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Use of a Novel Imaging Technology for Remote Autism Diagnosis: A Reflection on Experience of Stakeholders

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Use of a novel imaging technology for remote autism diagnosis: a reflection on experience of stakeholders

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Abstract

Timely diagnosis and early interventions are critical to improving the long term functioning of a child with ASD. However, a major challenge facing parents is difficulty in obtaining on-time access to appropriate diagnostic services. To address this need, an imaging technology, NODA[®] (Naturalistic Observation Diagnostic Assessment), has been successfully developed and field-tested. NODA[®] includes 1) NODA SmartCapture; a smart-phone based recording system for parents to capture and share in-home video evidence of their child behavior and 2) NODA Connect; a HIPPA compliant web-platform for diagnosticians to conduct remote autism diagnostic assessments based on in-home video evidence of behavior, developmental history and their clinical judgment. In the field study, parents captured and shared videos evidence from their homes via NODA SmartCapture and diagnosticians conducted remote diagnostic assessment via NODA Connect. Results show that parents were able to successfully collect video evidence of behavior as per given prescription and diagnosticians were able to complete remote diagnostic assessments. This paper is a reflection on the first hand experience of key stakeholders (parents and diagnosticians) using NODA[®] in the field.

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1. Background and introduction

1.1. Motivation

Autism is the fastest-growing neurodevelopmental condition, and is diagnosed based on three main criteria that include difficulties with social interactions, impairment in verbal or non-verbal communication, and restrictive interests and repetitive behaviors [1]. According to the Centers for Disease Control and Prevention (CDC), the prevalence of autism in the United States has significantly increased by 119.4%, from 1 in 150 to 1 in 68 children between 2000 and 2010 [2,3]. While the cause of this neurodevelopmental condition is unknown, clinical evidence has shown that early diagnosis and early intervention are critical to improving the long term functioning of a child with ASD [4,5,6,7]. However, a major challenge facing parents today is difficulty in timely diagnosis of autism. Research shows that there is a 20-60 months gap between the time when parents first get concerned and final diagnosis [8,9,10]. Ethnic minorities, rural and low-SES communities lack access to the diagnostic services whereas urban communities have long waiting lists at autism centers that hinder timely autism diagnosis [11,12,13,14,15]. To address this need, we have successfully deployed and field-tested a behavior imaging technology, NODA[®] (Naturalistic Observation Diagnostic Assessment), for remote diagnosis of autism based on parent-collected in-home video evidence of the child behavior. This system has potential to connect parents and diagnosticians to enable timely diagnosis of autism. In addition, it allows diagnosticians to conduct diagnostic assessment based on in-home naturalistic behavior evidence. Its optimal since clinical professionals acknowledge that observing behavior in the natural environment is preferred for obtaining a comprehensive assessment of a child's behavior but in practice it is not feasible on a large scale and is limited to in-clinic observation [11,16,17].

1.2. Previous research

NODA[®] was iteratively designed and its implementation includes a) NODA SmartCapture; a smart-phone based recording system for parents to capture and share in-home video evidence of their child behavior and b) NODA Connect; a HIPPA compliant web-platform for diagnosticians to conduct remote autism diagnostic assessments. The initial prototype was informed by an interview study conducted with 11 clinicians and 6 parents of children with autism as well as our pilot research [18,19,20]. The initial design of NODA SmartCapture was iteratively improved through an initial experience of families (n=8) of children with autism using it in a controlled home-like setting [20]. NODA Connect was iteratively improved through a participatory design process involving a collaborating diagnostician who had more than 20 years of experience in autism diagnosis and a researcher in the autism domain [21]. NODA design resulting from this process was subjected to an initial feasibility study with parents (n=5) and diagnosticians (n=3) of children with autism [21]. The initial feasibility study demonstrated that without any prior training, parents found NODA SmartCapture easy to use and were able to successfully record videos in their homes. In addition, 96% of the videos recorded by parents in the initial feasibility study were clinically useful for autism diagnosis. Furthermore, 91% cases (10 out of 11 assessments) diagnosticians were able to confidently arrive at a diagnostic outcome via NODA Connect that matches the child's medical record.

