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Improving Adherence to Care Recommendations Using a Community Health Worker (CHW) Intervention with the Pediatric Medical Home

Sarah P. Justvig¹ · Justine Li² · Giuseppina Caravella³ · Minqin Chen⁴ · Hua Wang³ · Lisa A. Benz Scott⁵ · Susmita Pati^{1,3}

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Abstract While CHW interventions improve health outcomes, evidence identifying specific domains of CHW-delivered support resulting in positive outcomes is limited. Our goals were to identify domains of CHWdelivered support that assist families with adhering to recommended pediatric care; and, to identify predictors of successful completion of an enriched medical home intervention (EMHI) using trained CHWs making home visits to provide health education and support positive health behaviors. We performed a prospective descriptive study of 88 families participating in a protocolbased EMHI. Completers (N = 46) finished the program with mutual agreement that the family can independently adhere to recommended clinical care. Non-completers (N=42) were lost to follow-up or dropped out of the program before reaching this milestone. Using Grounded Theory, two trained coders evaluated CHW tasks recorded in an electronic database and classified these tasks across 17 domains. We assessed predictors

Susmita Pati susmita.pati@stonybrookmedicine.edu

- ¹ School of Medicine, Stony Brook University, Stony Brook, NY, USA
- ² College of Arts and Sciences, Stony Brook University, Stony Brook, NY, USA
- ³ Department of Pediatrics, Stony Brook University, Stony Brook, NY, USA
- ⁴ Department of Applied Mathematics and Statistics, Stony Brook University, Stony Brook, NY, USA
- ⁵ Program in Public Health, and School of Health Technology and Management, Stony Brook University, Stony Brook, NY, USA

of EMHI completion using logistic regression. The 88 EMHI participants were primarily <24 months of age (80%), Hispanic (56%), and Medicaid enrollees (67%). Hispanic families (OR = 2.76, p = 0.04) and those with self-reported program goals to 'facilitate family's creation of a system to keep track of child's medical information' (OR = 3.11, p = 0.02) or a 'newborn-specific goal' (OR = 3.21, p = 0.04), such as feeding and safety tips, were more likely to complete the EMHI compared to their counterparts. The most consistent CHW tasks were supporting medical appointments, medication maintenance, and providing health education. CHW interventions designed to improve health behavior outcomes of 'at-risk' families, including Medicaid enrollees, may benefit from support in goal-setting and strategies to systematically manage their child's medical care.

Keywords Child Health · Community health worker · Outcome evaluation · Health promotion · Training health professionals

Introduction

The patient-centered medical home is a model of health care delivery originally proposed by the American Academy of Pediatrics (AAP) in the 1960s and growing in popularity [1, 7, 17]. AAP support of this model is manifested in its formation of the National Center for Medical Home Implementation with the Maternal and Child Health Bureau and creation of resources such as the Education in Quality Improvement for Pediatric Practice Medical Home course to support implementation [9, 25]. The AAP specifically champions interventions by trained lay educators such as community health workers (CHWs), especially for newborns and children with

special needs, to support child health and well-being as part of the medical home model [2, 6, 21, 31].

The American Public Health Association and World Health Organization define CHWs as trusted public health aides (paraprofessionals) familiar with the community served [8, 29]. CHWs are liaisons between health or social services agencies and the community to facilitate access and reduce modifiable barriers. The CHW "builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy [8, 29]." The Department of Labor published an occupational classification for CHWs in 2010 (SOC 21-1094), but CHW selection, training, roles, and even titles are, by definition, determined by their respective communities [19, 28, 29].

CHW interventions have a positive impact on health outcomes among diverse populations, such as improving the quality of life of caretakers of asthmatic children and dietary outcomes in pregnant women [18, 27]. While the importance of CHWs is well-documented, models directly integrating CHWs into the pediatric medical home are understudied and CHW roles are varied. Some studies have quantified the effects of CHW interventions targeting a specific patient population, such as asthmatics [18], but few have identified the specific tasks performed by CHWs who are directly integrated with medical home services that lead to positive health outcomes in socio-demographically diverse populations.

