# "Informing Young Women About Heart Disease and Stroke: New Media and New Approaches" and "\#HeART: A Positive Youth Development Approach to Cardiovascular Disease Prevention" 

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# Informing Young Women About Heart Disease and Stroke: New Media and New Approaches 

 and\#HeART: A Positive Youth Development Approach to
Cardiovascular Disease Prevention

Scholarly Report submitted in partial fulfillment of the MD Degree at Harvard Medical School

Date: 16 April 2019
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#### Abstract

Title: Informing Young Women About Heart Disease and Stroke: New Media and New Approaches

Purpose: While cardiovascular disease continues to be the greatest lifetime health risk for women in the United States, adolescents and young women are infrequently targeted in heart health prevention campaigns. To date, no studies have evaluated the cardiovascular health information sourcing habits of this population.

Methods: We surveyed 331 female participants ages 15-24 years from the waiting rooms of an academic and a community-based clinical practice between September 2017 and January 2018 to describe and analyze cardiovascular information source habits and preferences. We developed linear, and logistic regression models to assess the association between participant demographics and our primary outcomes (feeling informed about heart disease and/or stroke) and our secondary outcomes (health information sources and preferences).

Results: $48.5 \%$ of Adolescent and Young Adult participants rated themselves as not at all informed about heart disease and $59.0 \%$ rated themselves as not at all informed about stroke. $61.8 \%$ of respondents had never spoken to a physician about heart disease. There was a positive association between being exposed to more sources and feeling more informed about heart disease and stroke ( $\mathrm{p} \leq 0.001$ for each), while those who had not seen/heard/read anything in past 12 months rated themselves as less informed about heart disease (OR 0.09, 95\% CI 0.04-0.20) and stroke (OR 0.33, 95\% CI $0.18-0.59)$. The most common sources for heart disease information in the last 12 months were television (38.2\%), social media (30.3\%) and the web (26.0\%). Exposure to television, social media and the web were most strongly associated with feeling informed about heart disease and stroke (OR 1.67-2.79). Respondents were most likely to feel informed about heart disease and stroke if they had discussed their personal risk with a healthcare professional (OR 3.67-7.02).

Conclusions: Few adolescent and young adult women feel informed about heart disease and stroke. How informed participants feel about heart disease/stroke is related to having been exposed to information about the subject in the last year, and/or physician interaction. The most preferred medium of communicating cardiovascular information to this age group is through social media. The most preferred discussion topic to engage this group is personal risk of heart disease stroke.


#### Abstract

Title: \#HeART: A Positive Youth Development Approach to Cardiovascular Disease

\section*{Prevention}

Summary: Fewer than 1 in 5 adolescents and young adults correctly identify cardiovascular disease as the most common cause of death for US adults. There is an urgent need for developmentally appropriate messages to improve awareness of heart disease and preventive behaviors in this age group. In the fall of 2018, we partnered with students and educators at Oak Park and River Forest High School (OPRFHS) in Oak Park, Illinois to create \#HeART, a Cardiovascular Disease prevention campaign grounded in positive youth development theory. Students were invited to use visual art or poetry to explore topics related to cardiovascular disease including risk factors and demographic disparities related to age, race, and gender. Four winning works were selected by the initiative designers after examining submissions for content, originality and tone.


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## Glossary of Abbreviations

AHA-American Heart Association
AYA- Adolescent and Young Adult
CVD- Cardiovascular Disease
FUTURE Study- Awareness of Women's Health Issues in Adolescent and Younger Adult Women OPRFHS-Oak Park and River Forest High School

## Scholarly Project Statement

Cardiovascular disease continues to be the greatest lifetime health risk for women in the United States. ${ }^{1}$ Concurrently, it is well known that the process of atherosclerosis begins in young adulthood, and that individuals with cardiovascular risk factors in adolescence and young adulthood are at increased risk for developing atherosclerosis as well as coronary heart disease. ${ }^{23,4}$ Therefore, adolescence and young adulthood are critical time periods whereby promotion of patient awareness about heart health can significantly reduce the incidence and prevalence of cardiovascular disease later in life. To date, no studies have evaluated the heart health information sourcing habits and preferences of the adolescent and young adult (AYA) women population. This Scholars in Medicine project used data from the FUTURE survey to describe and analyze the heart health information sourcing habits and preferences of the AYA women population. Insights derived from the study were then used to design \#HeART, an arts-based intervention which seeks to bridge the cardiovascular knowledge gap by engaging the critical and underaddressed population of adolescent and young adults.

