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## **Cover Page Footnote**

Acknowledgement: We would like to thank Nithin Ellanki for his help in analyzing the physiological trend data. This article is associated with the Innovation & Technology lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_InnovTech](http://bit.ly/PX_InnovTech)

## A novel mobile biobehavioral regulation system for personalized trauma recovery support

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### Abstract

Even years after experiencing a physical trauma, individuals describe trauma-specific distress, as trauma triggers present as sensory reminders that initiate physiological reactions at time of exposure. Mobile technologies offer tremendous potential in helping individuals who have experienced trauma manage symptoms as they transition out of hospital care and move back into their communities where they are at risk of trauma trigger exposure. A personalized wearable device, tailored to a patient-specific diagnosis (e.g., PTSD) with programmable neurophysiological behavioral risk set-points, could be a useful tool in helping individuals monitor symptomology. When this type of monitoring device is also connected to a personalized recovery cue intervention on a smartwatch or phone, and activated when the wearable sensor detects heightened risk, there is the opportunity for in-the-moment symptom management. In this study we sought to understand the value for trauma survivors of using this type of personalized mobile recovery support system. Study participants were all trauma survivors or family members of survivors who were involved in the Trauma Survivors Network. A semi-structured interview was conducted with participants to understand perceptions on the utility, sensory experiences, and innovation insights of a mobile recovery sensory support system overall, and about the recovery cue intervention most specifically. Results from participant interviews inform the further development of our mobile recovery support system model in significant ways, suggesting that three components must be included: 1) Recovery cues; 2) Relationships (connecting to supportive network); and 3) Regulation (neurophysiological regulation and behavioral risk reduction).

### Keywords

Wearables, mobile technology, recovery support, trauma, transition care

### Introduction

Trauma is the leading cause of death among people ages 0 – 44 in the United States and among the leading cause of hospital admissions for adults younger than age 65<sup>1-3</sup>. Traumatic injuries have immediate and long-term impacts on physical and psychosocial functioning of survivors<sup>4</sup> such as physical disability, inability to work, impaired social functioning and financial burdens<sup>5-7</sup>; research suggests that caregivers experience many of these same stressors<sup>9</sup>. Poor outcomes in the trauma population have been shown to be related to mismanaged pain and unmanaged symptoms of depression, anxiety and posttraumatic stress<sup>8,10</sup>. Posttraumatic Stress Disorder (PTSD) affects 7-8 percent of the population as a result of experiencing or witnessing a life-threatening event<sup>11</sup>. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) PTSD includes intrusive symptoms, negative mood, dissociative, avoidant and arousal symptoms<sup>12</sup>. Psychosocial treatments that focus

on symptom management are essential, particularly early in the aftermath of trauma. For example, “Findings from research among veterans suggest that even modest reductions in PTSD symptoms may lead to employment gains, even if overall symptom level remains severe (Smith, Schnurr, & Kosenheck, 2005)”<sup>13</sup> (p. 64).

Mobile technologies and wearable devices offer tremendous potential in helping individuals struggling with PTSD manage their symptoms as they transition out of hospital care and back into their communities. Such medical devices are increasing in use, particularly for conditions that require frequent monitoring. For example, wearable trackers have been shown effective in providing real-time data on the condition of ICU patients post-discharge<sup>14</sup>. Applications have also been developed for behavioral health. For example, “lifestyle physical activity” devices provide real-time support to women who are suffering from depression and addiction. Fitness trackers have been used to help individuals cope with mental

illness/substance abuse, resulting in improved affect and reported high satisfaction with the devices<sup>15</sup>. Other researchers are examining the use of wearables to help engage in “digital phenotyping,” collecting information about patients from their smartphones, to determine who is at risk of harm to notify supports when intervention might be necessary<sup>16</sup>.