In this study, we examined the role and impact of CHWs as part of a rigorous evaluation of an ongoing enriched medical home service intervention (EMHI) offered by pediatric primary care practices affiliated with a tertiary care academic medical center. CHWs are fully integrated with medical services by functioning as a direct extension of the medical home to support families in adhering to recommended clinical care. The primary aim of this study was (1) to identify the different types of support CHWs provide to assist families with completing recommended pediatric care services; and (2) to identify characteristics that are significant predictors of successful completion of the EMHI program. We believe these results advance our current state of knowledge about the type of support provided by CHWs [2, 6, 21] that lead to improvements in health care outcomes. Furthermore, our findings may be used to develop standardized CHW training programs that can be replicated elsewhere.

Methods

Study Population

We performed a prospective descriptive study of an existing EMHI entitled Keeping Families Healthy (KFH). KFH is a free program for eligible families, offered by Stony Brook University (SBU) Hospital's Department of Pediatrics since July 2011. The program has demonstrated positive impact on immunization adherence, reducing emergency department visits, and promoting asthma management [15, 16, 22, 24]. EMHI-eligible families are those with at least one child between 0 and 17 years of age who is deemed "at-risk" for poor health outcomes, such as a first-born infant or child with a chronic condition(s) (e.g., asthma, diabetes, obesity, etc.), and is referred to KFH by the child's primary care physician (PCP) or specialist. EMHI families are matched with a trained CHW by the KFH program coordinator based on cultural characteristics (e.g., language, neighborhood). The CHW schedules home visits to occur between the child's scheduled physician appointments. CHWs help families adhere to recommended clinical care by offering resources, information, and support tailored to meet each family's unique needs. CHWs address PCP and specialist reasons for referral, the families' self-reported program goals, and family concerns presented at each home visit supplemented by between-visit phone and text message contacts. In this way, the program aims to support the provision of tailored pediatric preventive care because PCPs refer children based on their understanding of each child's situation, and the needed services are provided based on the CHWs' evaluations of level of risk using a validated family psychosocial risk assessment instrument [23, 30].

Informed Consent

Our study protocol was approved by the Stony Brook Institutional Review Board (IRB), and informed consent was obtained from all study participants in accordance with IRB guidelines. Notably, EMHI participation is voluntary and families may opt to receive EMHI services without consenting to participate in any EMHI-related research.

Study Participants

We chose to study EMHI participants enrolled from May 2013 through July 2014 because these were the most recent data available at the start of this qualitative study and this time period provided a sufficient sample size for our planned analyses. Of the 259 total enrollees between May 2013 and July 2014 who had at least one home visit, 161 (62.2%) participants consented to research and, of those, 88 exited by October 2014 and were included in analyses. The 73 participants still actively engaged with the program were not included in this study. Completers (N=46) finished the program with mutual agreement that the family was independently able to adhere to recommended clinical care. Non-completers (N=42) were lost to follow-up or dropped out of the program before reaching this milestone.

CHW Training and Intervention Protocol

Fig. 1 The seven KFH goals,

examples of CHW tasks used in

with the 17 domains and

coding*

KFH CHWs are trusted individuals from the community who are not required or expected to have a clinical background. Clinical and program staff train CHWs using a standardized protocol that entails over 60 hours of in-person didactic classroom and experiential training, including shadowing experienced program CHWs. Training includes conditionspecific health education (i.e. newborn care, healthy lifestyle habits, asthma, and diabetes), communication skills, motivational interviewing techniques, and data collection protocols. CHWs use a preconfigured electronic database, Research Electronic Data Capture (REDCap) [12], to both collect evidence-based psychosocial family risk information and record home visit summaries, which are sent to the child's clinician after each home visit. CHWs also record the clinician's reason for referral and family self-reported goals for program participation in this database.

To guide the structure of all home visits, KFH has seven broad goals with specific objectives that must be met for the family to complete the program successfully (Fig. 1). Families may begin the program with the ability to meet some of the objectives or need assistance with all seven goals. Each family's needs are determined during the initial visit and reevaluated during subsequent visits. In this way, CHW support is specifically tailored to each family's strengths and needs.

