

Parent Preferences for Dental Preparatory Aids for Children with Autism Spectrum Disorders

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Abstract

Parent Preferences for Dental Preparatory Aids for Children with Autism Spectrum Disorders

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Purpose: To investigate caregivers' preference regarding the use of storyboard preparatory aids to prepare children with Autism Spectrum Disorders (ASD) for dental visits.

Methods: Caregivers of new patients with ASD were given a survey regarding demographics, behavioral and medical characteristics, and media preferences. They were then shown dental preparatory aids available via different media (print or digital) and image types (photographs, drawings, or videos). Caregivers were invited to use these preparatory aids and complete a follow-up survey. Fisher's exact tests were used to determine associations between predictive factors and media preferences.

Results: Forty initial and 16 (40%) follow up surveys were completed. Subjects were male (85%) and white (48%). Mean child age was 6.7 years (SD =2.9 years). Nine (64%) caregivers found the aid useful for themselves and their child. Two (14%) caregivers found the aid helpful for themselves but not their child. Preferred media type was associated with language understanding ($P=.038$) and home media preference ($P=.002$). Prior use of preparatory aids ($P=.043$), media type ($P=.009$), and image type ($P <.001$) of aids the child had used in the past were associated with child preferences. Preferred dental aid image type was significantly associated with the image type used in prior aids ($P=.013$)

Conclusions: Practitioners should consider using visual aids to help prepare children for dental visits. Individual preferences for media and image types vary, asking parents which types of media their child has been responsive to in the past may aid in selecting preparatory aids that are effective.

Introduction

The diagnostic criteria for an Autism Spectrum Disorder (ASD) include deficits in social communication, difficulty developing relationships, and altered responses to sensory stimulus.¹ Providing dental care to pediatric patients with ASD therefore presents a myriad of challenges to providers. Individuals with ASD may not cope with routine social situations, let alone one that is perceived as stressful and invasive, such as a dental visit. Traditional behavior management in pediatric dentistry is often dependent upon the ability to communicate.² Therefore, when caring for patients with communication difficulties, the effectiveness of many behavioral techniques is reduced or eliminated.

In addition to challenges in receiving care, sensory hyper-responsiveness, intellectual impairment, and inconsistent home hygiene routines can contribute the oral health challenges faced by those with ASD.³ Children with autism tend to have poorer oral hygiene than typically developing peers and may be at increased risk for dental caries.^{4,5} Reducing caries risk and facilitating dental care in this population is an important public health goal, as the prevalence of individuals with ASD is increasing.⁶ Because of behavioral difficulties, general anesthesia (GA) often becomes the treatment of choice for patients with ASD who require extensive dental treatment. However, the parents of children with ASD tend to prefer more basic and less invasive techniques to more advanced or invasive techniques such as GA.⁷ In addition, treatment under GA is costly and poses medical risks to the child. Therefore, there is much to be gained by providing preventative dental care for those with ASD in the traditional dental clinic setting.

Many strategies have been proposed to facilitate dental care for patients with ASD. These include desensitization,⁸ creating an environment designed to be minimally stimulating,⁹ structured appointments,¹⁰ and visual pedagogy.¹¹ Unfortunately none of these strategies is completely effective in securing cooperation, and predicting which strategy will be effective for a given patient can be a challenging process.¹²

Social Stories™ are a behavioral intervention used for children with ASD. Social Stories™ generally consist of a short sequence of pictures and sentences describing a situation.¹³ They are often used to generate a desired behavior, eliminate an undesirable one, or prepare a child for a new experience. Like other behavior management techniques, they are not effective for every patient, though they are relatively inexpensive, easy to administer, and can generate a positive result.¹⁴ Social Stories™ have been shown to be useful in effecting non-dental behavioral changes for about 60% of children with ASD,¹⁴ and this level of success may therefore be achievable with similar types of preparation aids. However there is considerable variability in individual response to these interventions, indicating a need to understand how they are best applied.¹⁴ Simple preparatory tools are not just potentially useful, but have also been shown to be an intervention that is well accepted by families that have used them.¹⁵

