A POTENTIAL WAY TO HELP CAREGIVERS BETTER UNDERSTAND THEIR NON-VERBAL PATIENTS

Negar Memarian, Stefanie Blain, Tom Chau
Institute of Biomaterials and Biomedical Engineering, University of Toronto
Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

INTRODUCTION

The challenge

People with severe and multiple disabilities are often aware of events and stimuli in their immediate environment, but as a result of their limited physical abilities, they may appear completely passive. They do not have the ability to deliberately and voluntarily convey their intentions, but rather rely completely on a third party (e.g. parent, nurse or caregiver) to discern and interpret their needs. While caregiver interpretations of preference are essential to the well-being of non-verbal individuals, they are ultimately subjective and based on inconsistent cues such as subtle facial expressions and gestures. Caregivers often report difficulty in interacting with non-verbal individuals due to their lack of expressive communication [1]. However, this communication challenge can also be viewed as a consequence of the caregiver's inability to decode the client's intention, which may be encoded by markers external to the typical conversational grammar (affective prosody, facial expressions, gestures, or reference to context) [2]. From this viewpoint, it is the caregiver who lacks the pragmatic competence to make inferences from the discursive and situational context at the time of the client's expression of intent [2]. For example, patients rendered voiceless after head and neck surgery reported fear and frustration over their caregivers' inability to comprehend their intentions [3] while ventilator-dependent amyotrophic lateral sclerosis (ALS) patients lamented about their caregivers delayed appreciation of their expressions and needs [4].

People with severe and multiple disabilities include, but are not limited to, persons with disabilities secondary to neurological conditions such as cerebral palsy, degenerative neuromuscular disorders such as muscular dystrophies and amyotrophic lateral sclerosis, autoimmune diseases such as multiple sclerosis, and strokes especially in the brain stem [5].

Objective

We suggest that providing further insight into client reactions to contextual stimuli may augment caregiver perspective, reduce their uncertainty and stress, and eventually lead to more meaningful interaction between non-verbal clients and their caregivers. Specifically, we propose to use the four peripheral autonomic nervous system (ANS) signals as a potential means of augmenting caregiver perspective when interacting with non-verbal clients.

METHODS

In this descriptive case study, we measured four peripheral autonomic nervous system signals (electrodermal activity, blood volume pulse, skin temperature and respiratory effort) from a non-verbal adolescent male with severe and multiple congenital disabilities over 3 different days within a one month period. The participant was repeatedly presented with visual and audiovisual stimuli, representing variations of three contextual factors: presentation modality, familiarity, and startle. For each stimulus, the interpretation of the participant's reaction by a familiar caregiver (mother) was compared to the number of reactions detected in the recorded physiological data.

Instrumentation

Four peripheral ANS signals, namely, electrodermal activity (EDA), temperature, heart rate, and respiration pattern were non-invasively acquired using a ProComp Infiniti multi-modality encoder from Thought

Technology Ltd. and a laptop computer. Electrodermal activity was measured via two Ag-AgCl electrodes (SA9309M, Thought Technology Ltd.), placed on the palmar surface of the second and third finger of the participant's left hand. Heart rate was recorded using a photoplethysmography sensor (SA9308M, Thought Technology Ltd.) fastened to the tip of his fourth finger. Thoracic respiration was measured using a stretch sensitive belt (SA9311M, Thought Technology Ltd.) positioned around the upper aspect of the trunk. Skin temperature was detected with a 0.125 inch bead thermistor (SA9310M, Thought Technology Ltd.) securely fastened to the fifth finger of the participant's left hand.

Data collection

Three data collection sessions were conducted over three different days within a one month period, in a controlled, indoor environment with minimal distraction. At the beginning of each session, a baseline recording of at least 300 seconds was obtained, wherein no stimulus was presented to the participant. This was followed by stimulus presentation tests, which involved the following:

a) Presentation modality (visual versus audiovisual): The visual modality test consisted of an 80 s random sequence of two types of visual stimuli: (1) mute fireworks, and (2) mute grey static screen. The audiovisual modality test consisted of an 80 s random sequence of: (1) fireworks with sound, and (2) grey static screen without sound.

b) Familiarity with stimulus (familiar tone versus unfamiliar tone): A 100 s random audio sequence of words was spoken to the client in familiar (participant's mother) and unfamiliar (stranger's) voices.

c) Startle (interesting versus uninteresting): A 100 s random sequence of dull repetitious sounds (e.g. hammering, knocking) and paper crumple (startle stimulus identified by participant's parent) was played.

