

BACKGROUND

Nearly 40% of children with hearing loss have one or more disabilities in addition to hearing loss (1). These include intellectual and developmental disabilities (I/DD), cerebral palsy, autism spectrum disorder, and blindness, all of which have higher rates of prevalence in children with hearing loss when compared to the general population (2). It has also been well documented in the literature that people with I/DD have less access to healthcare, resulting in higher rates of undetected and unmanaged health problems (3). In addition, even when people with I/DD are able to access the healthcare system, providers often find themselves poorly equipped to work with these populations (4).

Recognizing these issues, the Special Olympics Healthy Hearing (SOHH) was implemented in 1999 in an effort to identify previously undiagnosed hearing loss. In the year 2014 alone, 18,398 hearing screenings were performed globally, resulting in 4,710 referrals (5). Unfortunately, data are not actively collected on how many of these referrals lead to diagnosis and treatment for hearing loss. As one of the goals of the Healthy Hearing program is to improve accessibility to health care, obtaining information on referral outcomes following Healthy Hearing screenings is needed to determine if hearing screening programs are accomplishing their goals. As with all screening programs, it is the intervention that occurs as a result of screening that is most important. This study was designed to gain insight regarding important questions concerning the rate of follow-up, potential barriers to follow-up, and possible solutions to improve access to hearing healthcare for people with I/DD.

RESEARCH QUESTIONS

- 1) What is the referral rate for Healthy Hearing screenings at Special Olympics events in North Carolina?
- 2) What is the rate of follow-up for participants who receive a referral?
- 3) Of those participants who **did** follow-up, how many were diagnosed with hearing loss?
 - How many were treated for hearing loss?
 - What were the outcomes of treatment?
- 4) Of those participants who did **not** follow-up, what were the barriers preventing them from doing so?

PARTICIPANTS

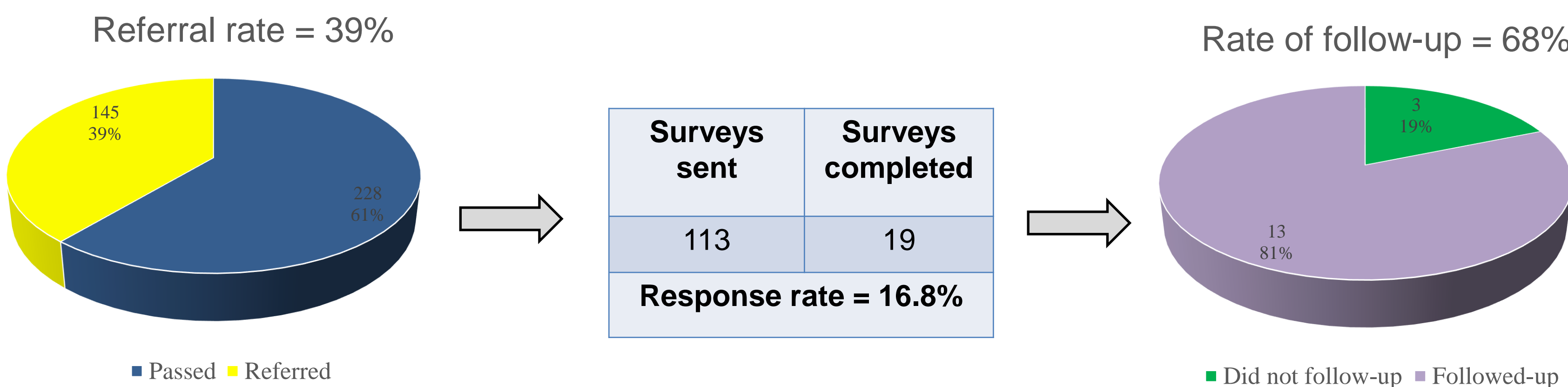
The inclusion criteria for participants include: English-speaking athletes participating in Special Olympics events in North Carolina (or their legal guardians) who have received a referral following a Healthy Hearing screening. Per Special Olympics requirements, athletes must be at least 8 years old and identified by an agency or professional as having one of the following conditions: intellectual disabilities, cognitive delays as measured by formal assessment, or significant learning or vocational problems due to cognitive delay that require or have required specially designed instruction (5).

METHODS

A survey was developed and mailed to Special Olympic athletes (or legal guardians if applicable) who received a Healthy Hearing referral from the Fall 2017 and Summer 2018 Special Olympic Games in North Carolina. Screening data was obtained from these events through the Special Olympics International Research Headquarters. Athlete mailing addresses were then obtained from the NC Special Olympics Office via their Games Management System (GMS). Those not in GMS were excluded. A return envelope was provided with postage. Upon receipt, data was entered into Excel for analysis.



