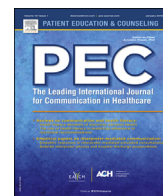




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Short Communication

Increasing patient activation scores of vulnerable youth by partnering medical residency programs with public high schools[☆]

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ABSTRACT

Objective: To assess whether participation in Stanford Youth Coaches Programs (SYCP) increases patient activation scores and patient activation levels for vulnerable youth from low income communities.

Methods: From 2016 to 2018, seven high schools and four residency programs in California, Alabama, Kansas and Missouri participated in SYCPs. Enrolled youth participants completed online pre and post-participation surveys including the Patient Activation Measure (PAM[®]10). We used paired T-tests, chi square tests, and linear multivariate models to compare pre-and post-scores and levels.

Results: 143 participants completed pre- and post-participation surveys. The PAM[®]10 mean pre-test score was 64.5 and post-test was 69.37, with mean difference 4.89 (p=.002). Participants showed significant improvement in patient activation levels after participation. 60 % participants in lowest activation Level 1; 63 % in Level 2; and 32 % in Level 3 moved to a higher level of activation after participation; 46 % who started in Level 4 moved down to Level 3 after participation.

Conclusion and Practice Implications: Participation in SYCPs has potential to significantly increase patient activation for vulnerable youth which could lead to lifelong improvements in health outcomes and decrease in healthcare costs.

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1. Introduction

Patient activation refers to knowledge, skills and confidence a person has in managing his or her own health and health care. Higher patient activation is strongly associated with improved health outcomes [1], decreased healthcare costs [2], and improved patient satisfaction with care provided [3]. In a randomized controlled trial, Kaboli et al. showed that teaching patients strategies to communicate with healthcare providers improved patient activation scores and significantly improved blood pressure control [4]. Research shows that the process of improving patient activation must also include breaking cycles of negative self-perception and emotions and increasing self-efficacy [5]; as well as specific patient education focused on understanding patients' roles in decision making processes [6].

Increasing patient activation scores for vulnerable groups, such as low-income and racial/ethnic minority communities, has potential to address well documented health disparities for those groups [7]. Extensive health disparities are well documented for youth from low-income and racial/ethnic minority backgrounds [8]. Although some studies suggest methods for increasing patient activation in adults, little is known about how to increase patient activation in youth. With this exploratory research, we seek to understand how to support youth from low-income and racial/ethnic minority communities to increase their patient activation levels.

The Patient Activation Measure (PAM[®]10) [9] licensed through Insignia Health ©2014 assesses knowledge, skill and confidence for health and health care self-management. PAM[®]10 scores range from 0–100 with lower scores indicating lower self-awareness about medical conditions and less likelihood of playing an active role in their care process; and higher scores indicating greater confidence and ability for self-management and maintenance of lifestyle change. PAM[®]10 scoring places individuals into one of four activation levels which correlate with patient motivation and readiness for change with patients at Level 1 disengaged and overwhelmed, lacking confidence and skills necessary to manage their own health and patients at Level 4 adopting and maintaining new behaviors and a healthy lifestyle [10].

[☆] <http://med.stanford.edu/stanfordyouthcoaching.html>.

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The Stanford Youth Coaches program is a validated and nationally implemented program in which resident physicians go to high schools to train healthy adolescents from low income and racial/ethnic minority communities to become self-management coaches for family members with chronic illness [11]. As part of the program, youth attend a one-hour session once a week for eight weeks at school where they practice communication skills; learn strategies for incremental health improvement; discuss responsibilities of patients within the healthcare system; and regularly interact with physicians who are the program instructors. After each program session, youth meet outside of school with a family member with chronic illness to complete a coaching assignment. In addition to increasing health knowledge, the program has been shown to increase problem solving skills, self-worth and self-efficacy of youth participants [11] (Fig. 1). In this study, we evaluated whether participation in the Stanford Youth Coaches Program increased vulnerable youth participants' patient activation scores and levels.

2. Methods

From 2016–2018, seven US high schools and four medical residency programs in California, Alabama, Kansas, and Missouri implemented the SYCP. High schools were selected based on serving majority low-income and racial/ethnic minority youth, as well as proximity to residency programs. Youth were eligible to participate if they were in grades 9 through 12 (approximate ages 14–18 years). Youth were eligible to participate regardless of academic standing. If unable to coach someone with a chronic illness, youth were asked to coach anyone who wanted to become healthier. School administrators determined whether receiving the program would be voluntary or mandatory (part of high school

class). Program was mandatory for all participants except in California.