The stimuli were presented on a laptop computer, which was connected to two speakers (for presenting the audio stimuli). Over the 3 sessions, the participant completed each stimulus test at least twice. Before commencing each test, we asked the participant's mother to predict her son's reaction to the variations of each stimulus.

The protocol was approved by the research ethics board of the pediatric rehabilitation hospital and affiliated university. The participant's parent provided written consent for participating in this study.

Data analysis

The recorded physiological data were analyzed offline. The number of reactions in the physiological signals was calculated using the algorithm previously described in [6]. Since all the analyses proceeded in one segment increments, there was at most one reaction per second per signal modality. For each trial, we counted the number of seconds which contained at least one reaction among the four physiological signals, yielding the total time in seconds, where the individual was responsive. This number, i.e. the total number of physiological reactions under each condition was compared to the total number of physiological reactions during baseline via a Chi-Squared (χ^2) test of homogeneity of proportions [7] at a 5% significance level.

RESULTS

Table 1 summarizes the number of reactions during the stimulus trials and their comparison with baseline reactions. For this comparison, we included all the baseline recordings from the participant, resulting in a total of 2331 seconds of recording time and 520 reactions. The cells marked with asterisks represent trials where the total number of physiological reactions significantly differed from that observed in baseline (χ^2 test, $p = 0.05$).

Table 1 also lists a summary of the caregiver's predictions about the outcome of each test, and whether or not the analysis of the corresponding physiological signals endorsed those predictions. Our results include instances of agreement between caregiver predictions and reactions in the participant's physiological signals. Figure 1 depicts sample recordings from the presentation modality test

Table 1: Summary of client’s physiological reactions to the test stimuli. Trials with a significantly different number of physiological reactions from that observed in the baseline condition are denoted by an asterisk (using χ^2, $p < 0.05$).

Test	Trial	Session	# of physiological reactions	Parent’s prediction	Agreement between parent prediction and physiological reactions
Presentation modality	Visual	1	5*	Most effective presentation modality: audiovisual Least effective presentation modality: visual only	Yes
		2	17		
	Audiovisual	1	24*		
		2	13		
Familiarity with stimulus	All content in familiar tone	1	21	Reaction to familiar content in familiar tone	No
		2	6*		
	All content in unfamiliar tone	1	24		
		2	22		
Startle	Startling sounds	1	3*	Reaction to paper crumple sound	No
		2	22		
		3	16		

(audiovisual trial, session 1 in Table 1), for which the total number of physiological reactions was significantly different from baseline ($\chi^2 = 3.93$, $p = 0.0476$). This finding echoed the perspective of the parent, who predicted considerable reaction to the audiovisual stimulus. For the other two tested stimuli however the number of reactions derived from the physiological signals contradicted the parent’s prediction. The client's mother predicted a definite reaction to familiar tone in the "Familiarity with stimulus" test and paper crumple sound in the "Startle" test. But in both cases, the client’s physiological signals exhibited very relaxed patterns, which resembled those of baseline. In fact, in the case of the "Startle" test, the total number of reactions to the paper crumple sound was even significantly lower than baseline in the first session.

CONCLUSION

We explored the level of agreement between the predictions of a primary caregiver and a nonverbal client’s physiological reactions to three contextual stimuli. Physiological reaction counts disagreed with caregiver predictions for familiarity and startle stimuli. Physiological data may complement caregiver acumen in deciphering the reactions of nonverbal clients with severe and multiple disabilities.

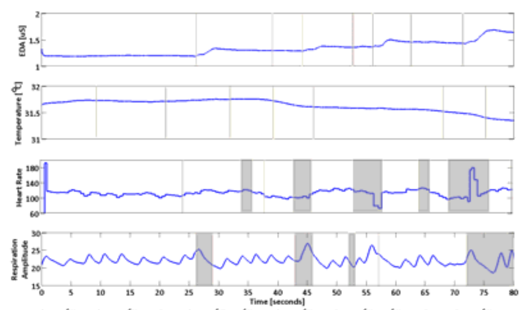

Figure 1: Participant’s physiological reactions to audiovisual stimulus as detected by the algorithm (corresponding to Table 1, presentation modality factor, audiovisual trial, session 1). ‘s’ denotes a static gray image, and ‘fw’ denotes a fireworks video. Vertical lines denote reactions in the EDA and skin temperature plots, while shaded blocks denote reactions in the respiration and heart rate signals, as detected by the algorithm. The total number of reactions in the participant’s physiological signals ($N = 24$) was significantly different from baseline in this trial ($\chi^2 = 3.93$, $p = 0.0476$).

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