HHS Public Access

Author manuscript

Res Gerontol Nurs. Author manuscript; available in PMC 2019 January 02.

Published in final edited form as:

Res Gerontol Nurs. 2018 January 01; 11(1): 39–47. doi:10.3928/19404921-20171129-01.

"Maybe This Generation Here Could Help the Next Generation":

Older African American Women's Perceptions on Information Sharing to Improve Health in Younger Generations

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Abstract

The prevalence of hypertension is highest among African American women, who often occupy caregiving roles. The purpose of the current study is to describe intergenerational caregiving and communication themes that emerged during focus groups with African American older adult women (mean age = 73 years) on information sharing and self-management of hypertension. Thematic analysis revealed two overarching themes: *Caregiving Responsibilities* and *Improving the Health of Younger Generations*. Women wanted to help younger generations better manage their blood pressures. These findings suggest that intergenerational relationships may have an important role in managing health conditions, such as hypertension. Further examination of intergenerational relationships as targets for blood pressure self-management intervention is warranted to: (a) address the need for women to share their wisdom, and (b) help improve blood pressure management among African American individuals across the lifespan.

The literature is replete with reports and research studies noting the significance of health disparities in hypertension that persist among African American individuals. In particular, more than 45% of African American women have high blood pressure (Mozaffarian et al., 2016). African American women make up more than 40% of those with poor blood pressure control, and thus have the highest risks for stroke and heart failure (Krakoff et al., 2014). In addition to having higher mean blood pressure levels, African American women tend to

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develop high blood pressure earlier in life compared to other women (Schiller, Lucas, Ward, & Peregoy, 2012).

Despite the plethora of recommendations and educational resources available, older African American women continue to have poor hypertension-related outcomes (National Center for Health Statistics, 2011). Possible reasons for this perpetuated disparity and lack of improvement of blood pressure control among African American women include: poor assessment, knowledge, and information processing (Ferdinand, 2010); increased difficulty adhering to medication regimens (Bosworth et al., 2006); and low feasibility of current guidelines given specific characteristics and experiences (Odedosu, Schoenthaler, Vieira, Agyemang, & Ogedegbe, 2012). For example, African American women are more likely to have comorbid conditions and access to fewer resources than their counterparts (Bushnell et al., 2014; Krakoff et al., 2014), the likelihood for which further increases with age.

African American individuals are the second largest group of caregivers in the United States at 20.3% (5.6 million) (National Alliance on Caregiving & AARP Public Policy Institute, 2015a). *Intergenerational care* describes caregiving provided to a family member from another generation, such as an adult child caring for an aging parent (Bowers, 1987). Many intergenerational caregivers are African American women providing care to grandchildren (Burton, 1996; Minkler & Fuller-Thomson, 2005; Taylor et al., 2010). A better understanding of social factors, such as the benefits and challenges of intergenerational caregiving, is needed to improve intervention strategies for this vulnerable population of African American older women. According to Ryan and Sawin's (2009) Individual and Family Self-Management Theory, self-management is a process that incorporates health-related behaviors into the daily lives of individuals and their families. The process includes social facilitation, meaning that family members influence, support, and collaborate with one another to achieve specific outcomes, such as improved health status and quality of life.

Previous studies have shown that women who share blood pressure information may be more likely to participate in hypertension self-management behaviors (Jones, Veinot, Pressler, Coleman-Burns, & McCall, 2017). The current authors conducted focus groups with African American women with hypertension to better understand how they share information about self-management of blood pressure with their peers. Women discussed who they shared information with, how they adapted self-management strategies to work in their everyday lives, what information they shared, and where and when they shared information (Jones, Wright, Wallace, & Veinot, 2017). Specifically, women talked about strategies they told others to help remember medication, such as taking it with morning coffee (Jones, Wright, et al., 2017). Another self-management strategy discussed was how to incorporate exercise into daily activities, such as how exercises could be performed while sitting (Jones, Wright, et al., 2017).

Although the goal of these focus groups was to discuss the process of sharing information about blood pressure self-management strategies, many women spoke about their caregiving responsibilities. In fact, several women talked about caring for others and expressed "strong feelings" about preventing future generations from experiencing hypertension. Given the reports in the literature about high prevalence of hypertension and frequency of

intergenerational care among African American older women with hypertension, the purpose of the current study was to describe intergenerational caregiving and communication themes that emerged during the focus groups.