1.3. Focus and contributions of this paper

Recently we conducted a large-scale in-field evaluation with 43 parents, 51 target children (who were assessed) and their siblings and 10 diagnosticians. One goal of in-field evaluation was to validate the clinical significance of NODA[®] based remote diagnosis in comparison with ones concluded through current best in-person autism diagnostic practices [22]. Details about validity of diagnostic outcomes are not addressed in this paper. The second goal of in-field evaluation, which is the primary focus of this paper, was to reflect on the first hand experience of key stakeholders (parents and diagnosticians) using NODA[®] in the field. For this purpose, follow-up interviews were conducted with stakeholders to solicit their feedback about their experience of using NODA[®]. Data from these interviews was subjected to qualitative data analysis.

In the next section, we present high-level details of the design of NODA[®] that resulted from our previous work. Section 3 and 4 describe the in-field evaluation and report results from qualitative analysis of follow-up stakeholder

interviews. In the discussion section we briefly summarize our proposed workflow for large-scale in-field integration of NODA[®] within current remote diagnostic practices and transferability of NODA design to other use cases where direct observation of behavior plays a central role in the assessment process. We conclude this paper with one example, medication administration, which shows transferability of NODA design.

2. NODA design overview

2.1. NODA SmartCapture

NODA *SmartCapture* is a smartphone-based recording application for parents to record and upload four 10-minute NODA scenarios as per embedded prescription (see figure 1). Each scenario has an embedded prescription that includes a sample video and instructions to guide parents about the environment setup (e.g. desired field of view) and required interactions (social presses like calling child's name) [23,24,25,26]. NODA scenarios include the child playing alone, the child playing with others, a family mealtime, and a behavior of parent's concern.

2.2. NODA Connect

NODA Connect is a HIPPA compliant web portal for diagnosticians to conduct a remote diagnostic assessment based on in-home videos, a brief developmental history and their clinical judgment. If required they can send notifications to parents with specific recording instructions. Diagnosticians can tag behavior relevant to diagnosing autism (see figure 2). NODA Connect has a predefined list of tags as behavior markers (e.g. no eye contact, no facial expression). Tags are extracted from the standard autism diagnostic criteria known as Diagnostic and Statistical Manual of Mental Disorders [1] and include both typical behavior tags and atypical behavior tags. Tags are auto-mapped to relevant DSM criteria. In the DSM checklist each criterion is auto-populated with assigned tags and their video snippet. The diagnostician completes the DSM checklist by indicating whether each individual criterion has been met or not (see figure 3). An assessment report is generated once the DSM checklist is submitted.

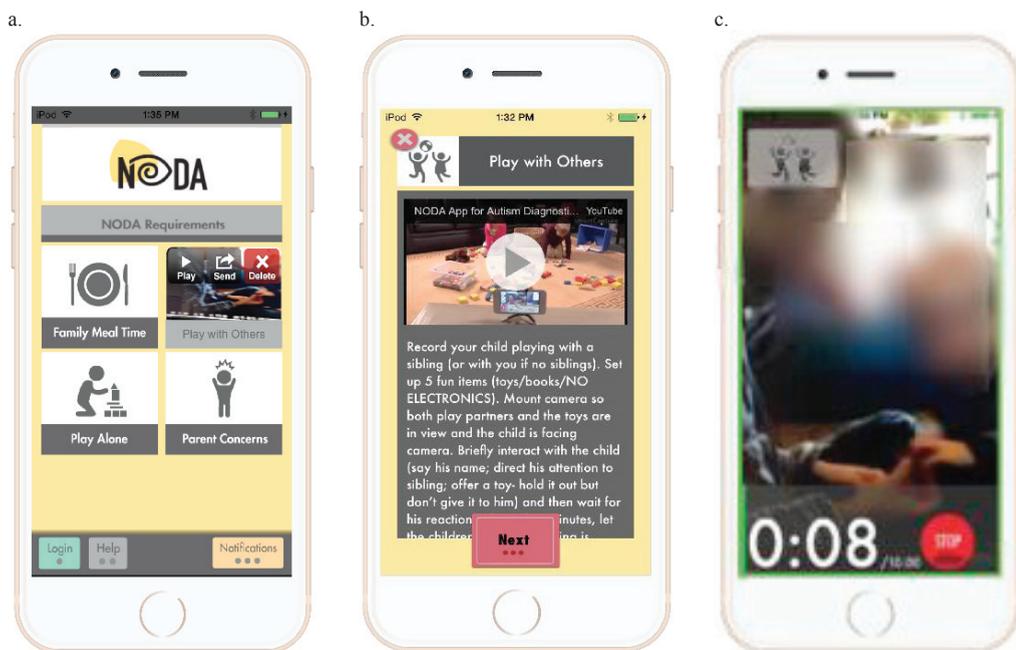


Fig. 1. (a) Home screen; (b) embedded prescription; (c) recording mode.