A total of 165 youth participated in this study. Youth were considered “vulnerable” because their risk of chronic illness is elevated based on living in low-income communities and being primarily racial/ethnic minorities. Of those, 113 participated in a coaching program focused on diabetes and 52 participated in a very similar program focused on diabetes, heart disease, and cancer. Enrolled youth completed online surveys in the week before starting the program and within one week after program completion. Pre- and post-surveys included the validated instrument, PAM® 10 which is a 10-item Likert scale survey with statements related to health and healthcare. Post-surveys also included questions about changes in lifestyle/health behaviors after program participation, with an open-ended question about specific lifestyle changes.

2.1. Difference in PAM® 10 scores

We calculated and analyzed the difference in PAM® 10 pre- and post-test scores for each participant using the scoring algorithm provided by the developers (Insignia Health © 2014). Participants had to respond to 8 of 10 questions to record a valid score.

2.2. Difference in PAM® 10 activation levels

PAM® 10 scores were coded into 4 levels of activation and differences in pre/post activation level was recorded for each participant.

The Institutional Review Board (IRB) of Stanford University approved our study and granted it an exempt status as per regulations 45 CFR 46 or 21 CFR 56.

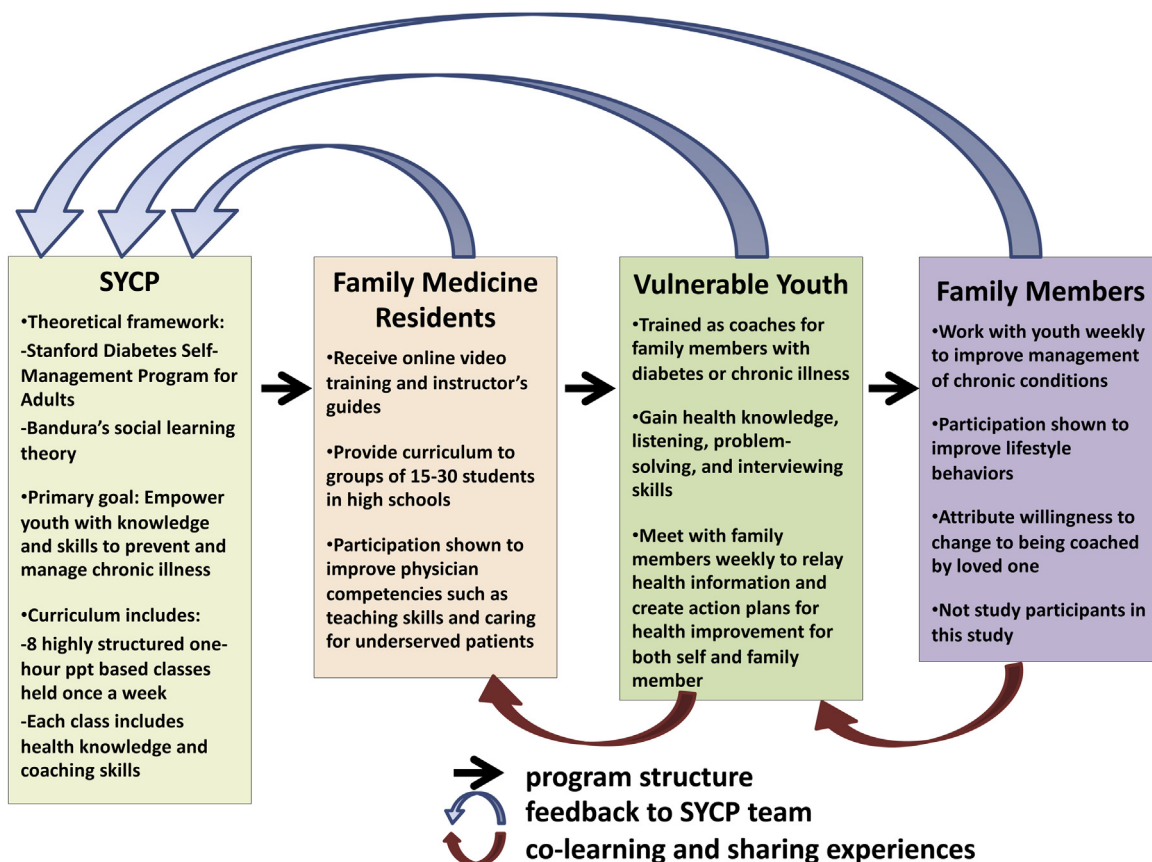


Fig. 1. Stanford Youth Coaches Program Framework (2019).