AFRICAN AMERICAN WOMEN AND CAREGIVING RESPONSIBILITIES

An African American family caregiver is typically female and approximately 44.2 years old. They are often high school graduates and may have completed some college courses (but not obtained a degree), with an average household income of $37,700—which is below the national median across all backgrounds (National Alliance on Caregiving & AARP Public Policy Institute, 2015a). African American caregivers are usually employed, work 32.9 hours per week, are single (not married), and report “very good” to “good” physical health (National Alliance on Caregiving & AARP Public Policy Institute, 2015a).

Caregiving is the process of physically, mentally, emotionally, or socially helping others who are unable to help themselves (Hermanns & Mastel-Smith, 2012). Caregiving responsibilities add another layer of complexity to responsibilities associated with self-management of hypertension. The relationship of a caregiver to his/her care recipient shapes the caregiving experience (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). The 2016 National Academies of Sciences, Engineering, and Medicine (NASEM) report “Families Caring for an Aging America” highlights the need to focus caregiver priorities on diverse populations. The family is a cultural environment in which caregiving is learned (Otis-Green & Juarez, 2012). Although data suggest that the impacts of caregiving are significant physical, emotional, and financial strain on the caregiver (NASEM, 2016; Northouse, Katapodi, Schafenacker, & Weiss, 2012), on average, African American caregivers report little to no physical or financial strain and moderate to low emotional stress (National Alliance on Caregiving & AARP Public Policy Institute, 2015b). However, these caregivers report high rates of hypertension and other chronic conditions (Piamjariyakul et al., 2015). Reasons for these findings may be due to cultural factors that promote resiliency among African American family caregivers (Piamjariyakul et al., 2015). In addition to the difficulties of caregiving, many caregivers report positive outcomes from this experience, such as becoming closer to their loved ones, increased self-efficacy, and satisfaction that their loved one is being well-cared (NASEM, 2016).

Caring for Grandchildren

In a large percentage of U.S. families, the traditional role of grandparents in multigenerational household structures has transitioned from co-parenting to the permanent role of a primary caregiver. According to analyses of U.S. Census Bureau data by the Pew Research Center, one of every 10 children in the United States lives with a grandparent (Livingston & Parker, 2010). This is an example of intergenerational care. Approximately 41% of those children who live with a grandparent are also being raised primarily by that grandparent (Livingston & Parker, 2010). A disproportionate number of African American children co-reside with or are being cared for primarily by their grandparents compared to other racial and ethnic groups (Livingston & Parker, 2010). Much research emphasis has been placed on the “skipped generation” or grandparent-headed household families (GHF)

and its impact on the grandparent caregiver. The context of GHF often comes about because of highly stressful and stigmatizing adverse life circumstances and events of their adult children. However, this circumstance has been shown to isolate grandparents from needed social and emotional support and often prevents them from being treated equitably by social service providers (Hayslip, Blumenthal, & Garner, 2014, 2015).

Raising a grandchild has the potential to disrupt the life plans of the grandparent, including attempts to self-manage blood pressure. A number of studies highlight the impact of this disruption, which includes poor physical or emotional health, role overload, less satisfaction with grandparenting, less meaningful grandparenting, impaired or strained relationships with spouse and their grandchildren, and isolation from other grandchildren and friends because of their parental responsibilities (Lee, Ensminger, & Laveist, 2005; Luo, LaPierre, Hughes, & Waite, 2012; Strom & Strom, 2015). Poorer health, in particular, has been linked to a variety of outcomes among grandparent caregivers including lowered use of preventive health measures, risky health behaviors (e.g., lack of exercise, obesity), smoking, and alcohol use (Hayslip et al., 2014). Moreover, grandparents often prioritize caregiving and neglect their own health in deference of the health and well-being of their grandchildren (Hayslip et al., 2014).

The preponderance of research on grandchildren living in GHF tends to emphasize the impact of grandchildren's behavior on the grandparents' functioning and not on the well-being of the grandchildren. According to one study, there is the assumption that if the grandparents' functioning improves, the grandchildren will benefit (Hayslip et al., 2014). Studies that identify the strengths of GHF are interspersed throughout the literature and although many of the challenges are considered, the studies highlight the positive cultural tradition of African American grandparents and their roles as caregivers, resilience, and distinct ways of coping across the generations (Hovick, Yamasaki, Burton-Chase, & Peterson, 2015; Sheridan, Burley, Hendricks, & Rose, 2014; Simpson, 2008).

