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Adolescent, caregiver, and friend preferences for integrating social support and communication features into an asthma self-management app

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Abstract

Objectives—This study examines: 1) adolescent preferences for using asthma self-management mobile applications (apps) to interact with their friends, caregivers, medical providers, and other adolescents with asthma and 2) how caregivers and friends would use mobile apps to communicate with the adolescent and serve as sources of support for asthma management.

Methods—We recruited 20 adolescents aged 12–16 years with persistent asthma, their caregivers (n=20), and friends (n=3) from two suburban pediatric practices in North Carolina. We gave participants iPods with two preloaded asthma apps and asked them to use the apps for 1-week. Adolescents and caregivers provided app feedback during a semi-structured interview at a regularly-scheduled clinic appointment and during a telephone interview one week later. Friends completed one telephone interview. Interviews were audio-recorded and transcribed verbatim. An inductive, theory-driven analysis was used to identify themes and preferences.

Results—Adolescents preferred to use apps for instrumental support from caregivers, informational support from friends, and belonging and informational support from others with asthma. The majority of adolescents believed apps could enhance communication with their

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caregivers and medical providers, and the theme of self-reliance emerged in which caregivers and adolescents believed apps could enable adolescents to better self-manage their asthma. Friends preferred to use apps to provide instrumental and informational support.

Conclusions—Given preferences expressed in this study, apps may help adolescents obtain social support to better self-manage their asthma. Future app-based interventions should include features enabling adolescents with asthma to communicate and interact with their caregivers, medical providers, and friends.

Keywords

mHealth; self-reliance; adolescents; self-management; social support

Introduction

Asthma is the most common chronic pediatric condition in the US, affecting 1 in 11 children. [1] The prevalence of asthma has increased in the last decade and adolescents with asthma are at greater risk of morbidity and mortality than other age groups; this is partially attributed to suboptimal asthma self-management. [2] The support of family, health care providers, and peers can positively impact self-management behaviors directly or indirectly through mechanisms such as increasing self-efficacy, defined as an individual's confidence in his or her ability to perform specific self-management behaviors. [3–5] Self-management programs grounded in Social Cognitive Theory (SCT) emphasize the influence of supportive others on behavior and are useful to improve health care outcomes for adolescents with asthma. [6]

According to SCT, family support can reduce adolescent self-management barriers by encouraging more positive attitudes toward medication taking and providing structured and nurturing family routines to encourage treatment knowledge and adherence, which in turn can improve asthma control and quality of life. [7–9] Additionally, research shows that children who feel supported and encouraged by providers and ask more asthma-related questions during the medical visit engage in more self-management behaviors and report fewer asthma symptoms and better quality of life. [10–12] Peers' attitudes toward adolescents with asthma are generally positive and serve to facilitate adolescents' asthma self-management. [12] Adolescents with chronic conditions are twice as likely to adhere to their medical regimen when they perceive that their friends are supportive, yet research has shown that adolescents with asthma may not be aware of their peers' supportive attitudes. [12]

Although social support from parents, providers, and peers is a major determinant of selfmanagement behaviors, few studies have assessed whether eHealth and mHealth interventions can help adolescents meet their asthma-related social support needs. [11, 13] Social support needs include instrumental (provision of tangible aids and services), informational (suggestions, advice, and problem solving information), and emotional (expressions of love, empathy, trust, caring, and sense of belonging) support. [3, 14] Asthma self-management apps are very promising for adolescents, given the potential support benefits, appeal and widespread use of such communication technologies. [15–17] For

example, youth with asthma reported that Internet chat rooms allowed them to communicate freely and anonymously, sharing issues and emotions as well as information concerning disease and treatment therefore serving as a source of informational and emotional support. [11, 18] Apps that are used on portable technologies, such as smartphones, are even more promising given nearly three-quarters of adolescents have access to a smartphone, and 91% of teens use mobile devices (e.g. cell phones, iPods) to go online. [19]

We are not aware of any studies identifying adolescent, caregiver, and friend preferences for using apps on any platform (i.e. mobile or stationary) to enhance asthma-related social support and increase communication. [13, 20, 21] This study examines: 1) adolescent preferences for using apps downloaded on mobile devices to communicate with and foster supportive relationships with their friends, caregivers, and medical providers and 2) how caregivers and friends would use apps to communicate with the adolescent and serve as sources of support for asthma management. Given that previous research has found that family and friends are generally supportive of adolescents' asthma self-management [11, 12, 22], we hypothesized that adolescents, their caregivers, and friends would view an app as an effective tool to provide and receive self-management support.

