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Establishing the key components of an eye gaze assessment for a child with a severe neurodisability using nominal group technique

Tylie Suzanne Stokes, Paul Roden

ABSTRACT

Aims: Eye gaze devices enable users with a disability, to participate in computer activities using eye movements. Health professionals assess client's ability to access such devices, yet there remains limited research to guide assessments particularly among children with severe neurodisability. Methods: Nine health professionals, considered experts in digital assistive technologies, were recruited from special interest groups and service providers across England. Participants attended a focus group, seeking to establish consensus in response to the question: "What are the key components of an eye gaze assessment for a child with a severe neurodisability?" using nominal group technique. The discussion was recorded, transcribed and evaluated using content analysis. Results: Components achieving highest consensus were; motivation, visual ability, posture, purpose of the device, cognition and ongoing support. The need to manage expectations was highlighted. A flexible, multi-disciplinary, health professional-led assessment was considered important. Conclusion: Key components of an assessment were identified. The ability to have repeated flexible assessments further strengthen the assessment process. Further consideration should be given to managing client/family expectations and ensuring ongoing support is in place. Devices are more likely to be abandoned when neither a clear purpose for the device nor provision of ongoing support is identified during assessment.

Keywords: Assessment, Children, Eye-gaze, Neurodisability

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INTRODUCTION

Digital assistive technologies (DAT) are electronic devices which increase independence for individuals with disabilities [1]. Access to DAT has been shown to increase participation in a variety of occupations for children with severe neurodisabilities [2, 3]. Children and young people are increasingly surrounded by technology and commonly report computer or technology based occupations as

preferred 'leisure' activities [4]. Access methods such as switches, eye gaze or touch screen, are the method with which a user interacts with the device. A successful access method therefore, is one which enables the user to operate the DAT purposefully. Health professionals assess potential to access DAT, however when movement is extremely limited or uncontrolled, access to such technologies can be challenging.

Eye gaze devices are a popular way for clients with limited movement to access computers. These devices are predominantly aimed at clients with good cognition and limited physically ability. Increasingly however, eye gaze accessible software is also produced for clients, in particular children with associated impairments in cognition and language. The cost of the technology has also continued to decrease making it more accessible and appealing for a wide range of users with disabilities [5]. Evidence to support the use of eye gaze devices and guide the assessment process, particularly among children with severe neurodisabilities remains weak.

Health professionals are expected to assess a child's ability to access an eye gaze device with minimal evidence to support these assessments.

LITERATURE REVIEW

Although there is limited research to guide an eye gaze specific assessment, there is some evidence to support and guide DAT assessments in general. Angelo [6] sought to establish expert consensus regarding key components of a switch assessment. Occupational therapists considered experts in DAT (N=6) attended a focus group using nominal group technique (NGT). Participants were asked to rank in order of importance, components affecting the use of a single switch with AT devices. Eleven key items were identified as by the group. Use of switches to access assistive technologies is a well-established access method for clients with severe neurodisability and the study by Angelo [6] has been useful in guiding health professionals when assessing for optimal switch type and placement.

Griffiths and Price [7] propose a framework based on The International Classification of Functioning, Disability and Health: Children and Youth Version [8] aimed at promoting a common understanding and equal weighting for the varied uses of computer technology among clients with disabilities. When assessing and decision making regarding the effectiveness of such devices for a child with severe neurodisability, this framework encourages a broad assessment of all occupations. Although this framework is not aimed at eye gaze specifically, it is a useful framework for DAT assessments and can be used to inform and guide the eye gaze assessment process.

Technology solutions can have a lure, which can lead to the device itself becoming the focus of goal setting and assessment, rather than the needs and goals of the child and their family [7], which in turn can lead to devices being under used or abandoned. Kintsch and DePaula [9] suggest that if the user is unable to integrate the DAT device into their daily life, devices may be rejected. Many parents of Augmentative Alternative Communication aid (AAC) users report that they do not use or know how to programme the device, reporting insufficient information and training [10].

The importance of a multi-disciplinary approach to DAT assessments, involving the family and child is well documented in the literature [11, 7]. Holmqvist and Buchholz [12] propose a model for eye gaze assessment, outlining key components of an effective assessment. Similarly to Griffiths and Price [7] multi-disciplinary and family led goal setting is emphasized, alongside understanding of strengths and limitations of the user.