Previous studies have noted the effect the caregiving role may have on disease management, such as diabetes and HIV, among African American women (Carter-Edwards, Skelly, Cagle, & Appel, 2004). In their study with 12 African American women with type 2 diabetes, Carter-Edwards et al. (2004) found that their multi-caregiving roles can be a source of empowerment and hindrance to disease management. However, little is known about how caregiving responsibilities affect African American women's hypertension management and how they incorporate management of the disease and caregiving responsibilities into their routine lives.

METHOD

Sample and Recruitment

The current study was approved by an Institutional Review Board. African American women who were: (a) clinically diagnosed with hypertension and (b) reported sharing information with others about how they self-managed their blood pressure were invited to participate in the study. In September 2016, women from a large, Midwestern urban area who agreed to participate ($N = 13$) were invited to one of two focus groups. According to the U.S. Census

data, the median income for this area was $28,831 (U.S. Census Bureau, 2015). Although the Census shows between 5% and 8% of women in this area are uninsured (U.S. Census Bureau, 2015), all women in the current sample had health insurance and primary care providers (internal medicine) that helped them manage their hypertension. Women were on average 73.08 years old (*SD* = 9.87 years), had controlled blood pressures (mean = 130.54/78.23 mmHg; *SD* = 14.79/11.95 mmHg), were taking between one and three blood pressure medications, and had been living with hypertension for ≥5 years (mean = 15.23 years; *SD* = 5.07 years) (Jones, Wright, et al., 2017). All women were caregivers in some capacity, with the majority (85%) reporting they were primary caregivers for or assisted with caring for grandchildren.

Data Collection and Analysis

The focus groups were held in a large, private meeting room. As participants arrived, informed consent was obtained, and refreshments were offered. Once the focus groups started, participants responded to questions from an interview guide (Table). Each session was audiorecorded, transcribed verbatim, and verified by the principal investigator (PI; L.M.J.) and two research assistants. Using thematic analysis, the transcripts were independently reviewed and categorized with descriptive codes (Boyatzis, 1998). To ensure inter-rater reliability in coding and credibility of themes, the PI and research assistants met to reach consensus and aggregate codes into categories agreed on by each coder (Auerbach & Silverstein, 2003; Boyatzis, 1998). During the second round of coding, the PI collapsed similar categories into themes (Saldaña, 2015).

The PI conducted member checking with five participants to verify that the findings rang true to them (Lincoln & Guba, 1985). Participants were randomly selected and asked permission to be contacted at a convenient time to verify the data and findings. Once permission was confirmed, each of the five participants listened to a brief description of the themes and were asked to provide feedback. Participants agreed with the themes identified and provided minor suggestions about how to prioritize the themes, so no revisions to the themes were required.

RESULTS

Each of the 13 women identified at least one individual with whom they shared information on blood pressure self-management. Most women (92%) acknowledged multiple individuals with whom they shared information, many of whom they were responsible for providing care. More than one half of the women (62%) made comments during the interviews regarding the difficulties of caring for others while trying to care for themselves, prioritizing their loved one's health over theirs, or the importance of helping their family members live healthy lives, because their loved one's health was connected to their own.

Two overarching themes, not specifically related to information sharing for self-management of hypertension, were derived from the data: *Caregiving Responsibilities* and *Improving the Health of Younger Generations*. Subthemes of *Improving the Health of Younger Generations* that emerged were: *Concerns about their health status*, *Difficulty connecting with younger generations*, and *Motivation to share blood pressure information*. Many participants

discussed caregiver responsibilities centered on caring for grandchildren. Women also discussed reaching out to younger generations and helping them prevent hypertension and experiencing the associated negative outcomes of this disease. Older women were concerned about not being able to communicate with younger women, but wanted to connect with them to share their wisdom.

Caregiving Responsibilities

All women in the study discussed responsibilities for caring for others. Women occupied various caregiving roles. One role women talked about was spousal caregiving. One participant discussed caring for her husband by stating, “My husband is a myeloma patient and we go to [his appointments].” Another participant described caring for siblings. In particular, one participant was the primary caregiver for her sister. She was very upset about her sister falling before she arrived to her sister’s home to care for her, stating:

> My sister said, “I hear something,” and she had fell, and she opened the entry door, and she had no clothes on, and she just looked like a skeleton laying up there. So, my sister had to go to the doctor. I said, “Oh my god”… I called 2–1-1 and asked how could they direct me to get her some help.