Fig. 2. Video observation and tagging.

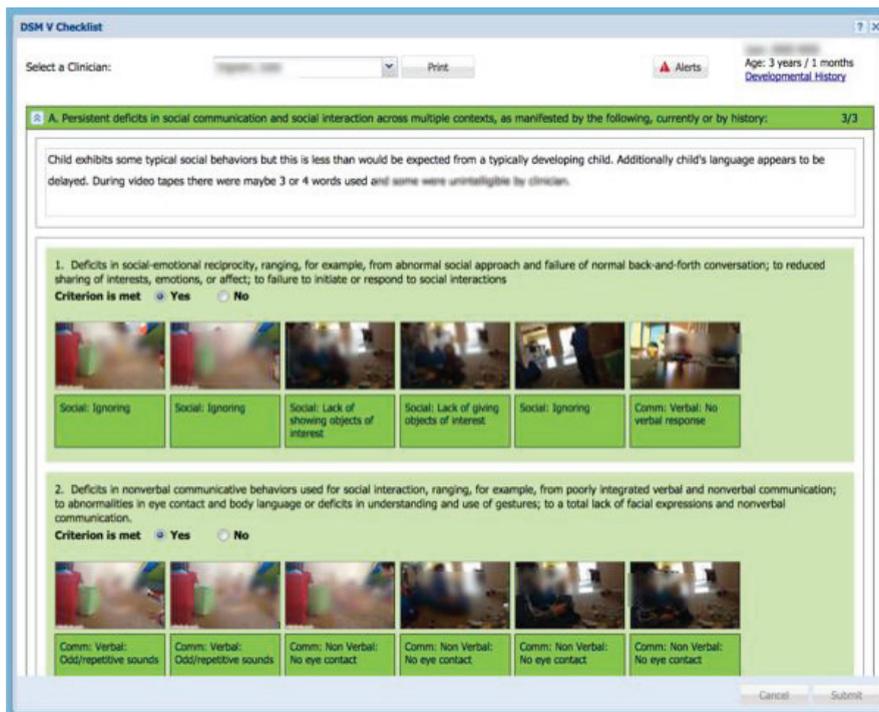


Fig. 3. DSM V checklist.

3. In-field evaluation: Method

A larger scale field study was conducted with 43 parents, 51 target children (40 who families were seeking evaluation for autism, 11 were typically developing) and their siblings, and 10 diagnosticians. Some of the parents had more than one child participating in the study. Typically developing children were included so that diagnosticians can experience using NODA® for wide range of behaviors. Children were between the ages of 18 months and 6 years, 11 months.

In the first phase, during in-home deployment parents recorded and uploaded NODA scenarios through NODA SmartCapture. Parents also completed a brief online developmental history of their child. During in-home behavior

collection, when and if required, a collaborating diagnostician guided in-home data collection by sending notifications with specific recording instructions for parents. Once all scenarios were collected and shared, each parent participated in a semi-structured follow-up interview to reflect on the experience of using NODA SmartCapture and their perspective about remote autism diagnosis through in-home videos. In the next phase, each diagnostician, blind to the children's condition, independently conducted diagnostic assessments for five children (since here were 51 children so one diagnostician assessed one additional child) via NODA connect. After completing all assessments each diagnostician participated in a semi-structured follow-up interview to reflect on the experience of using NODA Connect and its utility for remote diagnostic assessment.

4. In-field evaluation: Results and findings

Comparison of remote autism diagnosis via NODA[®] with in-person diagnosis via best current diagnostic practices was conducted [22]. Details about validity of diagnostic outcomes are not addressed in this paper. Our focus in this paper is to reflect on the first hand experience of key stakeholders using NODA[®] in the field. This section outlines the key outcomes of qualitative analysis of follow-up interviews with stakeholders.