For the information sourcing study, I contributed to participant recruitment and led statistical analysis and manuscript writing. In addition to official mentorship from Dr. Holly Gooding, I also received mentorship from Dr. Caterina Stamoulis for the statistical analysis of survey data. I conducted statistical coding and primary data analysis. Dr. Stamoulis advised me on appropriate statistical tests and reviewed data interpretation. For \#HeART, I led all aspects of the initiative from idea conception and design, to execution, to manuscript writing. I collaborated with arts educators from the Oak Park and River Forest High School in Oak Park, Illinois to formulate age-specific prompts and to operationalize the initiative.

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# Informing young women about heart disease and stroke: new media and new approaches 

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## Introduction

Preventing heart disease risk factors from developing early in life is critical to reducing lifetime cardiovascular disease (CVD) burden. ${ }^{5}$ While heart disease remains the number one killer of women in the United States, adolescent and young women are infrequently targeted in heart health prevention campaigns. ${ }^{6}$ In contrast, abundant literature exists about health information campaigns related to young women's reproductive health. Studies on the reproductive health information sourcing habits of adolescents and young adults demonstrate that their information sources vary substantially by demographics, and that health knowledge is highly dependent on the information source. ${ }^{789}$ For example, receiving contraceptive information from medical professionals was associated with greater accuracy in knowledge about contraceptive use and efficacy as compared to receiving information from other sources such as the internet, friends and partners. ${ }^{9}$ To the authors' knowledge, no studies have evaluated the cardiovascular health information sourcing habits and preferences of this population. We aimed to investigate the associations between two main information sources - media channels and health professional office visits - and young women's knowledge of heart disease and stroke, as well as to understand young women's future cardiovascular health information preferences.

## Methods

We surveyed 331 female participants ages 15-24 years from the waiting rooms of an academic and a community-based clinical practice between September 2017 and January 2018 to describe and analyze cardiovascular information source habits and preferences. We utilized the previously published American Heart Association (AHA) Women's Health Study survey with permission ${ }^{6}$; we modified questions slightly to focus on young women's health issues and to reflect new media sources. We developed linear and logistic regression models to assess the

[^1]association between participant demographics and our primary outcomes (feeling informed about heart disease and/or stroke) and our secondary outcomes (health information sources and preferences). We controlled for participant race, ethnicity, age, and/or caregiver education in multivariate logistic regression models to assess the association between health information sources and our primary outcomes. Additional methodological details are reported in Gooding et al., 2019. ${ }^{10}$

| Table 1: Demographic characteristics of 331 adolescent/young adult (AYA) participants completing the modified American Heart Association Women's Health Survey |  |
| :---: | :---: |
|  | N (\%) |
| Age |  |
| 15-17 | 91 (27.5) |
| 18-21 | 140 (42.3) |
| 22-24 | 69 (20.8) |
| Missing | 31 (9.4) |
| Race |  |
| Black | 91 (27.5) |
| White | 74(22.4) |
| Other (includes Asian, Native American, and participants reporting more than one race) | 112 (33.8) |
| Missing | 54 (16.3) |
| Ethnicity |  |
| Hispanic | 123 (37.2) |
| Non-Hispanic | 162 (48.9) |
| Missing | 46 (13.9) |
| Caregiver Education |  |
| Less than college | 170 (51.4) |
| College or above | 92 (27.8) |
| Missing | 69 (20.8) |

## Results

Almost half of AYA participants rated themselves as not at all informed about heart disease ( $48.5 \%, 147 / 303$ ), and more than half of AYA participants rated themselves as not informed about stroke $(59.0 \%, 171 / 290)$. The majority $(61.8 \%, 191 / 309)$ had never spoken to a healthcare professional about heart disease.