Analytic Approach

We used quantitative and qualitative approaches to answer our research questions. We used Grounded Theory to guide our approach to develop a qualitative coding scheme [13,

1. Clarify how to seek appropriate medical treatment

- a) Give contact information for appointment line, PCP, and/or specialist
- b) Medical Appointment Logistics:
 - o "Reviewed information for mom to schedule or reschedule appointments"

2. Empower families to be prepared for doctors' appointments

- a) Discuss questions/issues to raise during upcoming appointment
- b) Address family's specific concern/interest
- 3. Facilitate families' understanding of the doctor's recommendations
 - a) Clinical care plan review:
 - o "Spoke to mom about Dr .-- 's sleep recommendations. Mom has stopped ... "
 - b) Maintenance follow-up of appointment:
 - "Mom said baby was rejecting medication and...gave it only a few times."
- 4. Facilitate families' creation of a system to keep track of their child's medical information
 - a) Medical Maintenance:
 - o "Reviewed medications, dose and expiration dates."
 - b) Medical Records: folder, notebook, or calendar for appointments and contact info:
 - "Helped develop a system to keep track of child's medical information."
 - c) Family status of keeping track of Medical Records
 - d) Record Keeping ('Logging'):
 - o "Mom has been...logging ... measurements on KFH sheets."
 - e) Family status of record keeping

5. Identify and address barriers to obtaining health care

- a) Health insurance coverage
- b) Status of health insurance issue
- c) Transportation to doctor's office
- d) Language barrier
- 6. Provide appropriate health education

a) Verbal, paper, internet-based (e.g., Text4baby)

- 7. Connect families with local community resources
 - a) Introduce, troubleshoot, or follow-up on use of resources: WIC, food pantry, welfare, breastfeeding, or other
- * Excerpts taken verbatim from CHW visit summaries

20] designed to address our primary aim, identifying specific CHW-delivered support that assists families with adhering to recommended pediatric care. First, the code creator (SJ) read all of the home visit summaries written by CHWs for the 88 program participants in this sample. These summaries detail the discussions that took place during that visit and the materials given to families (e.g., recordkeeping templates, preventive care information, etc.). The code creator noted trends across patients and created 17 domains corresponding to CHW tasks frequently performed during home visits and the seven KFH goals (Fig. 1). These 17 domains spanned themes of adherence to the doctor's recommendations, preparing for medical appointments, organizing medical information, reviewing health education, and community resource referrals. Each domain was further divided into tasks, the completion of one or more of which signified utilization of that domain during the home visit. A second coder (JL) was trained using a coding guide that outlined these domains and tasks. The coding guide illustrated the meaning embedded within each domain and task with excerpts from cases exemplifying narrative meeting (and not meeting) the intended meaning (Fig. 1). By creating and applying this coding scheme, we described the types of support CHWs provided.

Secondly, we sought to identify the characteristics that are significant predictors of program completion, that is predictors of the likelihood a family will be independent (no longer need a CHW) in adhering to recommended clinical care. To answer this second question, we examined the beta coefficients in logistic regression models using candidate predictors collected in demographic information, physician reasons for referral, and family self-reported goals.

After coder training was complete, the two coders were blinded to the work of the other and did not communicate about the codes. Both coders read the 253 visit summaries for all 88 program participants in the sample. For each visit summary, coders determined whether each of the 447

17 domains was addressed, and recorded the specific tasks completed during home visits. Each coder then re-coded a 10% subset of the sample to enable assessment of intra-rater reliability. We created conditional formatting rules to help determine alignment between the two coders.

We calculated inter- and intra-rater reliabilities in each of the 17 domains and identified coding discrepancies. Where there were discrepancies, the coders reviewed the visit summary source together, discussed their reasoning for choosing particular codes, and resolved differences.

Results

Participant Demographics

In total, 253 visits were made to the 88 participants during the study observation period; 179 visits were made to completers (N=46) and 74 to non-completers (N=42). The 88 participants were primarily <24 months (N=70; 80%), Hispanic (56%), and insured by Medicaid (67%) (Fig. 2). Notably, 49 of the 88 participants (55.7%) self-identified as Spanish/Hispanic/Latino and, of those, 25 spoke only Spanish as their primary language (51.0%) and 7 spoke both English and Spanish (14.3%).

The majority of participants (N=65: 37 completers, 28 non-completers) were newborns (Table 1). 10 were asthmatic (2 completers, 8 non-completers), and 2 (1 completer, 1 non-completer) had diabetes. As expected, we found a significant difference between the mean number of home visits made to completers vs. non-completers (3.9 vs. 1.8, respectively, p < 0.00001).