3. Results

143 participants completed PAM[®] 10 pre- and post- surveys. 22 participants were excluded because of incomplete pre and/or post surveys. 83 % were female; race and ethnicity were evenly distributed across Asian, Black, Caucasian, and Hispanic; the majority were in 9th or 10th grade; 46 % had a regular healthcare provider; 46 % lived at home with both parents; and almost half coached their mother or father (Table 1). Census data showed average family income in the locations in which our participants lived is \$58,263/yr.

3.1. Difference in PAM[®] 10 scores

Overall the mean PAM[®] 10 pre-score was 64.5 and mean post-score was 69.37, which demonstrated statistically significant improvement (p=.002) based on paired T tests. In multivariate linear regression analysis, improvement in test scores remained statistically significant after controlling for gender, ethnicity and person coached. Participants with lower PAM[®] 10 pre-test scores were significantly more likely to improve post-test scores (Table 2).

Table 2

Multivariate linear regression model^a for factors influencing change in PAM[®] 10 pre and post test scores for Stanford Youth Health participants, 2016–2018.

	β Coefficient (SE)	P value	CI (lower, upper)
Intercept/Constant	52.57 (7.57)	<0.001	37.6, 67.53
PAM [®] 10 pre-test score	-.627 (.083)	<0.001	-.79, -.46
Gender (Female, male = ref)	-5.64 (3.55)	0.115	-12.67, 1.39
Race and Ethnicity (White = ref)			
Asian	.210 (3.58)	.953	-6.87, 7.29
Black	.469 (3.86)	.904	-7.16, 8.10
Hispanic	-5.617 (3.76)	.138	-13.06, 1.8
Person Coached (ref = father)			
Mother	.023 (3.98)	.995	-7.86, 7.91
Other family member	-3.03 (4.07)	.458	-11.09, 5.02
Friend	-1.76 (4.04)	.664	-9.76, 6.24

^a Dependent variable: Difference in post-test and pre-test scores R² = .325.

3.2. Difference in PAM[®] 10 activation levels

Chi square tests comparing pre- and post- patient activation levels indicated significant improvement after participation (p<.001). 60 %

Table 1

Demographics of Stanford Youth Coaches Participants (n = 143); California, Alabama, Kansas, and Missouri, 2016–2018.

	Number	Percent
Gender		
• Female	119	83.2 %
• Male	24	16.8 %
Grade		
• 9 th and 10 th grade	103	72 %
• 11 th and 12 th grade	40	28 %
Race/Ethnicity		
• Hispanic	33	23.1 %
• Non-Hispanic White or Caucasian	37	25.9 %
• Non-Hispanic Asian	43	30.1 %
• Non-Hispanic Black or African American	30	21 %
Living situation		
• Living in home with both parents	65	45.5 %
• Living in home with one parent	32	22.4 %
• Other	14	9.8 %
• Missing responses ^a	32	22.4 %
Person Coached		
Mother	39	27.3 %
Father	25	17.5 %
Other family member	37	25.9 %
Other friend or teacher	40	28.0 %
Missing responses	2	1.4 %
Made lifestyle change after program participation		
• Yes	114	79.7 %
• No	27	18.9 %
• Missing responses	2	1.4 %
Have regular health care provider ^b		
• Yes	66	70.2 %
• No	13	13.8 %
• Not sure	15	16.0 %

^a Missing responses refers to survey questions that were not answered by SYCP participants.

^b This question was asked to only one group of participants (N=94).

Table 3
Change inPAM® 10 levels of activation for Stanford Youth Coaches participants (n = 143) based on pre and post PAM® 10 scores¹; California, Alabama, Kansas, and Missouri, 2016–2018.