Eye gaze devices have been shown to be faster and more efficient than switches alone for some children with severe neurodisability. Curry and Woodward [13] describe the effectiveness of an eye gaze device with two boys with cerebral palsy (CP). Both were able to communicate faster using an eye gaze device than with their existing head switches. Although findings based on case studies cannot be easily generalized, they do suggest potential benefits of eye gaze for clients with severe neurodisability. It is also worth noting that although both clients did have severe neurodisability in terms of physical impairment, they were reported to have little or no cognitive and language impairment.

There remains however a paucity of evidence to support functional use of eye gaze devices among users with associated severe cognitive impairments. A small sample (N=9) of children were recruited from The Brazilian Rett Syndrome Association of Sao Paulo [14]. The study explored cognitive performance using tasks considered simple enough to be completed by a 36–48 months old child. Findings indicated that children with severely impaired cognition were able to use eye gaze devices to make simple choices. Notably however, participants were excluded from the study if they were unable to follow a calibration process. Making it difficult to generalize the results to users who are unable to achieve a callibration. Particularly as the calibration process can be problematic, time consuming, boring and frustrating [15, 16].

Evidence relating specifically to eye gaze assessment remains anecdotal in nature [12]. With growing pressure on clinicians to make financially viable evidence-based decisions, more robust evidence is required to support the use of eye gaze devices, particularly for clients with severe neurodisability who are likely to also need ongoing support and customization of the device. The primary aim of the study is to establish expert consensus on the key components of an eye gaze assessment for children with severe neurodisability, providing evidence to support and guide the assessment process.

MATERIALS AND METHODS

The nominal group technique (NGT) requires a panel of experts to meet and rank responses to a specific question in order of importance in order to achieve a consensus (Table 1). The main consensus approaches used in health research are the NGT or the Delphi method [17]. Unlike the Delphi, NGT requires participants to meet to discuss a specific topic. The NGT uses a structured process [18], considered useful in minimizing researcher bias and issues with group members dominating a discussion [19]. NGT lends itself only to a single purpose, single topic meeting, with little scope for exploration of ideas or themes. The group discussion however can yield substantial data, whilst remaining time efficient. This was an important consideration, since the research involved busy health professionals giving up their time to participate, with no incentive.

The NGT method is a cost effective and convenient method, taking advantage of a known special interest group meeting, which enabled a group of experts to be easily recruited. Angelo [6] successfully used NGT to identify expert consensus regarding key components of single switch assessment, producing useful and clear guidance for clinicians undertaking a switch assessment. The study by Angelo [6] provides an effective framework for obtaining expert consensus and was particularly influential in informing the choice of research design for this current study. Ethical approval was sought and obtained from Brunel University Ethics Committee, further approval was also sought and obtained from NHS (National Health Service) Research Consortium, to use NHS email and property as a Participation Identification Centre (PIC) site to advertise and recruit additional participants.

Nominal group technique recruits expert participants; therefore those with experience working with children with severe neurodisability and experience in the assessment of DAT were selected. Controversy exists over the use of the term expert and how to adequately define a professional as an expert [20]. In the absence of clearly defined guidance, two years post-graduate experience was chosen as an acceptable length of time to develop expertise within a specialist role.

For the purpose of this study, experts were defined as those who met the following inclusion criteria:

- Health and Care Professional Council (HCPC) registration as a qualified allied health professional
- Two years post graduate experience
- Experience working with children with severe neurodisabilities
- Expected to assess, recommend or support clients with DAT including eye gaze as part of their role

Furthermore, in order to adequately participate in the focus group. Participants also were required to be fluent in written and spoken English. DAT is a specialist field with only a small number of experts across the United Kingdom, making access to participants problematic. The solution was to recruit from members of an existing DAT special interest group. The group met twice annually, with meetings attracting therapists from all over the United Kingdom and Ireland. As members of this special interest group were predominantly occupational therapists and clinical engineers, other disciplines such as speech and language therapy (SALT) were under represented. For this reason, permission was obtained from the NHS Research Consortium to use NHS email and property to advertise and recruit additional participants. Poster advertisements were placed in public areas in DAT service providers and were shared among contacts with a known specialist interest in DAT. A further advertisement was placed on The Foundation for Assistive Technology (FAST) electronic newsletter in September 2013. The newsletter contained a link to a website created by the researcher outlining details from the participant information sheet and providing contact details for interested participants to express interest. All members of the special interest group were invited and further email or postal invites were sent to participants who had responded to other advertisements such as the posters, websites or word of mouth. Additional participants who were not members of the special interest group were invited to attend the focus group only, held at the end of the group bi-annual study day.