More recently, technology has been used along with preparation aids to facilitate positive behavior in children who have ASD. Screen media¹⁶ and tablet computers¹⁷ have recently been implemented with varying degrees of success. Technology may be more accessible to some children and can be employed to leverage the success of traditional Social Stories™. Visual pedagogy is a similar technique using sequential photographs of a desired

behavior, and has been used effectively to improve behavior in the dental office and home oral hygiene routines. ^{11,18} Visual pedagogy has also been combined with more basic behavior guidance techniques to improve cooperation with dental examination. ¹⁹

Preparing children with ASD for dental appointments can lead to more successful oral examinations, which may in turn lead to improvement in oral health. Children with ASD are not a homogenous population, and individuals will likely respond differently to interventions. Given the diversity of patients, and number of preparation techniques available, providers are now faced with the challenge of determining which is most appropriate for each individual. The aim of this study was to investigate preferences of parents of children with ASDs for different types of dental preparatory aids.

Methods:

Caregivers of children with ASD were recruited in a university-based pediatric dental clinic at their child's initial dental visit. Inclusion criteria were: a child diagnosed with ASD, caregiver aged 18 and over, child aged 18 and younger, caregiver fluent in the English language, and child presented as a new patient to the clinic.

At the initial visit, subjects were asked to complete a 12 question survey regarding previous use of preparatory aids and parent-perceived child preferences for a dental preparatory aid. Caregivers were then introduced to three variations of a preparatory aid designed specifically for the clinic the patients were attending. These included a printed aid (Figure 1), a digital version of the same aid, and a YouTube video version (Figure 2). Caregivers were given a print copy of photographs showing the dental clinic with written detail of the steps involved in a visit to the dentist. They were also shown how to access a digital version of the same photos (<http://www.thecenterforpediatricdentistry.com/intranet/ss/socialstory.pdf>). Instructions for accessing a YouTube video showing the same sequence of events as the preparatory aid were given (https://www.youtube.com/watch?v=3uZ_Weiow9k). Participants were not given any specific instructions on preparatory aid use, and were told to use any version of the aid as often or as little as desired. The decision to view the aid on printed paper,

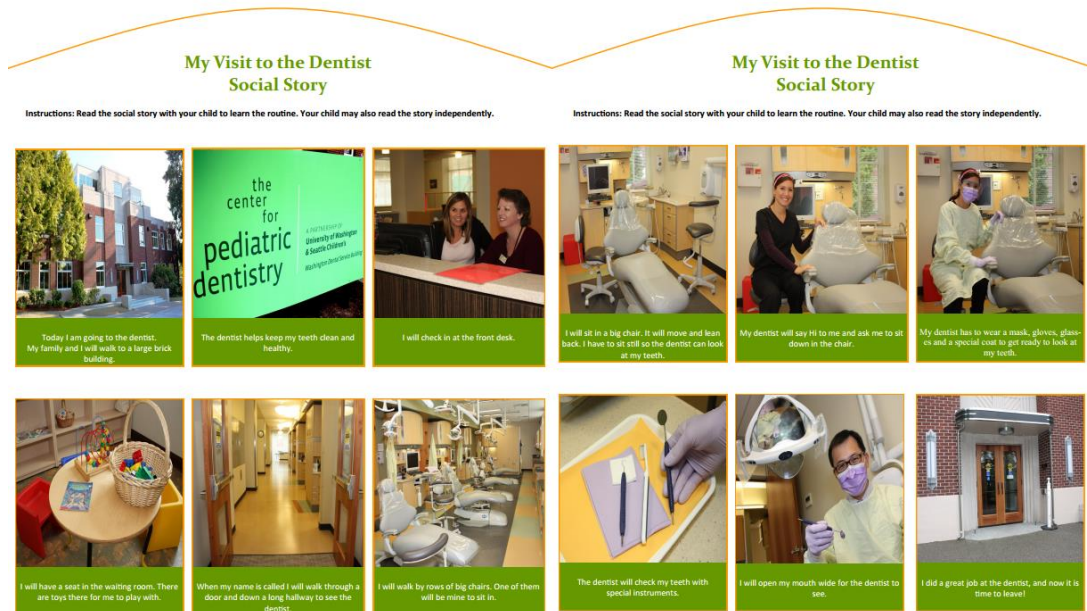


Figure 1 Print and Photograph Aid

iPad, computer, or other medium was referred to as “Media Choice”. The decision to view the video or photograph version was referred to as “Image Choice”.