Methods

Design and Participant Recruitment

This study was a formative study approved by the Institutional Review Board at (university name removed for blinding purposes) and all participants provided informed assent/consent. Adolescents were eligible if they 1) were 12–16 years of age, 2) were able to read and understand English, 3) owned a cell phone, smartphone, or tablet, 4) were present at the visit with an adult caregiver (biological parent or legal guardian), and 5) had persistent asthma. Persistent asthma was defined as experiencing asthma related daytime symptoms more than twice a week, asthma-related nighttime symptoms more than twice a month, or receiving one or more long-term control therapies for asthma. [23, 24] Caregivers were eligible if they 1) were at least 18 years of age, 2) could read and understand English, 3) were the biological parent or legal guardian of the adolescent with asthma and 4) were present at the appointment.

Adolescents and their caregivers were recruited at two suburban pediatric practices in North Carolina during 2013–2014. The following two methods were used to recruit adolescent-caregiver dyads: 1) A designated clinic liaison at the pediatric practice contacted caregivers of adolescents (aged 12–16) with asthma by phone or in person before their appointment and introduced the study research assistant (RA) to interested dyads on the day of the scheduled clinic appointment; and 2) The RA sat in the clinic waiting area with a large recruitment poster and explained the study to potentially eligible patients who approached the study table.

After providing consent/assent, caregivers and adolescents completed a brief questionnaire that assessed demographics and technology usage before the scheduled clinic appointment. After the appointment, the RA convened the dyad in a private room within the clinic. The caregiver and adolescent were each given an iPod Touch with two asthma self-management

apps preloaded on the devices. One app was targeted to adults and the other app was targeted to younger children because, at the time, no app available on the iOS platform in late 2012 was targeted to adolescents. These apps were selected because they were both user-friendly and included features for asthma self-management. The RA demonstrated how to use the apps and then allowed participants to explore the apps on their own for approximately 10 minutes. The RA then asked the dyad a series of questions in order to ascertain their initial impression of the two apps and their interview was audio recorded.

Separate adolescent and caregiver phone interviews were conducted by a RA one week following the in-person interviews. All interviews lasted between 30 minutes and an hour. At the end of the interview, adolescents were asked to share study information with their friends and ask them to call the research team to schedule an interview (i.e., snowball recruitment).

Interested friends called the study RA to be screened for eligibility. Friends were eligible if they 1) were 12–16 years of age and 2) were the friend or relative (e.g. cousin) of a study patient with asthma. For eligible friends, verbal assent was attained, and the friend was mailed an iPod Touch and asked to explore the two preloaded asthma apps. A telephone interview was conducted with the friend approximately 1 week following receipt of the iPod Touch. Interviews lasted 20–30 minutes.

All in-person and telephone interviews were audio recorded and transcribed verbatim. Participants were told after screening and prior to study enrollment that they would be allowed to keep the iPod Touch as an incentive.

Measures

Demographic and clinical characteristics assessed in questionnaire-

Caregivers reported the following: 1) gender (male or female), 2) age (in years), 3) ethnicity (Hispanic, Latino or Spanish origin or Non-Hispanic, Latino or Spanish origin), 4) race (White, Black or African American, other), 5) household income (range 1=<\$25,000 to 7= \$150,000 or more), and 6) education level (range 1= Less than high school education to 6=More than bachelor's degree). Adolescents reported the following: 1) gender, 2) age (in years), 3) ethnicity, 4) race, and 5) grade in school. Adolescents also reported 1) how long they have had asthma (in years) and 2) how serious they think their asthma is (very serious (1), fairly serious (2) somewhat serious (3), not at all serious (4)).

Technology use assessed in questionnaire—Using a yes/no response format, we asked adolescents if they 1) use their phone to text message their friends, 2) use their phone to text message their family, 3) enjoy spending time on social internet sites such as Twitter, Instagram, Facebook, or Pinterest, 4) have ever downloaded an app to a cell phone, tablet, or other handheld device, or 5) have ever downloaded a health-related app. Caregivers reported if they had 1) ever downloaded an app to a cell phone, tablet, or other handheld device or 2) ever downloaded a health-related app.