Initial PAM level of group	Original Level 1 ^a	Original Level 2 ^a	Original Level 3 ^a	Original Level 4 ^a
Survey Counts	5	32	71	35
Mean PAM® 10 score (pre-test)	34.5	50.69	61.89	86.61
Mean PAM® 10 score (post-test)	54.46	61.6	69.08	79.18
Mean point change from pre-test	19.96	10.91	7.19	–7.42
% Improved	60 % (3)	62.5 % (20)	32.4 % (23)	0% (0)
% Unchanged	40 % (2)	31.2 % (10)	59.2 % (42)	54.3 % (19)
% Declined	0% (0)	6.3 % (2)	8.4 % (6)	45.7 % (16)

Level 1: Disengaged and overwhelmed; individuals are passive and lack confidence. Knowledge is low, goal orientation is weak and adherence is poor. Perspective: “My doctor is in charge of my health.”

Level 2: Becoming aware, but still struggling; individuals have some knowledge, but large gaps remain. They believe health is largely out of their control, but can set simple goals. Perspective: “I could be doing more.”

Level 3: Taking action; individuals have the key facts and are building self-management skills. They strive for practice behaviors and are goal oriented. Perspective: “I’m part of my health care team.”

Level 4: Maintaining behavior and pushing further; individuals have adopted new behaviors, but may struggle in times of stress or change. Maintaining a healthy lifestyle is a key focus. Perspective: “I’m my own health advocate [1–6].”

^a PAM® Activation Levels [10].

youth in pre-test Level 1; 63 % in pre-test Level 2; and 32 % in pre-test Level 3 improved scores sufficiently after participation that they moved to a higher level of activation (Table 3). Of those whose pre-test scores placed them in Level 4 (highest possible level), 46 % moved down an activation level after participation.

4. Discussion and conclusion

4.1. Discussion

Our results indicate that youth significantly improved PAM® 10 scores after participation in the coaching programs. Additionally, there was a strong correlation between improvement in PAM® 10 scores and increases in activation levels. Participants benefited regardless of ethnicity/race, gender, or person they coached. These results corroborate those seen in adult studies evaluating the health impact of increasing activation scores and levels [12].

Participants at lowest activation levels initially appeared to benefit most from the program. Of those starting at the highest activation level before participation, almost half moved down a level after participation. This unusual finding may be the result of these participants better understanding the questions after participating in the program and answering more accurately or an adverse response to stress of mandatory program participation. The few studies that assess changes in activation levels in the literature focus on adults with significant illness and are not relevant to our study population. Measuring shifts in activation levels is important because moving up a level of activation is correlated with sustained behavior change [13].

Study limitations: This exploratory pilot study was limited because participants were not randomized; no control subjects were included; lifestyle changes were self-reported and not validated externally; and we were unaware of other interventions students may have received during the eight-weeks. Additionally, because individual schools were highly segregated by race/ethnicity, we did not control for school in regression analyses.

Next steps: Future work will include expanding program implementation, participant randomization with controls, external validation of reported lifestyle changes, and exploring why some participants' activation levels did not improve or decreased after participation. Additionally, based on preliminary results from this study, future studies will assess whether increases in patient activation scores correlated with reported positive lifestyle changes. In this study, improvement in activation scores was a significant predictor of self-reported likelihood to make lifestyle change (i.e. eat more healthfully, exercise more, improve sleep).

4.2. Conclusion

This study suggests the Stanford Youth Coaches programs improve patient activation of youth from low-income and racial/ethnic minority communities throughout the US and could lead to improved health outcomes for populations at high risk of developing chronic disease.

4.3. Practice implications

Empowering vulnerable youth with patient activation is a priority of the National Alliance to Advance Adolescent Health [14] and could be a powerful chronic disease prevention strategy if implemented widely. This work has potential to address the well documented burden of chronic disease in the US [15], and in particular, support low-income and racial/ethnic minority youth most at risk for developing chronic disease [16]. Because this intervention is free for participants and can be incorporated into public school settings, it is feasible to implement on a large scale.

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CRediT authorship contribution statement

Liana R. Gefter: Conceptualization, Methodology, Investigation, Project administration. **Nancy Morioka-Douglas:** Conceptualization, Methodology, Supervision, Funding acquisition. **Ashini Srivastava:** Formal analysis, Data curation. **Eunice Rodriguez:** Conceptualization, Methodology, Formal analysis.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.08.035>.

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