Figure 2 Screen Captures of the Video Aid

Demographic information, medical history, and additional details regarding ASD symptoms were abstracted from a new-patient information packet that parents provided to the clinic in advance of the first visit. If this information was noted as missing, participants were asked to complete a supplemental survey. Those participants who returned for follow-up care from April 21, 2014 to January 1, 2015 were asked to complete a 9 question follow up survey. The follow up survey evaluated preparatory aid use and caregiver opinion of its effectiveness. Caregivers were asked to describe why they did or did not feel as though the aid was useful. Additionally, they were asked for suggestions on how to improve the aid.

Descriptive statistics were calculated for all variables. Associations between hypothesized predictive variables and reported usefulness were tested using Chi-squared or Fisher’s Exact tests. Associations between suspected predictive variables and preparatory aid type were also

tested using Chi-squared or Fisher's Exact tests. All data analysis was performed using Stata 12 (StataCorp LP College Station, Texas). The significance level was set to 0.05 for all tests.

Results

A total of 40 caregiver/child dyads of children with ASD were recruited into the study. Of those, 16 (40%) returned for a follow up appointment within six months of April 21, 2014. The mean age of children in the study was 6.7 years (standard deviation [SD]=2.9 years). Child participants were primarily white (47.5%) and male (85%). Payer type was predominantly Medicaid (55%), followed by private insurance (42.5%), and self-pay (2.5%) (Table 1).

Media Preferences

When presented with the option of print, digital, or a combination of aids most caregivers selected digital aids (40%) or a combination of digital and print aids (50%). Four (10%) selected print aids only. Those with children who had a greater language understanding selected a combination of print and digital media for their aid, while those with less understanding selected digital only ($P = .038$). Families were most likely to match preparatory aid selection with the child's preferred media type at home ($P = .002$). Caregivers with children who had used aids in the past were more likely to select the media type that they had experience with ($P = .009$). There was no relationship between age, ASD severity, or reading level and media selection (Table 2).

Image Preferences

Selection of image type was independent of the media type. When asked if their child would prefer photographs, comics or drawings, or videos, the majority of caregivers expressed a preference for a combination of these image types (70%). Most dyads had experience with multiple image types, and once again were most likely to express a preference for multiple image types ($P = .013$) (Table 2). There were no statistically significant differences between image type selection and age, ASD severity, reading level, language understanding, home media preference, prior preparatory aid use, or prior preparatory aid media type.

Preparatory Aid Use

Seven (44%) of the 16 caregivers that returned for follow up reported using the aid a single time. Six (43%) reported using the aid 5 or more times. Eight (50%) caregivers used the aid in the week prior to the appointment, while 5 (31%) used it more than 1 week prior to the appointment. Ten caregivers used the aid with their child (63%). Six (37%) used the preparatory aid with their child and also had the child use the aid alone (Table 3). None of the caregivers in this study had the child use the preparatory aid alone.

Parent Reported Usefulness

Nine (56%) of the 16 caregivers felt that the aid was helpful for both themselves and their child. One caregiver found the aid helpful for themselves but was unsure about the usefulness to their child. One additional caregiver thought the aid was helpful for themselves, but not their child. There were no statistically significant associations between predictive variables and reported usefulness (Table 3).

Qualitative Results

Families expressed appreciation that the aids provided structure, the ability to practice before the exam, and reduced the fear of the unknown. Multiple families appreciated the opportunity to practice a dental visit based on what they saw in the preparatory aid. The caregivers of children who did not find the aids helpful raised valuable points as well. One family mentioned that their child had significant anxiety specifically related to dentistry. The preparatory aid only increased her anxiety by serving as a reminder of an uncomfortable environment. Another family mentioned that the aids just did not interest their child, who liked animated cartoons but no other media types. Several families also expressed great appreciation for the fact that the dental providers in this study were providing tools to try and help children with autism become better prepared for dental appointments.

Discussion:

This study provided caregivers with a number of preparatory aid options and asked them to rate those that they believed their child would prefer most. The vast majority of parents selected either digital, or both a print aid and a digital one (90%). The clear preference for digital format is reflective of the current state of media in general. It is important to recognize that some families requested preparatory aids in print-only form, so practitioners should also consider making more conventional aids available to their patients. In regards to images displayed, most caregivers thought that their child would respond to a combination of photographs, cartoons, and other image types (70%). Once again, to best accommodate all patients the need for variety is once again highlighted. These findings may also be reflective of

the challenges facing caregivers of children with ASDs. It can be difficult to know what a child's true preferences are, and like all children their preferences can change often. With modern technology it is relatively simple for a dental office to offer preparatory aids in multiple media formats. For example, an office could fabricate a single aid, but have it available in multiple media types. On the other hand, it may be more difficult for individual offices to provide a wide variety of image types. To increase the number of available to families, providers may consider sharing links to preparatory aids that other organizations have produced.

