05	0.82	1.03	0.13
Overall						
Case vs Comparison (Reference)	0.06	1.06	0.04	0.98	1.14	0.13
Helper vs Member (Reference)	0.14	1.15	0.05	1.06	1.25	<0.01

Note: Score from survey 1 is defined as 10 times number of questions answered correctly on survey 1 divided by number of questions answered on Survey 1. A single unit increase of Score from survey 1 is associated with a 10% higher score.