Interview Content

Researchers employed evaluation methodology, including a process of qualitative inquiry to assess participant app support preferences and needs. [25] For the in-person interview,

adolescents and caregivers were jointly asked about their initial impressions of the apps including ease of use, perceived usefulness, and suggestions for improvement. In the followup interviews, adolescents were asked questions about how asthma apps could be integrated into their asthma care as well as their preferences for using the apps to communicate with their provider. Adolescents were also asked preferences for using apps to involve caregivers, other adolescents with asthma, and friends in their asthma management. Caregivers were asked their preferences for using the apps to interact with their child about their asthma care and their views on friend involvement in their child's asthma management. Friends were asked several questions about how they would use the apps to help their friend manage their asthma. Given participants were able to better familiarize themselves with the apps over the course of the week and provide more input on their experiences using the apps, only followup data and baseline technology usage questionnaires were used in this analysis. Table 1 lists the relevant interview questions with code variables and coding descriptions that were used to assess adolescent, caregiver, and friend preferences. It includes questions that were analyzed quantitatively and qualitatively.

Data Analysis

Quantitative descriptive statistical analyses were conducted using IBM SPSS Version 21. Each semi-structured interview transcript was analyzed thematically using MAXQDA 11 (Berlin, Germany). Three research team members engaged in an iterative process of reading and rereading the initial transcripts. [26] A detailed coding tool was developed over a 3-month period and contained code definitions and example quotations to help improve intercoder reliability for each theme. [27] Open coding was utilized to sort data and identify emergent themes while axial coding was used to identify relationships among themes. [28] Throughout the study period, all tape-recorded transcripts were coded independently by one research team member. A second team member coded 10% of all interview transcripts to assess inter-coder reliability, which was k=.85.

Results

Sample Characteristics

Table 2 presents the demographic characteristics of the study participants. Twenty adolescent-caregiver dyads completed the baseline interviews and sixteen dyads completed the one-week follow-up interviews. Of the four adolescents who did not complete the follow-up interview, the mean age was 14.5 years, and these individuals were not demographically different from those who completed the study. Three were female, two were white, and two were black. Of the four caregivers who did not complete the follow up interview, four were female, two were white, two were black, and the mean age was 37.8. Only three friends completed interviews.

Adolescent and caregiver technology use

A majority of adolescents (80%; n=16) said they used their phones to text message their friends and family. All adolescents reported downloading an app to a cell phone, smartphone or tablet, but only 3 (15%) had downloaded a health related app. Three quarters of adolescents (75%) reported enjoying spending time on social internet sites. Almost all

caregivers (95%; n=19) had downloaded an app to a cell phone, smartphone or tablet, and half (50%) had downloaded a health related app to their cellphones, tablets, or hand held devices.

Adolescent preferences for involving friends in an asthma app

Ten (63%) adolescents said they wanted their friends involved in an asthma app and suggested they could be involved in the following ways: 1) video chatting, 2) creating a communication network on social media, 3) sharing the app, and 4) adding their friends from school on the app. However, two of the ten adolescents who wanted friends involved in the app expressed concerns about involving friends who didn't also have a diagnosis of asthma.

One adolescent stated,

Um, I mean, I think I could get my friends who have asthma to do it, but I don't know how I'd get friends without asthma to do it. You know? Cause I don't really...I don't know why they'd want to go if they don't -- on the app if they don't have asthma. (Female, age 16).

Two adolescents who were less likely to want to get their friends involved in their asthma management preferred that their friends get involved through education, and therefore suggested using the app for informational support. For example,

I think, I mean, everyone that I know, unless they're my very close friends, they don't really understand what it [asthma] is. The main thing is they don't understand the severities of it because I have a more severe type of asthma and they'll say, oh, you know, my, my, you know, my sister had asthma once, you know, when she was little. She had inhalers. And, you know, they take it the same as people who are on like oral steroids, and that's -- it's very different. I think that it would be nice just like there was some ways to like educate your friends about it. I don't know. (Female, 14)

The majority of adolescents (81%; n=13) did not want their friends to text message them to remind them to take their medications. As expressed in the following quote, some of the adolescents were hesitant to disclose the fact that they had asthma and didn't want to draw attention to it with their friends.