The majority of children in this study had used a preparatory aid prior to enrollment in this study. This population is likely skewed given that they were recruited from a specialized dental clinic focused on treating patients with ASD. These caregivers likely take an active role and seek out interventions in many aspects of their children's lives. For parents like these, having dental-specific preparatory aids available could be a distinguishing characteristic when selecting a dental office. For caregivers who have not yet experienced preparatory aids, exposure to this type of intervention in the dental office could prompt them to introduce visual preparatory media in other areas of the child's life.

We found that caregivers tended to prefer aids in the same format that their child used previously. Dental providers should inquire about the child's previous experience with preparatory aids when discussing their use in the dental office. This can be used as a conversation starter when working with parents to make a selection. In addition, both language understanding and home media preference were predictive of preparatory aid media selection. Caregivers of children with lower language understanding were more likely to select digital aids only. Caregivers of children with higher language understanding were more likely to

select a combination of print and digital aids. Providers should therefore inquire about a child's communication ability and preferences for media at home when selecting preparatory aids.

It was difficult to predict the types of images caregivers would choose for their children. The only factor associated with image type selection was image type used previously. This may be an area where it is more difficult for solo practitioners to provide multiple options.

There was a wide variety in the timing and frequency of preparatory aid use by the caregivers who participated in this study. When no preference is expressed we recommend that based on their knowledge of their child and his or her preferences families use their judgement in determining how often and when to use the preparatory aid.

Qualitative observations provided by families indicated aspects of the aids that were and helpful and unhelpful. Having the dental aid follow the same progression as the dental visit appears to be valuable to families, and is a key consideration when constructing new aids. However this comes with a caveat that a child who has prepared extensively with an aid may respond poorly to variations in the structure that they are expecting. Practicing new experiences at home where the child is comfortable was perceived as very helpful in reducing patient anxiety when returning for dental care. Multiple caregivers expressed that the shared experience of using the aid together helped both themselves and their children feel more comfortable about the dental experience.

The aids were found to be unhelpful for a child who had a high level of baseline dental anxiety. Providers need to use caution with children who have had a prior negative experience

or have a specific dental anxiety. For a patient who associates the sights of a dental clinic with negative emotions, an alternative intervention should be considered.

Families who expressed uncertainty about whether aids were useful mentioned primarily young age and a lack of understanding. Although this was not a statistically significant finding, it is reasonable to expect that aids will not be effective for children who can't comprehend them. When discussing preparatory aids, practitioners should be sure to inquire about the child's ability to understand preparatory media. Although the focus of the provider is often on the patient, the role of caregivers when interacting with pediatric patients has long been recognized. Two of the caregivers found the aid only useful for themselves. Although it would be preferable to have the aid be helpful for both parties, reaching only the caregiver should not be considered a failure.

Limitations of the study included a small sample size in a diverse population. This study was conducted in a 6 month time frame, which limited the number of follow up surveys completed. Given the diversity of subjects in the study, it was necessary to use a self-reported subjective measure of utility, rather than more objective measurements of actual patient behavior at the dental visit. Due to the limited number of preparatory aids available, we were unable to accommodate the specific requests of each individual family.

This was a preliminary investigation of the use of dental preparatory aids for children with ASD. Further research should investigate the effectiveness of aids in improving patient behavior in the dental environment and focus on the optimum timing and frequency of use. An

improved understanding of preparatory aids for children with ASD will aid providers in making recommendations that improve the patient experience.

Conclusion

We found that a history of preparatory aid use and a child's preference for home media serve as useful indicators of future preparatory aid preferences. In general parents expressed positive opinions regarding the use of preparatory aids in the dental environment. This suggests that dental preparatory aids can serve as a relatively simple, low cost, and effective tool for families of children with ASD.