Predictors of Program Completion

As previously described, we sought to identify predictors of program completion from data collected about the



	Overall (N=88)		Completers $(N = 46)$	
	Counts (Total = 122)	Percent- age of total (%)	Counts (Total = 66)	Per- centage of total (%)
Newborn	65	53.3	37	56.1
Complex medical history	25	20.5	12	18.2
Language barriers	15	12.3	12	18.2
Difficulty navigat- ing the health care system	9	7.4	2	3.0
Social issues	6	4.9	3	4.5
Other	2	1.6	1	1.5

 Table 1 Reasons for physician referral of children to the Keeping
 Families Healthy enriched medical home intervention (EMHI)

Physicians could indicate more than one reason for referral for each of their referred patients

clinicians' reasons for referral, family-reported program goals, and participant demographics.

The most frequent reason given by physicians for referring families to the KFH program was that the child was a newborn (N=118, 54.2%). There were also 25 counts of referrals due to complex medical history (20.5%) and 15 counts for language barriers (12.3%) (Table 1). Notably, all 15 of these families selected Spanish as a primary language and 12 of the 15 completed the EMHI.

Of the 266 goals selected by all 88 participants, the most common family self-reported goals were to 'receive basic health education' (19.2%), know 'what to prepare for doctor's appointments' (16.2%), 'keep track of child's

medical information' (15.8%), and 'understanding doctor's recommendations' (14.7%) (Table 2). Our logistic regression models showed that families who were Hispanic and selected 'facilitate family's creation of a system to keep track of child's medical information' or 'newborn-specific goal' (e.g. feeding and safety tips) as a program goal were more likely to be completers than non-completers (Table 3).

CHW Tasks Corresponding to the Seven KFH Goals

CHWs' most consistently performed tasks fell into domains involving reviewing medical appointment logistics, assisting with medication maintenance, and providing health education (Table 4). Inter- and intra-rater reliabilities for coding tasks surpassed the 0.80 threshold in each of the 17 domains. Inter-rater reliability for coding tasks was 0.96 overall, and intra-rater reliabilities were 0.91 and 1.00 separately.

Table 3 Predictors of EMHI program completion

	Beta co-efficient	p-value
Demographics: Hispanic Ethnicity	1.02	0.02
Reason for referral: language barriers	1.72	0.03
Family self-reported goals		
Keep track of medical information	1.14	0.01
Newborn-specific	1.17	0.02

Results from single variable logistic regression models using completion status (yes vs. no as outcome). P-value <0.05 denotes significance

Reference level of all variables is "yes"

Table 2 Family self-reported goals for the Keeping Families Healthy enriched medical home intervention program (EMHI)

	Overall (N=88)		Completers (N=46)	
	Counts (Total=266)	Percentage of total (%)	Counts (Total = 146)	Percentage of total (%)
Receive basic health education	51	19.2	25	17.1
What to prepare for doctor's appointments	43	16.2	21	14.4
Keep track of child's medical information	42	15.8	28	19.2
Understanding doctor's recommendations	39	14.7	22	15.1
Newborn-specific goal (e.g., feeding/safety)	25	9.4	18	12.3
Scheduling appointments/calling doctors	24	9.0	11	7.5
Address barriers to receive care	17	6.4	10	6.9
Connect with local resources	16	6.0	10	6.9
Asthma specific goal	4	1.5	1	0.7
Other	3	1.1	0	0
Diabetes specific goal	1	0.4	0	0
Healthy lifestyle specific goal	1	0.4	0	0
Refuse to answer	0	0	0	0

Families could choose more than one goal for their family

Goal 1: Clarify How to Seek Appropriate Medical Treatment

CHWs assisted with medical appointment logistics during all of the home visits for patients in this sample. Notably, four of the five families in the sample for whom CHWs assisted with scheduling appointments early on during the program were later documented to have appointments proactively scheduled by the family rather than requiring assistance from CHWs to schedule appointments.