It is important to consider the user experience in adoption of tracking devices. Researchers examined perspectives on Fitbit use in treatment for PTSD and found reasons for slow adoption that included: Lack of understanding how the device works, difficulty interpreting data, and strained relationships with providers. PGD (patient-generated data) could mitigate this latter barrier by giving providers specific, personalized information on how to improve their relationships with patients. Among the veterans studied, self-monitoring was a positive way of enhancing self-awareness. However, the link between physical and mental health must be clear to patients in order for them to understand the mental health benefits of using a tracker<sup>17</sup>.

The ability to customize such technologies is an important design consideration. For example, tailored technologies that are personalized by individual characteristics and offer survey feedback, increase abstinence rates for some user populations<sup>18</sup>. Our mobile recovery support system seeks to expand on the current innovations by offering in-the-moment neurophysiological monitoring of a PTSD-trigger reaction and reducing risk by activating a sensory-based, personalized recovery-regulation intervention in real-time. Personalized wearable support systems, tailored to a patient-specific diagnosis (e.g., PTSD) with programmable neurophysiological behavioral risk set-points can be a useful tool in helping individual monitor symptomology. When also connected to a personalized mobile intervention on a smartwatch or phone, that is activated when the wearable sensor detects heightened risk, there is an opportunity for in-the-moment symptom management that could be particularly useful to trauma patients discharging from hospital care who are at risk of exposure to triggering experiences in their environment<sup>19-20</sup>.

### **Mobile Recovery Support System**

In this study we sought to understand the value for trauma survivors of using this type of personalized mobile recovery support system, and how they perceived it could affect their recovery journeys. We believe this system has the potential to benefit those who have experienced trauma, including physical trauma, as trauma triggers present as sensory reminders that reside outside of conscious awareness, and trigger physiological reactions at time of exposure<sup>21</sup>. Specifically, this study explored the value of generating personalized recovery-relevant sensory cues on calming the body's physiological reactivity to trauma stressor cue presentation. This is consistent with a

continuum of care behavioral health model that utilizes technology-based solutions for community-dwelling symptom management and sustained recovery post-discharge. The broad aim of our recovery system is to reduce avoidance symptomology and promote social reintegration into the community following hospitalization for traumatic injury. For example, epidemiological studies suggest that one-year point following injury is a particularly vulnerable time for development of PTSD, depression and functional impairments, with approximately 20-40% experiencing these diagnostic symptoms<sup>22-23</sup>.

This type of mobile recovery support system may be able to offer important affect regulation support in the early stages of trauma recovery in ways that reduce hospital recidivism risk and promote enhanced well-being. Studies have shown positive affect negatively correlates with stress-damaging physiological effects and may indirectly modulate the Hypothalamus-Pituitary-Adrenal (HPA) axis stress response system to promote health and well-being<sup>24</sup>. In addition, images are directly connected to the sensory brain: “Imagery exists at the intersection of mind and body. What we see and what we imagine produce psychophysiological and behavioral responses”<sup>25</sup> (p. 21). Other researchers have explored the utility of sensory experiences for monitoring PTSD symptomology associated with nightmares, such as aromatherapy, auditory cues, and “gentle waking”, focusing on “selective sequencing” to promote more restful sleep. For example, if aromatherapy affects heart rate in a favorable way and more quickly than auditory cues, the device will automatically move to a “state” of aromatherapy<sup>26</sup>. Our system invites patients to identify their own preferred auditory, visual, tactile sensory cues that are most meaningfully associated with their healing journey to be used in their day-to-day routines to manage trigger reactivity. We hypothesize that this system could be designed to offer both passive and interactive intervention features. *Passive* recovery cue exposure could activate the pre-programmed cues on a smartwatch or phone screen and adjust the frequency of exposure (dosage) presentation according to the physiological data monitoring, and *interactive* features would allow a person to interactively change the sensory characteristics of the image on the screen (e.g. color, visualized texture, tactile sensation such as vibration, size, and shape), using a pop-up menu of regulation selections.