I don't really -- I don't really want my friends to know what kind of medications I'm taking, cause I like to keep it to myself. So I don't really want them knowing, cause like a lot of my friends don't even know I take so many medications anyways, like a lot of people think I'm just fine, so I'd only like trust my parents with that. (Female, 16)

Over two thirds of the adolescents (69%; n=11) said they wanted to interact with other adolescents who have asthma. Many expressed an interest in using the app to create an online community that would serve as both a source of informational and emotional support. When one adolescent was asked about his likelihood of using an asthma app if he could interact with other kids with asthma he said *"Yeah, yeah, yeah, because like you all have like the same like kind of problem and you can really kind of have like fun and like meet some*

new friends on there." (Male, 13) However those that did not want to interact with other adolescents with asthma tended to be older (ages 15 or 16), had been living with asthma for a longer period time, or cited privacy/security concerns or a lack of desire to talk about or hear asthma experiences of others.

Adolescent preferences for interacting with caregivers

Three quarters (75%; n=12) of adolescents wanted their parents to text message them to remind them to take their medications and therefore provide instrumental support. Many adolescents discussed how syncing the app with their caregiver would aid in shared knowledge regarding asthma care and open up opportunities for joint decision making regarding asthma care.

I think if me and her were able to see my asthma, like what was going on at the same time, cause like most of the time, I -- like I said, I'm a forgetful person, I forget stuff, so she can remember, she can probably be like -- put it in her iPod and say, "Oh, but on this day, I -- you posted that you were wheezing on this day." (Female, 15)

While some adolescents saw the apps as an opportunity to enhance communication about asthma care between themselves and their caregivers, others saw the apps as an opportunity to be self-reliant.

Well, not a little, but like pretty much like it [the app] helped a lot because it helped me like just track it, because normally my parents do most of the tracking... Yes, because normally it was parents doing it before, and, um, I would just, um, not keep track of it, but now that, uh, I see that there are apps out there for this sort -- certain purpose, then I can do it myself and not have to rely on my parents to do it. (Male, 12)

Adolescent preferences for communicating with providers

14 adolescents (88%) would use the app to send information to their medical provider. The majority expressed satisfaction at using the app to show the doctor how they are doing or feeling better prepared and confident in their ability to communicate with their doctor during a medical visit.

I could keep up with how I'm doing on a daily basis, and it just --it helps me, so when I go back to my doctor I could tell her this is how I was feeling and so on and so forth. I can give her a report of how I was feeling. (Female, 15)

Maybe if you forgot a medication, I know that the doctors they always ask you and I know a lot of people don't remember the doses, so they can say, oh, you know, hold on. I have the dose. I'll pull it up for you right now. It makes you seem like you have more control over it, instead of you're just part of doing what your doctor tells you to. Although, I mean, that's very good but you seem like you have a larger part in it I guess. (Female, 14)

Friend preferences for communication

All three friends said they would like to text message their friend who had asthma to remind them to take their medication, therefore using the app as a medium for instrumental support. One friend remarked, "Yes, that would make me like really responsible for it. That would also give her the ability to be able to be reminded to take her medicines."

Friends also discussed other ways they could use the apps to provide both instrumental and informational support to their friends. They all expressed uncertainty about what to do when their friend was having an asthma attack. They described a need for information and guidance on what to do in this situation. For example,

Let's say we were out somewhere and she started having an asthma attack and I didn't know what to do, it might be kind of cool to have something on there where you can say, "Okay, if your friend is having an asthma attack, this is what you need. Tell them to take slow breaths. Tell them to find their inhalers."

Caregivers' preferences for communication

Fourteen (88%) caregivers would use an app to text message their children to remind them to take their medication. Caregivers mainly discussed using the apps as a medium for instrumental support. Similar to adolescents, caregivers discussed a desire to use the apps for monitoring and tracking purposes as well as syncing data.