Goal 3: Facilitate Families' Understanding of the Doctor's Recommendations

CHW follow-up after medical appointments was a common and vast topic such that it was split into two categories: clinical care plan review and follow-up regarding adherence. Clinical care plan review, the more common domain of the two, signified that the CHW and families reviewed the appointment content, the doctor's recommendations and treatment plan, health education given, medications prescribed, and/or any necessary specialist follow-up. Clinical care plan review also included specifically identifying families' remaining questions and ways to address them. Adherence follow-up focused on whether the caregiver adhered to the doctor's recommendations or, if not, why the caregiver was unable to do so (e.g., couldn't afford medication, did not understand). CHWs performed clinical care plan review in more than half of home visits, and the most common task covered within the clinical care plan review domain was reviewing 'appointment content/discussions.' CHWs performed adherence follow-up at nearly one-fourth of home visits.

Table 4 CHW tasks performed in home visits

Goal 4: Facilitate Families' Creation of a System to Keep Track of their Child's Medical Information

Within this goal, CHWs completed tasks in the medical maintenance domain during all 253 home visits made to families in this sample. Of all related tasks, CHW medication confirmation was the most frequently used during home visits. CHW review of medication storage (11.1%), medication expiration/refills (10.3%), and proper medication administration/use/dosage (8.7%) were also common tasks during home visits, particularly during initial visits.

The two domains involving record keeping are particularly relevant for families of asthmatic and diabetic children, who comprised 12 of the 88 families in this sample. 11 of the 12 families in this subset were introduced to record keeping through KFH, and 84.0% of visits to families of asthmatic and diabetic children involved either an 'introduction to logging' or a 'follow-up logging progress.' Notably, all 11 families to whom 'logging' was introduced agreed to try recording medication use. In addition, 4 out of the 5 families who had multiple visits where record keeping was discussed were ultimately successful in recording medication use independently.

Goal 6: Provide Appropriate Health Education

CHWs provided health education during 94.9% of home visits using various communication methods, including paper educational handouts (94.1%), verbal discussion (7.9%), and internet-based referrals (7.9%), for educational support based on the family's preferred learning style. Notably, 24 out of 65 newborn families (36.9%; 14 completers, 10 non-completers) registered for Text4baby [10], the nation's only free health text messaging program designed

Goal and domain	Frequency of use (%)		Most common task
	All Families	Completers	
Goal #1: medical appointment logistics	100.0	100.0	Recorded appointment information (date, time, etc.)
Goal #4: reviewed medication maintenance with caregiver	100.0	100.0	Confirmed medications
Goal #6: provided health education	94.9	50.3	Gave paper handout
Goal #4: helped family with logging medications (when applicable)	84.0	66.7	Gave paper logging sheet
Goal #4: reviewed family status of logging medications (when applicable)	84.0	90.0	Agrees to try
Goal #3: clinical care plan review	52.6	63.7	Verbal review of appointment content/ discussions
Goal #7: connected families with local resources	51.8	60.9	Reviewed WIC status

Only domains utilized in at least 50% of the 253 total home visits and 179 completer family home visits are listed in this table. Frequency calculated using denominator of applicable patients, e.g., 12 total (3 completer) home visits made to families with medications (asthma/diabetic)

to target expectant mothers prior to and throughout the newborn's first year of life [32]. CHW visit summaries often detailed positive reception to daily text messages with newborn health information.

Goal 7: Connect Families with Local Community Resources

Another common task domain of CHWs, exemplified by its use in more than half of home visits, was connecting families with local community-based organizations. Women, Infants, and Children (WIC) was the most frequently utilized resource, which is congruent with our sample comprised mainly of newborns.

Other Goals

The remaining 10 domains, which include items such as CHWs helping families obtain contact information for PCPs and specialists, solving insurance issues, and overcoming transportation and language barriers to health care, were utilized in less than half of all home visits in this sample. Notably, however, among the 15 participating families who selected Spanish as a primary language, language barriers were discussed at 46 home visits (18.2%) of the 253 total visits in the sample.

Discussion

We found that families who self-identified as Hispanic and selected 'facilitate family's creation of a system to keep track of child's medical information' or 'newborn-specific goal' as a program goal were more likely to be completers than non-completers of this EMHI. The most consistently documented CHW tasks were supporting medical appointment logistics, medication maintenance, and providing health education. These tasks were the ones most often documented in visits made to completer and non-completer families. Taken in concert, our findings support continued efforts to ensure EMHIs are targeting populations most likely to benefit and ensure CHWs are trained to perform tasks that are most likely to result in positive health behaviors and outcomes. Stakeholders, including clinicians and community advocates, can improve CHW programmatic training and content by aligning with families' self-reported health care goals. Focusing CHW interventions on target populations known to benefit from these interventions is also a wise investment of limited health care dollars [3, 5].