Many women talked about caring for their children, with most describing responsibilities for their grandchildren. One woman felt responsible for helping her nieces, nephews, and their children and described it as stressful, stating, “Yeah, because right now, I’m dealing with my brother’s and sister’s kids, grandchildren and coming up with them, looking at them. You can’t. It’s hard. You could lose your appetite and everything else, [and it can cause] high blood pressure.”

Many women (85%) in the current study discussed caring for their grandchildren. One participant stated, “A lot of like women my age and older [are] taking care of their grandkids.” Another participant talked about the lack of stability at home for her grandchildren, so she took them to her house: “So it was rough, and grandkids, I got them.” Another participant was concerned about her grandson and wanted to petition for custody of him. She shared, “Then she looked at me and she said, ‘Now they’re in jail.’ I mean you know I didn’t expect to hear that, and I said, ‘Oh boy.’ That’s when I said ‘I’m [gonna] get my grandson.” This grandmother immediately felt a strong conviction to step into the parental role for her grandchildren. Cooking for grandchildren was part of the caregiving role and used to pass on changes made to dietary habits related to hypertension self-management. For example, one participant described, “You know even my great grandkids say, ‘Oh G-Ma, this taste nasty.’ [I’ve got] five kids, 16 grandkids and four great grandkids, and you know what? I said, ‘Well honey, that’s good. I’m glad I don’t use salt no more.’” Clearly, this grandparent was unapologetic for this change to her meal preparation toward managing her hypertension. A grandparent caring for her pregnant granddaughter stated, “I talked my granddaughter in through her whole pregnancy and through the Braxton Hicks.” This was an example of this grandmother using her role as grandparent to educate a member of the younger generation in managing her health. These were just some examples of how grandmothers in the group took on the caregiving role for their grandchildren, either part- or full-time.

Improving Health of Younger Generations

Concerns About Their Health Status.—Although all participants were not grandmothers, many talked about concerns they had about the health of younger family members, neighbors, and other community members in general. One participant stated:

> …how do we get someone or get young people to come and do [something]? ‘Cause I went to a funeral. One of my neighbors had a 53-year-old daughter die… and how do you get them to understand that we look like we look ‘cause we tried to live healthy lifestyles?

She also raised a concern by stating that:

> I still live in the neighborhood that my son was raised in, and when I see the other kids, it’s always “Hi, Ms. <Participant>. You look just like you did when C was in school,” but I appreciate you saying that, but telling me that and you look as old as I look, how do I get you to understand that you can’t do certain things?

This participant was lamenting over seeing younger generations experiencing illness, particularly because she felt that making different lifestyle choices could have prevented their suffering. Another participant talked about her concern for her niece: “She had so many things wrong with her. Then she lost her ability to walk. So naturally when you can’t move, and at a very young age (32)….” Concern for the health of future generations was paramount for these caregivers, those closely related to them as well as those not so close.

They were also concerned about the lack of community resources available to share with younger members. One participant reminisced about community resources that were previously available, stating:

> …I know you’re aware of this little street pamphlet they used to have that they have all the names and addresses to go for help, and then you go to these places, they’re not even in existence anymore, and so how are you gonna tell someone to go there for help, when you can’t tell them anywhere to go for help.

She wanted to be able to direct the younger generations to specific resources that might be useful for them to make healthy lifestyle choices.

Difficulty Connecting With Younger Generations.—Although all women were interested in helping their grandchildren and other members of that generation, some of them expressed concerns that they were not sure how to interact with younger generations. One participant stated:

> What can we do to help the younger generation? And it all has to be, maybe not professional, but you can’t do it one-on-one ‘cause whether we like it or not, we’re living in a society now that everybody, we might not admit it, but you’re afraid to approach anyone.

She indicated that professional assistance would not be required to resolve the problem if she had strategies to connect with young men and women. When queried about using the internet to reach the younger generation, many women were not interested in using technology and were worried that: “…we are in a society where the young people, they

share everything on Facebook®, Twitter®, and everything." This statement indicated that there was a concern for the lack of privacy that sometimes comes with the use of social media. In addition, one participant stated, "But you know now, this generation coming up, that's the only way they talk now. They snap you back before they even think to answer a decent question. No respect." This participant believed that individuals younger than her had a different and inappropriate communication style.