[^2]On average, participants reported exposure to 1.9 information sources about heart disease in the past 12 months, although $28 \%$ of the young women had not seen/heard/read anything about heart disease (Table 2). Hispanic participants were more likely than non-Hispanic participants to not have seen/heard/read anything about heart disease in the past 12 months (OR $1.71,95 \%$ CI 1.00-2.93). The most common sources for heart disease information reported amongst AYA participants were television (38.2\%), social media (30.3\%) and the web ( $26 \%$ ) (Table 2). Hispanic participants were less likely than non-Hispanic participants to have been exposed to information about heart disease through television (OR 0.57, 95\% CI 0.34-0.95). Participants who had never spoken to healthcare professionals about heart disease risk were also less likely to report exposure to information about heart disease through television, healthcare professionals, websites, friends/relatives and social media (OR 0.27-0.52), adjusting for participant race/ethnicity.

There was a positive association between being exposed to more sources and feeling more informed about heart disease and stroke ( $\mathrm{p} \leq 0.001$ for each), while those who had not seen/heard/read anything in past 12 months rated themselves as less informed about heart disease (OR $0.09,95 \%$ CI $0.04-0.20$ ) and stroke (OR $0.33,95 \%$ CI $0.18-0.59$ ) (Table 2) compared to those who cited at least one information source. Participants with caregivers with at least a college education rated themselves as less informed about heart disease compared to participants who caregivers had not completed college (OR $0.57,95 \%$ CI $0.33-0.98$ ). Web or social media exposure to heart disease information were the strongest exposures associated with feeling informed about heart disease and stroke (Table 2) after adjusting for caregiver education.

Many participants had spoken to their physician about their weight (180/311, 57.9\%), exercise ( $182 / 311,58.5 \%$ ), and nutrition ( $114 / 311,36.7 \%$ ); other heart disease risk factors were much less commonly discussed with health care providers (Table 3). Respondents were most likely to be informed about heart disease/stroke if they had discussed their personal risk with a healthcare professional (OR 3.67, CI 1.16-11.61 for heart disease, OR7.02, CI 1.49-33.17 for stroke) (Table 3). Participants who did not discuss any heart health topics with a physician were least informed about heart disease/stroke (OR 0.37, 95\% CI 0.18-0.74) (Table 3). Having discussed high blood pressure and family history of heart disease with a physician were each also associated with feeling informed about heart disease and stroke (Table 3).

Table 2. Sources of information reported by 331 adolescent and young adult women and association with reporting being informed about heart disease/stroke.

| Information Source | $\begin{gathered} \mathrm{N}(\%) \\ \text { reporting } \\ \text { ( } \mathbf{N}_{\text {total }}=304 \text { ) } \end{gathered}$ | OR (95\% CI) for reporting being informed about heart disease* $\left(\mathbf{N}_{\text {total }}=223\right)$ | OR (95\% CI) for reporting being informed about stroke $\left(\mathbf{N}_{\text {total }}=273\right)$ |
| :---: | :---: | :---: | :---: |
| Didn't See, Hear, Read Anything | 85(28.0) | 0.09 (0.04-0.20) | 0.33 (0.18-0.59) |
| TV | 116 (38.2) | 2.79 (1.57-4.96) | 1.67 (1.01-2.74) |
| Social Media | 92 (30.3) | 2.69 (1.46-4.94) | 2.07 (1.22-3.51) |
| Web | 79 (26.0) | 2.18 (1.14-4.19) | 1.83 (1.06-3.17) |
| Friend/Relative | 63 (20.7) | 2.34 (1.13-4.84) | - |
| Medical Professional | 57 (18.8) | 1.47 (0.74-2.92) | - |

"-" indicates this information source was not associated with being informed about heart disease or stroke

Table 3. Topics discussed with healthcare professionals reported by 331 adolescent and young adult women and association with reporting being informed about heart disease/stroke.