4.1. Value-addition

Participant parents and diagnosticians found NODA[®] an effective tool for remote autism diagnosis. Parents who had previously gone through the in-person diagnosis process for their older children anticipated NODA[®] being effective in getting timely diagnosis. One participant parent who had two children previously diagnosed with autism and one at risk for autism, stated that *"Its terrific (referring to NODA[®]). Original diagnosis for my older children took a very long time, this will allow families to get diagnosis sooner, which is much needed given waitlists at doctors offices."* Participant parents and diagnosticians emphasized that in-home video of behavior would allow clinical experts to observe the naturalistic occurrences of behaviors which might not be possible due to artificial setup of the clinic. Additionally, it would allow clinical experts to observe evidence of behavior which are otherwise inaccessible e.g. infrequently behaviors or ones triggered at home. Furthermore, all participants appreciated the inherent richness of video data augmenting communication between parents and clinical experts.

4.2. Design usability

Analysis shows that parents successfully collected and uploaded video as per given prescription and diagnosticians completed remote assessments. 95% of parents (42 out of 44) found NODA SmartCapture easy to use. As mentioned by one parent: *"Once you got into the system it was so straightforward. Options readily available. Simplified. Only a few options"*. Simple design was imperative for adoption-centered-design of NODA SmartCapture. Parents use it while attending as well as interacting with their child (as per given recording instructions). Since parents use this system within their daily routine; a simplified design would ensure that there is no added burden for these parents who already have additional care responsibility. In case of NODA Connect all diagnosticians found it easier after they reviewed the first one or two videos, which involved a sharp learning curve. As mentioned by a diagnostician: *"Really nice interface, loved how all of the tags come up under the DSM"*. Diagnosticians reported that on average it took one hour to complete assessment for a child.

4.3. Video sharing and privacy concerns

Privacy is an inherent concern particularly in recording and sharing of home videos. However, participant parents were less reluctant due to a number of factors that ease privacy concerns, including 1) they feel protected due to various privacy acts and confidentiality agreements in place, 2) they are willing to sacrifice some of their privacy concerns in order to get help with their child's condition, and 3) the system gives parents explicit control over video deletion and upload. Results show that only 8 out of 44 parents had high privacy concerns but they were willing to record and share if sharing policies explicitly identify 'who will have access to video data'. Few parents (n=2) were conscious of their self-image or fear of being judged based on their interaction with the child and/or their lifestyle.

4.4. Video capture and behavior reactivity

Video recording may possibly cause reactivity of the children and parents' behavior. In this context, reactivity would be parents or children changing their behavior simply due to their awareness of being observed. Diagnosticians stressed that minimizing the child's reactivity is necessary to observe the natural occurrence of behavior and argued that although reactivity is a major concern and may affect quality of the in-home behavior evidence, it does not necessarily make video evidence invalid. Nevertheless, there are always chances of reactivity even in direct observation and assessment. Diagnosticians reasoned that since NODA SmartCapture is an application on smartphones and iPod, children may quickly get use to these every day objects and then would be less distracted by them. Parent reports confirmed that children got used to NODA SmartCapture after a while and started ignoring it. Parents stated that using the rear camera instead of the front camera and mounting the camera in the environment instead of holding it helped in controlling reactivity. Some parents claimed that using a personal phone (instead of the one provided in the study) would be better since children are already used to it. Analysis shows that 59% (26 out of 44) of parents reported that their child noticed NODA SmartCapture but 91% (40 out of 44) parents stated that they were able to capture naturalistic representation of their child's behavior for all four (reported by 31 parents) or three (reported by 9 parents) NODA scenarios.

4.5. Acceptance

Parents and diagnosticians considered NODA[®] a valid approach to address challenges related to autism diagnosis. Diagnosticians cited various factors contributing to their acceptability of NODA[®] 1) NODA Connect facilitates the diagnostic assessment process effectively through a list of predefined tags and their mapping to DSM. 2) NODA Connect allows diagnosticians to add their "confidence rating" for each DSM criterion as well as for overall diagnosis 3) NODA SmartCapture has clear recording instructions (embedded prescription) for parents that ensures that the recorded videos are clinically meaningful for autism diagnosis.

However five parents recommended that NODA[®] should compliment the in-person diagnosis instead of replacing it and three parents questioned if in-home videos can be sufficient to diagnose children with mild behavior. Diagnosticians anticipated that children with classic autism symptoms would be easily and successfully diagnosed through NODA[®] whereas for children with mild conditions additional evidence (e.g. detailed developmental history and/or standard developmental assessments) would be needed. They suggested that for such complicated cases, NODA's two-way communication (between diagnosticians and parents) would be extremely valuable for asking parents for additional evidence and/or developmental history and/or to confirm their observation with parents.