### **Pilot Study**

#### **Study Aims**

The *primary aim* of our study was to identify potential end users' preliminary perceptions about the utility of this type of mobile recovery sensory support system to facilitate stress relief after trauma. A *secondary aim* was to collect pilot data on participants' physiological response to the presentation of trauma stressor-related sensory cues and to

presentation of their own personalized recovery-relevant sensory cues. This secondary aim was included to begin examining patterns among participants' physiological response to their recovery cues, with the hypothesis that presentation of their own personalized and preferred sensory cues paired with healing and recovery would down-regulate the heightened arousal response initiated by stressor cue exposure. Physiological data, such as variability in heart rate, galvanic skin response (GSR), skin temperature, and 3-axis accelerometer measurements in movement, were captured using Empatica E4 sensor watch (Empatica, 2018) during these cue exposure presentations.

### Sample

The participants in this study were all trauma survivors or family members of survivors who are involved in the Trauma Survivors Network (TSN)<sup>27</sup> at a major hospital system in the Mid-Atlantic region of the United States. The study was approved by the hospital and university researchers' Institutional Review Boards (IRB), and followed all human subject protection procedures for participant consenting and study implementation. The TSN was created to address the psychosocial needs of trauma recovery patients. Ninety-seven trauma centers in the United States have joined the TSN, a program of the American Trauma Society, since its launch in 2008. The program focuses on the needs of recovering trauma patients and their caregivers through four main components: peer support and visitation, self-management classes, informational resources, and an online social networking website.

### Methods

Trauma survivors (N=9) were invited to take part in three ~one-hour session interviews. One participant only attended the initial session; the remaining eight participated in all three sessions. Interviews educated participants about trauma stressor and recovery-relevant sensory cues, and engaged participants in an exploration of their own such sensory cues. Participants were asked to consider the question – “*What brings you back to safety?*” – and to bring in their own personalized safety-anchoring sensory cues (e.g., images, meditations, soundscapes, music, inspirational quotes, etc.) to the following session. In session two, participants were exposed to their trauma stressor cues immediately followed by presentation of their recovery cues, while wearing the Empatica E4 sensor watch to track physiological response. Participants were also invited to use their self-generated recovery cues during the following week in their daily routines. This semi-structured interview (see Appendix) was conducted with participants in sessions two and three, guiding participants to share their experiences with their recovery cues. These interviews were audio recorded, transcribed, and analyzed to understand perceptions on the utility, sensory experiences, and innovation insights of

this mobile recovery sensory support system overall, and about the recovery cue component most specifically. The first of the two interviews was conducted directly after the stress/recovery cue exposure experience, and the second at approximately one-week follow-up, and asked about their experience using their recovery cues between the two sessions. As the interviews progressed, concepts generated from first interviews were addressed in later interviews to seek out validity and applicability of such concepts across time and across participants.

Specifically, transcripts were analyzed line-by-line to identify salient and re-occurring codes that were later categorized into larger themes supported by direct quotes across interviews. Thematic analysis was based on the methodological principles of grounded theory, where line by line sentence content from each of the interview transcripts were aggregated into larger themes supported by the direct quotes derived from the transcripts<sup>28</sup>. Coding and themes were analyzed by the primary researcher who sought feedback from a second researcher who participated in transcribing the interviews and who provided insight into the thematic analyses and their relationship to the direct quotes.

### Results

Participants ranged in age from the 20's to age 60, with approximately equal representation across gender (See Table 1). Injuries included motor vehicle-related crashes and falls which resulted in orthopedic injuries, head injuries, or both.