Motivation to Share Blood Pressure Information.—Throughout the focus groups, women discussed ways in which they had adapted hypertension self-management strategies to work within their everyday lives. Several participants agreed with one of the women when she stated, "…I'd just like to know how to help." Women were speaking specifically about hypertension management. One woman talked about a plan her family made at an annual family reunion, stating, "Maybe this generation here could help the next generation…." These women wanted to share the approaches they had learned over the years, to prevent their grandchildren and other young individuals from making the errors they had previously made.

DISCUSSION

To the current authors' knowledge, this is the first published work that explored the role of intergenerational caregiving on hypertension management among African American older women. Specifically, the focus was on African American women's approach to not only self-manage, but also impart their knowledge about hypertension and hypertension self-management with younger generations (e.g., daughters, grandchildren). Hypertension remains a chronic illness that is highly prevalent among African American older women (Chobanian et al., 2003; Mozaffarian et al., 2016). In addition to being responsible for self-care, many African American older women with hypertension in the current study were also tasked with intergenerational caregiving responsibilities. This responsibility could potentially add complexity to hypertension self-management regimens. Intergenerational care themes that emerged from focus groups with these African American women with hypertension that promote information sharing were also emphasized.

Many women in the current study were grandmothers and had varying levels of responsibilities for caring for their grandchildren. Previous studies have highlighted pros and cons of these grandparent/grandchildren relationships. Cons outlined include poor physical health, strained relationships with their grandchildren, and isolation from other grandchildren and friends because of their parental responsibilities (Lee et al., 2005; Luo et al., 2012; Strom & Strom, 2015). Similar to previous research, women in the current study described some of the stressors related to caring for their grandchildren. In contrast, other studies have shown the benefits of caring for grandchildren. Hayslip et al. (2014) proposed that grandchildren's health will improve if their caregiver/grandparent's health improves. However, it becomes more of a concern when the health of the caregiver declines, and subsequently that of the grandchild(ren) (Lien & Huang, 2017).

IMPLICATIONS

There are several implications of the current study. Previous studies have outlined the benefits of information sharing among African American women with hypertension, for the sharer and recipient (Jones, Veinot, et al., 2017; Jones, Wright, et al., 2017). Moreover, the development of health messaging strategies to increase health communication among African American families is needed (Hovick et al., 2015). Exploring information-sharing strategies as self-management support for African American grandmothers caring for grandchildren is warranted. As demonstrated by the women in the current study, there was a strong desire to promote education in this way. They believed as if they had plenty of knowledge about how to lower their blood pressures and maintain them in a safe range and wanted to share it with younger individuals, including their grandchildren. This desire to share was also evident in women who were not grandmothers, as they were also interested in helping younger generations improve their blood pressure and overall health. Additional studies should examine the interaction of African American older women with hypertension as lay advisors to younger generations.

Previous studies have shown that patients prefer sharing and receiving blood pressure information and advice from others who look and speak like them (Jones, Wright, et al., 2017). Perhaps concerned members of the community and grandmothers can assist younger generations in developing self-management strategies to help maintain their own blood pressures within a safe range. Further examination of this relationship as a possible intervention strategy may be useful in helping African American individuals across the lifespan with blood pressure management and improved self-care. Use of trusted civic organizations, such as the church or intergenerational community centers, may be ideal places to initiate this approach. The familiarity of individuals with such organizations may enhance the teaching and learning environment.

Some participants expressed concern about connecting and communicating with younger generations. This concern must be addressed before using these relationships as a strategy to support African American older women’s management of their blood pressure, as well as African American younger individuals to improve their blood pressure and health. Perhaps their communication could be facilitated by specific interactions to find a common language, mutual respect, and determining what each group could offer one another. Despite concerns about how to communicate with the younger generation, women were compelled to reach out to them. Exploration around how these women received (or did not receive) health education from their parents and grandparents needs to be examined. Such lessons learned from the past may provide insight on how these women would be able to reach younger generations in a more effective manner.