Table 1: Sample Characteristics

Gender	N (%)
Male	34 (85.0)
Female	6 (15.0)
Age (years)	
<3	2 (5.0)
3 to 4	11 (27.5)
5 to 10	24 (60.0)
11 and up	3 (7.5)
Race	
Asian	3 (7.5)
African American	5 (12.5)
White	19 (47.5)
Other/Multiracial	9 (22.5)
Did Not Report	4 (10.0)
Insurance	
Medicaid	22 (55.0)
Private Dental Insurance	17 (42.5)
Self-pay	1 (2.5)

Table 2 Child Factors Associated with Media and Image Preference

	Media Preference				p value*	Image Preference				p value*
	Print Media N (%)	Digital Media N (%)	Both N (%)			Photo N (%)	Comic or Drawing N (%)	Video N (%)	Multiple N (%)	
Child Age (years)					0.773					0.79
Age <3	0	1(6.2)	1(5)			1(16.7)	0	0	1(3.6)	
Age 3-4	2(50.0)	5(31.3)	4(20)			1(16.7)	0	2(40.0)	8(28.6)	
Age 5-10	2(50.0)	8(50)	14(70)			3(50.0)	1(100.0)	3(60.0)	17(60.7)	
Age 11+	0	2(12.5)	1(5)			1(16.7)	0	0	2(7.1)	
Total	4	16	20			6	1	5	28	
Parent-Reported Severity					0.284					0.308
Mild	0	7(43.7)	4(22.2)			1(16.7)	0	4(80.0)	6(23.1)	
Moderate	2(50.0)	4(25)	10(55.5)			4(66.7)	1(100.0)	1(20.0)	10(38.5)	
Severe	1(25.0)	2(12.5)	3(16.7)			0	0	0	6(23.1)	
Don't Know	1(25.0)	3(18.8)	1(5.6)			1(16.7)	0	0	4(15.4)	
Total	4	16	18			6	1	5	26	
Language, Reading and Behavior										
Child Reading Level					0.066					0.833
N/A	0	5(31.3)	3(16.7)			0	0	2(40.0)	6(23.1)	
None	1(25.0)	6(37.5)	2(11.1)			1(16.7)	0	1(20.0)	7(26.9)	
Some Skills	2(50.0)	4(25.0)	7(38.9)			4(66.7)	1(100.0)	1(20.0)	7(26.9)	
Fluent	1(25.0)	0	6(33.3)			1(16.7)	0	1(20.0)	5(19.2)	
Don't Know	0	1(6.2)	0			0	0	0	1(3.8)	
Total	4	16	18			6	1	5	26	
Child Language Understanding					0.038*					0.174
None	0	6(37.5)	0			2(33.3)	0	0	4(16.0)	
Some	1(25.0)	5(31.3)	6(35.3)			2(33.3)	1(100.0)	4(80.0)	5(20.0)	

Most	1(25.0)	0	3(17.6)		1(16.7)	0	0	3(12.0)	
Other	2(50.0)	5(31.3)	8(47.1)		1(16.7)	0	1(20.0)	13(52.0)	
Total	4	16	17		6	1	5	25	
Child Home Media Preference				0.002*					0.368
Print Media	0	0	0		0	0	0	0	
Digital Media	1(25.0)	11(68.8)	3(15.0)		2(33.3)	1(100.0)	3(60.0)	9(32.1)	
Both	3	5(31.3)	17(85.0)		4(66.7)	0	2(40.0)	19(67.9)	
Total	4	16	20		6	1	5	28	
Prior Prep Aid Statistics									
Prior Prep Aid Use				0.043*					1.00
Yes	4(100.0)	10(62.5)	19(95.0)		5(83.3)	1(100.0)	4(80.0)	23(82.1)	
No	0	6(37.5)	1(5.0)		1(16.7)	0	1(20.0)	5(17.9)	
Total	4	16	20		6	1	5	28	
Prior Media Type				0.009*					0.427
Print Media	0	1(10.0)	2(10.5)		0	0	0	3(13.0)	
Digital Media	0	7(70.0)	3(15.8)		2(40.0)	0	3(75.0)	5(21.7)	
Both	4(100.0)	2(20.0)	14(73.7)		3(60.0)	1(100.0)	1(25.0)	15(65.2)	
Total	4	10	19		5	1	4	23	
Prior Prep Aid Type				0.001*					0.013*
Photo	0	5(50.0)	2(11.1)		2(40.0)	0	0	5(22.7)	
Comic	1(25.0)	1(10.0)	0		1(20.0)	1(100.0)	0	0	
Video	1(25.0)	2(20.0)	0		0	0	2(50.0)	1(4.5)	
Multiple or Other	2(50.0)	2(20.0)	16(88.9)		2(40.0)	0	2(50.0)	16(72.7)	
Total	4	10	18		5	1	4	22	

*=Calculated using Fisher's Exact tests

Table 3: Factors Associated with Assessments of Usefulness of the Preparatory Aid.