| Have spoken to health care provider about: | $\begin{gathered} \mathbf{N}(\%) \\ \text { reporting } \\ \left(\mathbf{N}_{\text {total }}=311\right) \end{gathered}$ | OR (CI) for reporting being informed about heart disease* $\left(\mathbf{N}_{\text {total }}=\right.$ 223) | OR (CI) for reporting being informed about stroke ( $\mathrm{N}_{\text {total }}=280$ ) |
| :---: | :---: | :---: | :---: |
| High blood pressure | 78 (25.1) | 2.29 (1.23-4.25) | 1.87 (1.08-3.21) |
| Cholesterol | 59 (19.0) | 1.16 (0.59-2.27) | - |
| Family history of heart disease | 69 (22.2) | 3.25 (1.62-6.51) | 1.93 (1.10-3.38) |
| Personal risk for heart disease | 29 (9.3) | 3.67 (1.16-11.61) | 3.70 (1.55-8.84) |
| Personal risk for stroke | 13 (4.2) | 5.39 (1.13-25.71) | 7.02 (1.49-33.17) |
| Weight | 180 (57.9) | 1.63 (0.94-2.84) | - |
| Stopping smoking | 33 (10.6) | 1.60 (0.70-3.65) | - |
| Heart healthy diet and nutrition | 114 (36.7) | 1.21 (0.69-2.14) | - |
| Exercise | 182 (58.5) | 1.09 (0.63-1.88) | - |
| None | 60 (19.3) | 0.37 (0.17-0.77) | 0.37 (0.18-0.74) |
| *adjusted for caregiver education |  |  |  |

"-" indicates this information source was not associated with being informed about heart disease or stroke

When asked how they would like to learn about heart health in the future, more participants chose from healthcare providers than from any other source ( $43.8 \%, 141 / 322$ ). Participants with caregivers with a college or beyond education were more likely to prefer healthcare providers (OR 1.72, 95\% CI 1.01-2.91) compared to those whose caregivers had not completed college. Participants reported being most motivated to learn about heart disease from family ( $64.3 \%, 207 / 322$ ), healthcare professionals $(61.5 \%, 198 / 322)$ and friends $(47.9 \%$, $154 / 322$ ). Black participants were less likely than white participants to be motivated by healthcare professionals (OR $0.49,95 \%$ CI $0.25-0.96$ ), adjusted for participant age. Participants ages 18-21 were more likely to report being motivated by healthcare professionals (OR 2.68, 95\% CI 1.50-4.81) than participants ages 15-17, adjusted for participant race.

## Discussion

Amongst a sample of 331 adolescent and young women recruited from two urban primary care practices, there is a significant information gap in the topic of cardiovascular health. Nearly 1 in 2 participants reported feeling not at all informed about heart disease and more than half reported feeling not at all informed about stroke. Although cardiovascular disease now affects almost half of U.S. adults, the majority (61.8\%) of participants in our study had never spoken to a healthcare professional about heart disease. ${ }^{11}$

There are many factors which may influence whether our participants rated themselves as informed about cardiovascular disease. Importantly, our study found that whether a participant feels informed about heart disease or stroke is largely independent of demographics. The only relationship between demographics and informed status was that participants with caregivers with a college or beyond education were less likely to be informed about heart disease. As caregiver education is a proxy for socioeconomic status, it is possible that participants of higher socioeconomic status have do not view themselves as at risk for heart disease or have competing priorities which prevent them from learning about heart disease.

We found that informed status about heart disease or stroke is primarily dependent on physician interaction and/or having been exposed to information sources in the past 12 months. Participants were more likely to report being informed about heart disease or stroke if they had
come across information about heart disease on television, social media or the web in the last year. The central role of new media in communicating health information to this demographic is not surprising. Digital media have successfully been used to engage and educate this age group in issues in sexual health, as well as issues in alcohol/tobacco/other drug use, internet safety and mental health. ${ }^{12,13}$ Moreover, evidence points to the ability for digital media to reach diverse populations of youth across socioeconomic, racial and ethnic boundaries. ${ }^{13,14}$ The potential of digital media to provide increased health information access is crucial. Our study showed that Hispanic participants were significantly less likely to be exposed to heart health information. Future public health campaigns seeking to bridge the heart health information gap in adolescent and young women should consider using new media approaches, such as television, social media or the web, as a platform for providing appropriate education and intervention.

While television, social media and the web were the most influential information sources on informed status, when asked about their preferred source of heart health information, participants still overwhelmingly chose medical professionals over all other media sources. The finding that participants still prefer medical professionals as a source of health information is consistent with literature on health information preferences for reproductive health. ${ }^{15}$ This may be related to the recognition that physicians are consistently reputable sources of health information, unlike digital media. Interestingly, participants who were exposed to heart disease information through a medical professional in the last year were not more likely than those who had not to rate themselves as informed about heart disease or stroke. This is likely related to the observation that participants were only more informed about heart attack or stroke if they discussed specific heart disease topics with their doctor, most notably personal risk. Discussing other heart disease related topics, such as weight, exercise, and following a heart healthy diet, did not make participants any more informed about heart disease or stroke. While these discussion topics were much more frequently reported by participants, it is likely that health care providers are not directly linking them to participant's future risk for heart disease and stroke. Our study

[^3]suggests that clinicians caring for adolescent and young adult women would most effectively engage this population in discussions about heart health by discussing personal risk.