However, diagnosticians highlighted that for a subset of children with mild behaviors, in-person assessment might be inevitable for comprehensive assessment but nevertheless in such cases NODA[®] would still be extremely helpful as an early screener. All diagnosticians envisioned that for remotely located and rural families, NODA[®] is a best fit. As stated by a diagnostician "*Absolutely (referring to NODA's adoption for remote diagnosis), because I have a lot of people coming remotely and a lot of people have to come a long way.*"

4.6. Potential enhancements

Both Parents and diagnosticians felt a need that an additional scenario or the existing "play with other" scenario should be recorded outside home environment such as school, community or play ground. Additionally, "play with other" scenario would be more informative if instead of parents or sibling it involves play with same age peer. Families in particular asked for multi language support and some of them suggested that in case of divorced families NODA should allow both parents to record and upload videos.

4.7. Conflicting needs of stakeholders

Like any other multi-stakeholder systems, one of challenges of NODA design is to balance the conflicting needs and demands of its multi-stakeholder groups. For example, some parents indicated that they should be able to stop a recording and resume it afterwards in situations when they have to attend to a different task. Diagnosticians considered this equivalent to editing or tampering evidence, which would lower their confidence in the validity of

the evidence. Therefore, NODA[®] allows parents to review a video before uploading it and if required they can re-record in order to capture a good sample without a need to edit it. Furthermore, parents indicated a need for recording and uploading multiple videos for each scenario whereas diagnosticians have time constraints. To balance this conflicting need, NODA[®] two-way communication enables diagnosticians to request more video evidence if needed and allows parents to connect to the diagnosticians and communicate their concerns.

5. In-filed adoption

5.1. NODA[®] adoption for remote diagnosis

In our proposed model for large-scale in-field adoption of NODA[®] for remote autism diagnosis, a pediatrician puts a referral for a remote diagnostic assessment for children who are at risk for autism. Parents collect and share in-home videos using NODA SmartCapture and a diagnostician at an affiliated diagnostic center completes a remote diagnostic assessment via NODA Connect. The diagnostician then shares the assessment report with the pediatrician, who subsequently shares it with the parents. See figure 4 illustrating this workflow.

5.2. Transferability to other use case scenarios

Parents and diagnosticians found NODA[®] to be an effective tool to support remote autism diagnosis. However, they envisioned a number of other important use case scenarios for which customized NODA[®] would be valuable. 95% of parents indicated that they would like to use it on a regular basis for monitoring progress and sharing behavior with other caregivers. Diagnosticians considered NODA[®] highly suitable for early screening. They also suggested using it for remote training of parents. Diagnosticians proposed that NODA[®] could support autism diagnostic centers in establishing consistency amid assessments completed by different professionals.

One successful transferability example of NODA[®] is medication administration system that helps clinical experts in the management of medication for individuals with autism. In-home behavior capture and sharing through the recording application called Med Smart Capture (a NODA SmartCapture customization) allows physicians to observe patient behavior and improvements in symptoms between office visits via an integrated web platform called Med BI-Connect (a NODA Connect customization). In a preliminary evaluation two physicians and three clinicians of individuals with autism evaluated this system and found it effective in monitoring patients with ASD more comprehensively and accurately than using subjective reports provided by caregivers during office visits [27].

6. Conclusion

NODA[®] is a novel behavior imaging system that supports remote diagnosis of autism using in-home videos recorded by parents. This paper is a reflection on the first hand experience of key stakeholders (parents and diagnosticians) using NODA[®] in the field. Results show that it allows parents to successfully collect videos as per given prescription and diagnosticians to complete remote diagnostic assessments. In follow-up interviews parents and diagnosticians reported that NODA design is simple and easy to use. They considered NODA[®] an effective tool for remote autism diagnosis and exhibited high willingness to adopt it in their practices. In addition, they highlighted potential adoption barriers such as privacy concerns and reactivity of behavior and suggested strategies



Fig. 4. Adoption workflow (a) referral (b) evidence collection (c) diagnostic assessment and report generation.

that ease these concerns. We conclude that NODA[®] has high potential to 1) connect remotely-located and rural families with clinical experts; 2) enable pediatrician or other primary health care providers to more easily refer families for a diagnostic evaluation; and 3) support autism diagnostic centers and clinics in more effectively triaging families who are on waiting lists for a diagnostic evaluation.

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