Resource allocation to support health care provider training in communication on focal topics, such as hypertension self-management among African American older adults, is needed. Formal programming that encourages and facilitates such conversations across generations may be influential in building relationships around a common health topic such as hypertension. Connecting women around a mutually important topic can facilitate camaraderie for further information exchanges on other important areas such as raising a

family, the benefits of planning ahead for the future, and making healthy lifestyle adjustments earlier in the life course rather than later. Whether initial education is conducted in a formal setting, and leads to informal education, or initiates informally, and leads to formal strategies, the potential benefits of these exchanges are evident.

LIMITATIONS

As with any research study, the current study has limitations. The sample comprised African American older women with hypertension from one community located in the Midwest region of the United States; therefore, these results may not be generalizable to women of other racial or ethnic groups in other regions of the country. In addition, these were themes that emerged from the study, but were not specifically related to the primary purpose. Additional details were unable to be captured for specific levels of intergenerational care, such as the number of grandchildren being cared for, their ages, and whether they had been diagnosed with any chronic illnesses. Therefore, these findings should be interpreted within these limitations. However, the impact for improvements in hypertension self-management using data provided by these women is potentially far reaching, as data gleaned from this group of women studied serve as an example of what is desired by these women to identify needed resources to facilitate these processes.

CONCLUSION

The current study contributes to an essential body of literature that focuses on reducing health disparities surrounding hypertension toward an end goal of elimination. Similar to previous studies, these findings suggest that intergenerational relationships may have an important role in managing health conditions, such as hypertension (Carter-Edwards et al., 2004). Further examination of intergenerational relationships as targets for self-management intervention is warranted. Future studies are needed to explore these established relationships as a mode for intervention, addressing the need for women to share their wisdom and helping improve blood pressure management among African American individuals across the lifespan. Therefore, the potential to positively influence hypertension self-management is significant. Study findings will inform future studies toward appropriate, culturally tailored intervention development to reduce hypertension and its risk factors for development while caregiving through intergenerational education.

Acknowledgments

The authors have disclosed no potential conflicts of interest, financial or otherwise. This publication was made possible by the National Institute of Nursing Research of the National Institutes of Health (NIH) (awards P30NR015326-S1, P30NR015326, and 4T32NR01421304); and the Clinical and Translational Science Collaborative of Cleveland (KL2TR000440), from the National Center for Advancing Translational Sciences component of the NIH. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

The authors acknowledge Mr. Edward C. Bennett and Ms. McKenzie K. Wallace for their assistance with data collection and analysis.

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TABLE

Interview Guide for the Focus Groups and Examples of the Associated Responses

Probe	Response
Tell me a story about a time you shared information about self-managing your blood pressure.	“Me and my baby daughter, we talk about it, ‘cause she’s trying to change some of her habits of eating…I try to eat three meals a day. I don’t eat a lot of sweets. I don’t eat a lot of potato chips. I don’t even really buy it, you know, and I have to get a taste for it to go buy me some candy or buy a bag of potato chips. I don’t buy pop…I drink a lot of water…So I just, you know I try to watch what I eat. That helps lower my blood pressure.”
Why did you choose to share information with this person?	“I talk to my daughter, ‘cause she has hypertension. I don’t know if I gave it to her or what, but she has hypertension, too…”
Why do you feel that you need to share blood pressure information with others?	“If you care or love someone, you want them to live…I help by giving them the information that I think is working for me…”
Why is it important to share this information?	“Your lifestyle has so much to do with how you live. That’s what I think about in trying to help someone else.”
Do you think that it helps the person who you share it with? How so?	“I love to help people in every way I can. If I can give a word of encouragement, or if there’s something that I’m trying to do to help myself, I want to try to help others in the same way.”
Do you think that it helps you to share information? Why or why not?	“It helps me because when I’m telling her these things, like it reinforces me that I need to do the same thing you know to also not only [watch my] salt, but watch my sugar.”
Tell me how you give information to the person you want to share it with.	“Well, if we get on that conversation, or if I’m around somebody and I see that they’re using too much salt and I’ll tell them, ‘You know you shouldn’t eat this/that.’”
Do you think that it would be best to share information with each person one at a time or would it be better if you talked in a group? Let’s discuss the pros and cons of each way.	“In a group setting, like we exchange more and then we find out things from each other, what she does and what they do...” “You know I think it depends on the person, because some people you can [only] reach one-on-one.”