	Useful for Parent N (%)	Not Useful for Parent N (%)	Don't Know N (%)	p value	Useful for Child N (%)	Not Useful for Child N (%)	Don't Know N (%)	p value
Age (years)				0.527				0.748
<3	0	0	1 (25.0)		0	0	1(20.0)	
Ages 3-4	3 (27.3)	1 (100.0)	1 (25.0)		3(33.3)	0	2(40.0)	
Ages 5-10	7 (63.6)	0	2 (50.0)		5(55.6)	2(100.0)	2(40.0)	
11 and up	1 (9.1)	0	0		1(11.1)	0	0	
Total	11	1	4		9	2	5	
ASD Severity				0.242				
Mild	1(10.0)	0	2(50.0)		0	1(50.0)	2(40.0)	0.409
Moderate	7(70.0)	0	2(50.0)		6(75.0)	1(50.0)	2(40.0)	
Severe	1(10.0)	1(100.0)	0		1(12.5)	0	1(20.0)	
Don't Know	1(10.0)	0	0		1(12.5)	0	0	
Total	10	1	4		8	2	5	
Verbal and Language Skills								
Reading Level				0.957				0.641
None	2(20.0)	1(100.0)	1(25.0)		2(25.0)	0	2(40.0)	
Low	3(30.0)	0	2(50.0)		2(25.0)	2(100.0)	1(20.0)	
Moderate	2(20.0)	0	0		2(25.0)	0	0	
High	3(30.0)	0	1(25.0)		2(25.0)	0	2(40.0)	
Total	10	1	4		8	2		
Child Language Understanding				1.00				1.00
None	2(20.0)	0	1(25.0)		2(25.0)	0	1(20.0)	
Little	4(40.0)	0	2(50.0)		3(37.5)	1(50.0)	2(40.0)	

Most	1(10.0)	0	0		1(12.5)	0	0	
Other	3(30.0)	1(100.0)	1(25.0)		2(25.0)	1(50.0)	2(40.0)	
Total	10	1	4		8	2	5	
Follows Directions				0.860				0.487
Not Able	1(10.0)	0	2(50.0)		5(62.5)	1(50.0)	1(20.0)	
Rarely	1(10.0)	1(100.0)	1(25.0)		1(12.5)	1(50.0)	3(60.0)	
Sometimes	3(30.0)	0	1(25.0)		1(12.5)	0	1(20.0)	
Often	5(50.0)	0	0		1(12.5)	0	0	
Total	10	1	4		8	2	5	
Preparatory Aid Use								
Actual Frequency				0.418				0.285
No uses	1(9.1)	0	1(25.0)		1(11.1)	0	1(20.0)	
1 use	5(45.5)	1(100.0)	1(25.0)		3(33.3)	1(50.0)	3(60.0)	
2 to 5 uses	0	0	1(25.0)		0	0	1(20.0)	
5 or more	5(45.5)	0	1		5(55.6)	1(50.0)	0	
Total	11	1	4		9	2	5	
Actual Timing				0.654				0.786
Day of	1(9.1)	0	0		1(11.1)	0	0	
Day Before	1(9.1)	0	0		1(11.1)	0	2(40.0)	
Week Before	6(54.6)	0	2(50.0)		4(44.4)	2(100.0)	2(40.0)	
More than 1 week	3 (27.3)	1(100.0)	1(25.0)		3(33.3)	0	1(20.0)	
Other	0	0	1(25.0)		9	2	5	
Total	11	1	4					
Actual Use With Caregivers				1.00				0.371
Yes	7(63.6)	1(100.0)	2(50.0)		7(77.8)	1(50.0)	2(40.0)	
No	0	0	0		0	0	0	
Both	4(36.4)	0	2(50.0)		2(22.2)	1(50.0)	3(60.0)	
Total	11	1	4		9	2	5	

*=Calculated using Fisher's Exact tests

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