Our study has several limitations. The limitations which apply to the main FUTURE study also apply here. ${ }^{10}$ Our participants were drawn from two clinical sites in the Northeast and therefore may represent a healthier patient sample. Furthermore, unlike the AHA Women's Study survey which used survey weights to adjust for population distribution, we did not apply survey weights to this analysis and the data therefore are not be nationally representative. Participants were asked to complete the survey online on a tablet device, which may have selected for participants with greater technologic literacy, a prerequisite for accessing digital media. Finally, a research assistant was physically present with participants during survey completion, although they did not answer questions or provide assistance.

## Conclusion

Few adolescent and young adult women feel informed about heart disease and even fewer feel informed about stroke. The most preferred media for communicating cardiovascular information to this age group are television, social media and the web. The most preferreddiscussion topic to engage this group is personal risk of heart disease stroke.

Acknowledgements: The authors would like to thank Karen Robb of the American Heart Association for technical assistance with the AHA Women's Heart Study survey and Dr. Sophie Allende and Ariana Hernandez for assistance with recruitment .

# \#HeART: A Positive Youth Development Approach to Cardiovascular Disease Prevention 

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Atherosclerosis begins early in life, and individuals with cardiovascular risk factors in adolescence and young adulthood are at increased risk for developing both atherosclerosis and coronary heart disease. ${ }^{16,17,18}$ In contrast, adults who reach middle age with a favorable cardiovascular risk profile have a significantly lower incidence of cardiovascular disease and live longer, healthier lives. ${ }^{19}$ Adolescence and young adulthood are thus critical time periods for the promotion of heart healthy behaviors. Unfortunately, fewer than 1 in 5 adolescents and young adults correctly identify cardiovascular disease as the most common cause of death for US adults. ${ }^{20,21}$ There is an urgent need for developmentally appropriate messages to improve awareness of heart disease and preventive behaviors in this age group.

In the fall of 2018, we partnered with students and educators at Oak Park and River Forest High School (OPRFHS) in Oak Park, Illinois to create \#HeART, a CVD prevention campaign grounded in positive youth development theory. ${ }^{22}$ Students were invited to use visual art or poetry to explore topics related to cardiovascular disease including risk factors and demographic disparities related to age, race, and gender. \#HeART had two main objectives: 1) to assess the status quo of adolescents' emotions and attitudes about cardiovascular disease 2) to raise awareness about cardiovascular prevention. The initiative began with a 45 -minute

[^4]presentation to OPRFHS students enrolled in creative writing and advanced art classes on the epidemiology, risk factors, and pathophysiology of cardiovascular disease. Students were then provided prompts relevant to their demographic, including, "What are the effects of corporate marketing on heart healthy habits?" and "What does it mean to you to be a 'relentless force'?"- a reference to the American Heart Association's new mission statement. ${ }^{23}$ The following winning works were selected by the initiative designers after examining submissions for content, originality and tone.

In his poem boiler, Henry Wolff (age 17) likens the heart to a machine both dependable and seemingly indestructible. He describes his artistic process, stating, "I chose to portray the body as a sort of steam-powered vessel - the imagery flipflops between robot and submarine with the heart as its boiler. It wasn't much of a jump from there to describe an air bubble or other fault in the heart like it was a bomb or other act of industrial sabotage."
$i$ am an engine of muscle, striated and strong
a vessel of flesh, unceasing in my service
adaptive but unwavering
my bassy double-thump, to move this great automaton
the dutiful strain in my walls, like the hull of a ship
now tempest-pressed and caving
my cavities echo with squeals of undue stress
my ballast - suddenly too thick, too heavy
chambers ballooning and arteries buckling
like lead pipes and pistons

23 American Heart Association. About Us. https://www.heart.org/en/about-us. Accessed February 1, 2019
a breath of air where none should be
like a coal-bomb in a firebox
In Fairy Dust, Adele Henning (age 18), depicts cigarette ash with a keen, almost childlike wonder. A sprinkling of "fairy dust" appears to magically bring about friendship, peer acceptance, and stress relief. She explains, "I chose this topic because young adults prefer not to think about the fragility of their bodies, especially through smoking. People smoke to bond with one another, to fit in, or even simply as a coping mechanism."