RESULTS



DID NOT FOLLOW-UP, N=6

Reported barriers to obtaining follow up:

"I have spoken to the group home supervisor who accompanied my son's group to SO and she was **not told about a referral.**"

"R.S. has **no insurance** at this time due to a lapse of Medicaid and deadline passing for enrollment in another plan."

"Guardians stopped it."

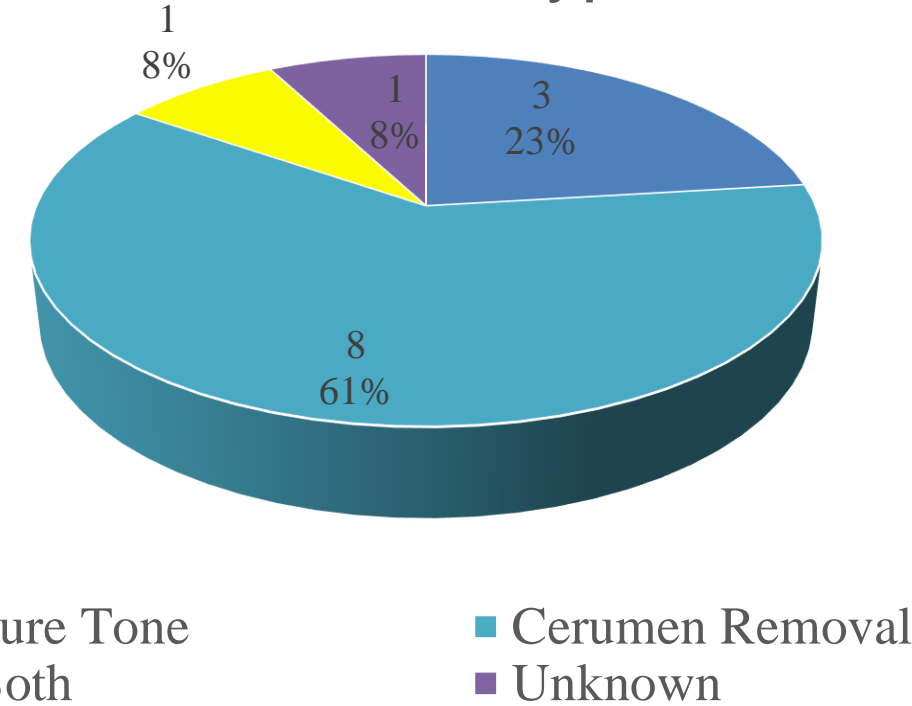
"In order to see an audiologist, you **have to have a referral** from PCP. Special Olympics does not provide them. If primary physician does not agree to the problem, you can't visit the audiologist. Being able to visit **WITHOUT** a referral would help."

Don't know where to go/can't find provider.

Haven't had time.

FOLLOWED-UP, N=13

Referral Type



Treatment Provided

Cerumen Removal	Monitor HL	Hearing Aids
10	3	0

Diagnosis Made

Normal Hearing	Mild HL	Moderate HL	Severe/Profound HL	Other
1	3	0	0	9

DISCUSSION

Screening is the first step in the detection of an ear/hearing disorder but assessment and treatment are the desired outcomes. Although over 18,000 hearing screenings are provided globally each year by Special Olympics resulting in over 4,000 referrals, to our knowledge this is the first study aimed at assessing referral outcomes in NC. The low return rate in this study (16.8%) limits our ability to answer the research questions but provides a starting point for future investigation. Possible reasons for the low return rate include:

- the length of the recruitment letter and consent form;
- the multi-step design of the survey;
- the time and effort required to return the survey package;
- a need for more information/education at the time of referral;
- A need for greater emphasis on the importance of referral and follow-up.

For those who did respond, the 68.4% follow-up is encouraging but difficult to generalize because of the low response rate. Of note, however, was the finding that more follow up occurred for cerumen removal than for failed pure tone screenings, suggesting that athletes may have had easier access to medical providers than audiology services. However, it is also possible that some athletes received appropriate assessment and follow-up as a result of the referral even though the survey was not returned.

FUTURE DIRECTIONS

- Explore the possibility of a web-based survey to improve returns and facilitate questions raised by survey respondents
- Provide a list of regional audiologists who accept Medicaid and would be willing to accept referrals from SOHH.
- Provide a more thorough explanation for why the referral is needed
- Explore the feasibility of providing cerumen removal if needed prior to hearing screening (5)
- Reminders or other prompts if surveys are not returned

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