I notice this iPod has a syncing mechanism between your computer and your device, I think if it -- if it syncs between devices, I don't know if it can, but it would be good between her device and my device we could sync, and that way it -- it -- I guess it eliminates email, but it would give me, um, I -- I just think that would be helpful if I just said, "Sync with," whatever, and I already have her stuff in here, I can bring it in, you know. (Caregiver of 16 year old female)

Caregivers also felt that adolescent app use would enable adolescents to be more responsible or self-reliant for their own asthma care.

That would have been good when [name], uh, was in his, uh, grade school because it would, uh, it would've helped him to be independent, uh, taking his medicine because sometimes he wouldn't, he didn't, uh, like he would just forget to take it cause when it was taking the, um, Flovent, he had to take it two times in the morning and two times at night... so that would have been good to have to help him remind to take his medicine and stuff. (Caregiver of 16 year old male)

Regarding friend involvement in asthma care, half of the caregivers (50%; n=8) would want the adolescent's friend to text message them to remind them to take their medication, 6 did not want the adolescent's friend to text message them, and 2 did not answer. A recurring reason for having the friends text was "As long as she takes her medicine, I don't care who tells her to do it." (Caregiver of 14 year old female). However, reasons for hesitancy included lack of necessity, belief that child would not approve, hesitancy regarding trustworthiness of friend or age of friend. One parent stated, "I don't really want a, a child telling my child when to take their meds." (Caregiver of 12 year old male)

Discussion

Our findings suggest that adolescents believe that an asthma app could be used to communicate with and obtain self-management support from peers, caregivers, and providers. The majority of adolescents would be more likely to use an asthma app if they could interact with other adolescents who have asthma. Adolescents discussed the apps in terms of providing support through creating a social network. However, they expressed less willingness in wanting to disclose asthma information to their friends who did not have asthma. Additionally, the majority did not want their friends to text message them to take their medications. These findings are not surprising given that previous studies have shown that adolescents want to avoid appearing different from their peers, which can lead to denying, hiding, or ignoring symptoms and subsequent failure to use medication in the presence of others. [29] This may also explain why only three of twenty adolescents recruited friends to participate in the study. Adolescents may have been uncomfortable asking their friends to participate in an activity that focused on their asthma; thereby, emphasizing how they were different from their friends.

Of the three friends that were interviewed, all wanted to use an app to provide instrumental and informational support to their friends with asthma. It is likely that adolescents with asthma in our study are unaware of their peer's supportive attitudes. However, because adolescents with chronic conditions are twice as likely to adhere to their medical regimen when they perceive support from friends, it is important that mechanisms of support be made clear to adolescents. [30] Future interventions should focus on identifying creative and acceptable ways to use apps to build peer support as well as include friends in asthma management. Furthermore, apps should develop asthma awareness messages for friends of adolescents with asthma, as friends want to be able to provide both informational and instrumental support.

Caregivers discussed using the apps to provide instrumental support in the form of medication reminders. Since caregiver support positively correlates with improved adolescent asthma management, this research confirms that empowering parents to continue support through app medication reminders is warranted. [8] Our study also indicates that adolescent app use has the potential to increase adolescent self-efficacy in asthma self-management. The theme of self-reliance emerged in which both adolescents and caregivers believed that apps enabled adolescents to feel confident about and be proactive in managing their own care. In addition, apps appeared to give both caregivers and adolescents increased feelings of control and preparedness, and increased adolescent satisfaction regarding provider-patient communication. Therefore apps may increase self-efficacy in the patient provider interaction as well. Given Social Cognitive Theory's emphasis on self-efficacy as a critical predictor of self-management behaviors, the utility of apps as an intervention mode seems promising. The positive feedback from adolescents related to their interest in using an app to enhance patient-provider communication highlights a need for the development of those types of application features.

Although our sample was racially, ethnically and gender diverse, our findings are not generalizable to the larger population due to the recruitment methods, small sample size, and

specificity of the analysis. The sample was a convenience sample from two suburban pediatric clinics. We did not collect data on whether adolescents were, in general, early adopters of technology, so the preferences reported in this manuscript may not reflect the preferences of the larger population of adolescents with asthma. Moreover four dyads were lost to follow-up. Although these dyads were demographically similar to those who completed the study, selection bias could have occurred in which those motivated to use the apps were more likely to complete the follow up interviews. It is also possible that given the iPod incentive, those who agreed to participate may have had stronger positive preferences for using technology and therefore may have been more receptive to using an asthma app for support. In addition, only three friends were recruited; thus, the perspectives of the friends we interviewed may not be generalizable. Friends who participated may have been more motivated to support their friends with asthma than the general population of friends. More research should be done to obtain diverse perspectives including the perspective of more friends of adolescents with asthma. Furthermore, although research shows that positive app preferences and interests are key factors that predict app usage, our study does not assess whether or not an app with support features would actually be used. [31, 32] Future research evaluating apps that incorporate the preferences of adolescents, their caregivers, and friends should additionally measure actual app usage and the effect of app usage on adolescent quality of life and health outcomes.