A total of nine participants attended the focus group. The NGT consists of a 5 stage process (Table 1) whereby participants rank and score proposed answers to a specific question. Participants were predominantly occupational therapists with only one clinical scientist and one speech and language therapist. The majority were recruited via the special interest group and as such attended the study day prior to the focus group, with only one additional participant joining to attend the focus group only in the afternoon. The focus group was facilitated by the researcher, also an expert on the topic in question and a member of the special interest group. The risk of researcher bias as a result of membership to the special interest group was acknowledged. In an attempt to somewhat address this, the researcher did not actively engage in any discussions relating directly to the research question during the study day.

RESULTS

A total of 30 different components were listed by the group, with similar themes grouped together by the facilitator. Scoring and ranking took place at the end of the NGT. Of the original 30 components listed, only 20 received a score (Table 2). Components considered to be similar were grouped together and agreed upon among

the group. For example, the component entitled 'visual ability' included; visual skills, visual attention, visual fatigue, eye pointing, functional vision, vision processing, eye palsy, eye sight and visual acuity.

The components scoring the highest were; motivation, visual ability, position/posture of the child, purpose of the device (goals & aims), cognitive and learning skills and ongoing support from staff or family. These top six components (Table 2) scored significantly higher than then the subsequent components, demonstrating particularly strong consensus.

The group discussion was recorded and transcribed. Through detailed analysis of the recording and transcription, the researcher sought patterns and categories that emerged or reoccurred frequently within the data [21]. Although the study sought to achieve consensus, analysis of the audio transcript also explored areas of disagreement or debate. One area of contention related to the purpose of the device. A number of participants felt that for a child, a clearly defined purpose was less important than allowing a child to simply explore using an eye gaze device; "with a child you might just try it". The scoring regarding this item was also widely spread, suggesting variability in opinions across the expert panel. Despite this, most participants felt that knowing the purpose of the device from the outset was useful in guiding their assessment; "The key there is purpose, what is your actual purpose of using it"

It was also suggested that if the device was to be used as a communication aid, then more rigorous assessment would need to be undertaken. This linked to further discussion around the need to achieve a successful calibration with participants feeling that for communication this was important: "If you are looking at … going down to smaller cells it would be more useful". However it was considered less important for sensory exploration and play based activities: "[if you] .. are just looking at screen engagement and stuff like that you are not going to calibrate it before you start using it because it's going to be really hard to them to focus on that"

Participants described how technology can be perceived as exciting or glamorous, which leads to unrealistic expectations of the technology: "There is that uncertain myth … that the higher the technology the more advanced the student is." Yet participants also described a lack of understanding and under use of the lower tech alternatives, among purchasers of assistive technologies: "They don't use the switches … because they are not as glamourous"

Concerns were expressed around staff and family expectations associated with advances in technology, particularly following a supplier-led assessment. These were described as often being a catalyst to a request for provision of an eye gaze device. Participants spoke of experiences whereby parents received reports that their child had 'excellent potential' to use an eye gaze device, possibly giving unrealistic hope or expectation regarding

Table 1: NGT 5 stage process

Stage	Process
1	Silent generation of ideas in response to research question written on the flip chart.
2	Each participant reads out their ideas, which are written onto a flip-chart as they are read out, until all ideas have been presented. Similar responses are grouped together by the facilitator where appropriate
3	Group discussion of ideas – new ideas can be added but none can be eliminated
4	Silent selection of top 10 ideas, ranked in priority order
5	Ranking scores tallied and top 'topics' presented back to the group

Table 2: Ranked Components List

Rank	Factor	Score (*note highest score achievable = 90)
1	Motivation / engagement	74
2	Visual Ability	57
2	Posture / positioning (of the child)	57
3	Purpose of the device (goals & aims)	55
4	Cognition / Learning Skills	51
5	Ongoing support from staff / family	43
6	Mounting/Portability/ Positioning of the device	25
7	Environment	21
8	Previous experience using low tech	18
9	Ease of use	15
9	Language and communication skills	15
10	Fatigue/Endurance	14
11	Comparison to other methods (history of other methods)	12
12	Contraindications / Risk Assessment (impact of the device on the child)	8
13	Head control	7
14	Calibration	5
15	Diagnosis/Prognosis	4
16	Accuracy	3
17	Managing Expectations	1
17	Funding Source	1

the child's prognosis. This supports findings from the literature review, highlighting the importance of multi-disciplinary, health professional led assessments: "Some of the parents who have had some of the companies in to do their assessments, and have been completely taken by the idea that their child is 'locked in' in some way"