Rivers of ash float from my lips as fairy dust
Floating up to join the clouds.
A thick, grey potion coats the wetness of my throat.
I've finished up my fourth wand,
I reach for another golden crown.
I like the fairy dust, it sends a warmth down my spine,
And a tar through my lungs
And a poison in my veins.
But I don't think of the long run.
I think of the fairy dust.
The poem closes with an acknowledgement that decisions made in the naivety of youth have serious consequences; the author writes, "young adults tend to ignore the potential long term effects of their actions. Right now...we may feel invincible, because we are young and our hearts and lungs are fresh. But to get hooked on a habit that started when we were young is so hard to break later on, and I wanted to capture the beginner smoker's mindset in this poem."

In Stress Fruit, Nicholas Berry (age 18) envisions the body as a piece of fruit that has begun to bruise and cave under the pressure of looming adulthood. He writes: "This poem was inspired mostly by my current circumstances as a senior in high school, and the new kinds of stress that come with that. There is a lot of pressure to deal with all at once. Stress is one of many factors that contribute to heart disease, and one of the factors that I feel is not addressed nearly enough." My body has become an apricot, Concave grooves bending my spine, arcing my clavicle into an acute angle.

This is what stress will do to you.
It will build extra muscles for your fingers,
So much so you think you can accomplish anything.
Stress will whisper a need for sleep into your backpack,
And that need will weigh your shoulders down to irresolute concrete.
Stress will be your best friend
until you realize you have no other tasks to complete.
That space of corpse like air,
in between project due dates and college applications,
That is when stress hates you most,
When all-nighters press your body into the corner of a couch.
Stress hates you most when all your work is done,
And there is nothing left of you but a heart that trips over its own veins.
Nicholas further explains that, "In this poem I illustrate how "useful" stress may seem when it comes to being productive, but once that productivity ceases that stress can have a huge
impact on the body. I really just wanted to give vision to the idea that even "useful" things, can also be detrimental to a person." Given that stress is ubiquitous among adolescents and young adults, discussions about stress management can be a natural starting point into conversations about cardiovascular health.

Finally, in her visual piece Heart Attack, Halley Bergen (age 18) has illustrated the myocardium in sickness and in health. The left half of the heart bears the weight of disease, symbolized by a barren tree. Instead of leaves, the tree is laden with McDonald's fries, a salt shaker, and the chemical formula for sucrose, representing a diet high in grease, salt and sugar, respectively.

The young artist states, "As a senior in high school, I have observed many students in the cafeteria consuming heavily salted, greasy, and sugary foods. With the combination of being unaware of the damage they're inflicting upon their body and the mentality of being immune to disease, many students later in their lives may experience an early onset of adverse side effects to countless diseases." This belief of immunity to chronic disease was a common theme amongst the submitted works; thus, clinicians should focus on dispelling this myth during conversations with adolescents about lifetime cardiovascular disease risk.


Heart Attack by Halley Bergen. Medium: Acrylic on gessoed canvas. Image courtesy of Halley Bergen. Reproduced with permission.

As primordial prevention emerges as a public health priority in the United States, adolescence and young adulthood are increasingly recognized as a critical period to initiate conversations about chronic disease risk. Beyond \#HeART, other efforts to engage this population in discussions regarding chronic disease include The Bigger Picture, which uses spoken word poetry to explore the social determinants of Type 2 Diabetes. ${ }^{24}$ We hope that the given works and their respective themes surrounding invincibility, peer influence, short versus long-term risks, and the importance of stress management contribute to clinicians' understanding of the current emotions and attitudes surrounding cardiovascular health amongst adolescents. These themes are particularly meaningful because they shed light on the needs of a significant

[^5]and under-addressed population. Finally, we hope that the \#HeART campaign provides proof of concept for using poetry and visual art as valuable tools in public health.

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