Conclusions

The National Heart, Lung, and Blood Institute Expert Panel Report states that "patient education that fosters a partnership among the patient, his or her family, and clinicians" is one of the four components of effective asthma management. [23] Support from these entities and peers can increase self-efficacy and lead to improved asthma outcomes. Apps can potentially help adolescents meet their social support needs for asthma care management. Adolescents generally preferred informational support (including asthma education and awareness) from friends, a sense of belonging and informational support from peers with asthma, and instrumental support in managing asthma from caregivers. The majority of adolescents believe that apps could enhance communication with their medical provider and give them more control in the patient-provider relationship. However, not all adolescents were uniform in their support needs, highlighting the complexities of creating applications that appeal to a diverse range of individuals.

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Table 1

Adolescent, caregiver, and friend preferences for asthma management support through app

Code Name	Coding Description	Example Interview Questions
A inter with provider	Adolescent preferences for using an asthma app to interact with medical providers about their asthma	Would you use an app to send information about you to your doctor?
Adolcare inter	Adolescent preferences for interacting with caregiver about asthma through asthma app	Are there any good ways for your caregivers to be included in the app? Probe: How would your caregiver be involved? Would you want your parent/caregiver to text message you to remind you to take your meds?
Inter with other asthma	Adolescent preferences for using an asthma app to interact with other adolescents who have asthma	Would you be more likely to use an asthma app if you could interact with other kids with asthma?
Friends involved	Adolescent preferences for interacting with their friends who may or may not have asthma through the app	How could we get your friends involved in an asthma app? Would you want your friends to text message you to remind you to take your meds?
Caregiver inter	Caregiver preferences for using an app to communicate with the adolescent regarding their asthma care as well as preferences for friend involvement in asthma care	How do you feel about using the app to communicate with your child about asthma? Probe: How would you want to use it? Would you want to text message your child to remind them to take their meds? Would you want your child's friends to text message them to remind them to take their meds?
Friend inter	Friend preferences for using an asthma app to help friend manage his/her asthma	How would you feel about text messaging your friend to remind him/her to take their medications? Would you use an app to learn how asthma can be controlled and managed so you can support your friend? Would you use an app to learn how to help your friend if he/she was having an asthma emergency?

Table 2

Sample Characteristics

Adolescents (n=20)	N(%) or Mean ± SD
Age in Years	14.7 ± 1.6
Female	9 (45)
Race	
White	9 (45)
Black	8 (40)
Other	3 (15)
Ethnicity	
Hispanic, Latino or Spanish origin	4 (20)
Non-Hispanic	
	16 (80)
Grade in School	8.3 ± 1.6
Years with Asthma	9.9 ± 4.8
Perceived Asthma Severity (range 1–4)	2.4 ± 0.9
Caregivers (n=20)	N (%)
Age in Years	44 ± 8.4
Female	20 (100)
Race	
White	8 (40)
Black	9 (47)
Other	3 (13)
Ethnicity	
Hispanic, Latino or Spanish origin	3 (15)
Non-Hispanic	17 (85)
Education	
Less than High school	2 (10)
High School/GED	1 (5)
Some college, no degree	6 (30)
Associate's degree	
Bachelor's degree	2 (10)
More than bachelor's degree	5 (25)
	4 (20)
Income	
<\$25,000	7 (35)
\$25,000 to \$34,999	3 (15)
\$35,000 to \$49,999	2 (10)
\$50,000 to \$74,999	2 (10)
\$75,000 to \$99,999	1 (5)

Adolescents (n=20)	N(%) or Mean ± SD
\$100,000 to \$149,000	1 (5)
\$150,000 or more	2 (10)