Participants also emphasized the importance of having a flexible approach to ongoing assessment: "You get a so much better picture if you are able to do (your assessment) in a flexible way … rather than [only] having one"

DISCUSSION

The study successfully established a number of key components relating to the assessment of eye gaze for children with severe neurodisability. These were; motivation, visual ability, position/posture, purpose of the device (goals & aims), cognition and ongoing support from staff or family. Additional themes emerging from the discussion included the importance of multi-disciplinary health professional led, rather than supplier-led assessments. The importance of a flexible and on-going approach to assessment and concerns regarding unrealistic expectations or misconceptions of technology also emerged as themes. This study supports and extends findings from Angelo [6] who successfully used NGT to identify expert consensus regarding key components of single switch assessment, providing clear guidance for clinicians undertaking an assessment of those devices. It also supports findings from the literature review which emphasised the importance of family-led goals and a multi-disciplinary approach to assessment [7, 11, 12].

The findings from this study suggest that vital components associated with severe neurodisability such as posture, cognition and visual ability should be addressed as part of the assessment. Motivation was also raised as a key component of an eye gaze assessment for a child with a severe neurodisability. Clinicians should also work in conjunction with families to identify the purpose of the device early in the assessment process. A collaborative goal setting process will in turn guide the depth of the subsequent assessment process and ensure that family expectations are well met. The need for ongoing support should also not be over-looked during the assessment. Families and clients are more likely to abandon devices if adequate ongoing support is not provided [9, 10].

The study was successful in providing evidence to guide and support future eye gaze device assessments for children with severe neurodisabilities. It was however, not without limitations. Recruiting from a known special interest group and utilizing the study day was convenient and ensured that a suitable number of participants attended the focus group. However, a variety of topics relating to DAT access were discussed directly prior to the NGT focus group, including aspects of eye gaze assessment. As the researcher is a member of the special interest group and a participant in these discussions, there is risk of researcher bias affecting the results. However, efforts were taken by the researcher not to participate in topics relating directly to the research project. Furthermore the experience and involvement of the first author within the contact group was essential in developing the study.

Eye gaze devices are only likely to be effective for children with severe neurodisability if they are motivated to use the device. Part of the assessment should include an understanding of the personal motivators for that child and grading the selected activity to achieve the right level of challenge. Although a number of physical and sensory impairments can be overcome with appropriate support and customisation, motivation and cognition remain key components which should not be overlooked during an eye gaze assessment. A flexible and continuous approach to assessment was also highlighted as key. Ongoing support was highlighted in both the quantitative and qualitative data as a key component of an eye gaze assessment. Suppliers have a responsibility to ensure that suitable training is available to those purchasing the devices. However, therapists, families and staff with eye gaze users also have a responsibility to ensure they are confident working with these technologies and that key staff are identified during the assessment process to be suitably trained, ensuring they have appropriate skills, knowledge and competencies to support the child and their family.

In terms of implications for future research, this study has highlighted some key aspects of an eye gaze assessment for a child with a severe neurodisability, but the question of eligibility remains unanswered. The findings reflect the opinions and experiences of health professionals but do not explore family and user perspectives, further research exploring user perspectives would be beneficial.

CONCLUSION

The findings highlight a need for further research, measuring outcomes in terms of participation focused goals among children with cognitive impairments, to explore the effectiveness of eye gaze in improving participation among children with severe cognitive impairments. There is also a need to explore, if and how progression beyond simple cause and effect games is established among this population.

KEY MESSAGES

- A clear purpose for the device needs to be established at the outset.

- Devices are more likely to be abandoned when there is a failure to assess for and provide ongoing support.
- Assessments should be flexible, ongoing and involve a health professional within the multi-disciplinary team.
- Components such as motivation, visual ability, posture and cognition need to be thoroughly assessed.

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Tylie Suzanne Stokes – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published
Paul Roden – Substantial contributions to conception and design, Revising it critically for important intellectual content, Final approval of the version to be published

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Conflict of Interest
Authors declare no conflict of interest.

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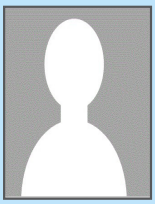

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