Our findings have proven extremely useful to our existing KFH program in several respects. First, our findings show that all participating families, completers and non-completers alike, benefit from the program. In addition, CHWs

have begun to discuss and share ideas about best practices in documenting tasks completed during home visits because improved documentation supports improved communication among health care providers, CHWs, participating families, and KFH program leadership. Our findings also highlighted ways to improve utilization of applications, such as Text4baby, that have proven positive impact. To this end, our program staff now emphasizes that the text messages are free and do not interfere with text limits and data plans. Finally, our results confirm that CHWs are doing their jobs well and carrying out a broad array of tasks. In particular, CHWs found these results encouraging and inspirational because they felt the results accurately reflected the depth of their impact. Thus, these results are promoting job satisfaction and refining program operations to be more goal-driven.

Our finding that Hispanic families are more likely than other groups to be completers raises questions about effective ways to help families overcome language barriers during health care encounters. This is particularly critical because families with limited English proficiency are known to have greater risk of receiving poor quality of care, including medical errors, and stifled access to health care [14]. To address this problem directly, one of our CHWs developed a pictorial, color-based asthma medication management system that has proven successful for use by illiterate caregivers. Further innovations in overcoming language barriers, including those that leverage technology, will require reimbursement from payers to be sustainable.

An important domain of CHW work in this study pertained to medical appointment logistics. Nonattendance at medical appointments has significant negative implications on the temporal, monetary, and physical resources of both patients and their physicians [11, 26]. Missed appointments have been largely attributed to forgetfulness, transportation problems, and perception of excellent health [26]. In this EMHI, CHW tasks include reminding families of upcoming appointments and resolving transportation issues. In this sample, families' progression from CHW-assisted appointment scheduling to appointments made without CHW aid was an indication that families were gaining independence under CHW guidance. Facilitating this transition to independence is one long-term positive effect of this CHW intervention.

Another common domain used by CHWs during home visits was connecting families with local resources. WIC was the most frequently-utilized resource, and this likely reflected the fact that the majority of the participants in this sample were newborns from low-income families. This finding shed light on the importance of CHWs' knowledge about the WIC program, including locations, eligibility requirements, and identifying grocery stores that accept WIC. Understanding the frequency of local resource referrals not only helps to tailor CHW education and training to best suit families' needs but also sheds light on the importance of CHWs hailing from the communities they serve. Matching CHWs to families based on geography and cultural characteristics further improves CHW capability in this domain, as doing so efficiently allocates CHW resources, caters to both CHW and family comfort levels, and effectively utilizes CHW knowledge base.

This work is not without limitations. First, we acknowledge that the information gathered from home visit summaries does not fully encompass the multifaceted roles that CHWs perform. CHWs make a variety of contacts, such as between-visit phone calls and text messages with families, pharmacies, and other stakeholders, that occur outside of the home visit environment that are not captured in our findings reported here. Furthermore, the informed consent criteria to participate in this research-based program engenders a degree of selection bias: however, our participation rate of 62% is consistent with other programs/ interventions targeting vulnerable populations and reflect 'real-world' implementation rates [4]. Another limitation is that our results may not be generalizable to other settings or patient populations; however, KFH participants are representative of the racial and socioeconomic distribution of Suffolk County residents, which further reflects national demographic statistics [33]. Finally, the use of two coders and high threshold for matching strengthen the validity of our data in regard to the domains of CHW roles that are likely to achieve positive impact on child health and well-being.

Conclusions

Our findings advance our current understanding of the key components to successful implementation of new models of health care service delivery that leverage the strengths of community health workers directly integrated within the medical home. Active communication with and involvement by clinicians is vital and a key component of successful CHW service programs. Our model featuring a single integrated bundle of medical home office-based services enriched by CHW home visit support holds much promise for improving health behavior-related outcomes at the population level in an evolving health care environment focused on value-based purchasing. Finally, this model serves as a blueprint that can be adapted for other populations, such as the elderly, and other conditions, such as diabetes, to improve health outcomes and, ultimately, population health in a cost-effective manner.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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