#### Perceived Utility

Even years after trauma, individuals described trauma-specific distress. One participant recounted being in a hospital and hearing the loud speaker alert indicating a “code” notifying staff of an inbound patient. This participant reported that other hospital sounds did not

**Table 1. Sample Description**

Participant Number	Age	Gender	Injury
P1	50-60	F	Orthopedic Injury
P2	50-60	F	Head Injury
P3	40 - 50	M	Orthopedic and Head Injury
P4	40 -50	F	Orthopedic Injury
P5	30-40	M	Orthopedic Injury
P6	50-60	M	Orthopedic and Head Injury
P7	50-60	F	Head Injury
P8	50-60	M	Family member of survivors
P9	20-30	M	Head Injury

F: female M: Male

**Table 2. Perceived Utility: Selected Illustrative Quotes**

Category	Quote
Offers immediate help or strategies	There are times when I didn't necessarily know what I was feeling. I was like, 'What's wrong with you? Don't think that! Don't feel that!' But this is what your body's feeling, going through, this is validated, here's what we can do to help it.
	[The device reminds you that]...'Hey, you're going through something right now, you're having an episode... and here's what you can do.' Versus, you're so in it, and you think 'nobody understands and there's nothing I can do. I'm all alone and there's nothing at all I can do about it. ... This is terrible.'
Examples of trigger experiences in which a device would be helpful	I've [been triggered] before when I didn't realize it. My hands would hurt, and I'd realize, it's because I'm squeezing the steering wheel so hard. And just a device giving me a kind of notification earlier on that would tell me, ok you need to breathe, you need to do some of that positive self-talk, whatever my plan would be.
	For no reason my body is making it harder to function. I put so much energy into thinking, my body forgets to breathe. I'm not doing it on purpose.
	Even talking about the trauma was ... not that bad. I know I'm in a safe place, I know that I'm okay... I think it's when it's the unexpected triggers that happen that it's really bad.
	An ambulance pulled up right next to me, and it wasn't an immediate reaction... I would've thought it would've been an immediate trigger, but it wasn't. But then it hit me, and I thought, 'Oh! I have to do x, y, z!' It was weird, though, because it was just a normal thing when I first saw it, and THEN it triggered...
	When I was in the room with the doctor [during a distressing visit], I was wondering if a watch would have helped me...if it buzzed. Would it have helped remind me to take a breath? I wouldn't have pulled my phone out – but a buzz might have helped.
Provides sense of control and confidence	And even just wearing it could make a person more aware of 'ok I have this,' not necessarily a security blanket, but 'I'm focusing on healing, I'm focusing on trying to be better and not let these fears have dominance over me.'
	When I made an effort to listen to my music or look at the pictures I printed, um...I felt safe, I felt, I realized that this was just now, it wasn't forever.
	I think it's been working, because in years past, I would have replayed the [distressing event] over and over again.
	I don't think [the device] necessarily has to work every time, but just having it and knowing that it's there, I think is a huge mitigating factor.
Importance of concurrent relationships	If the device was able to really read your level of where you are, and if it were to get to a certain level, it could contact that one person that could be your support. And that person could come to you or call you, or, that would be awesome. I would've really liked to have that.
	When one is so overwhelmed with 3 or 4 things going on at the same time, the cues failed because I needed something more ... I didn't have anybody available that could intervene. ...I didn't have that relationship lined up, and so one is left to fend for themselves kind of, and it's overwhelming.
	[I thought] 'I don't want my mom to know I'm upset, I don't want her to know I'm struggling.' But this device would kind of force you to. And I think that would've helped so much in my own recovery.

produce the same physiologically distressing experience as this particular one, as it is most related to the original trauma experience. Table 2 displays examples of participant feedback regarding perceived utility of a device. Participants felt a device that could “sense what is going on would be incredibly useful”; with potential value in being able to offer immediate help or strategies in the moment through awareness and redirection. Receiving real-time feedback was important to these participants, as many discussed the power of emotionally triggering

experiences and the limited awareness they had when the experience was initiated. One participant shared that viewing media where similar traumas are shown creates an actual sensation of physical pain, even though the participant's trauma occurred many years ago. Other participants discussed the unexpected nature of triggers, and the often delayed onset of physiological reactions; nearly all participants felt there was value in a device that could monitor their physiological reactions, particularly if

**Table 3. Individualized Coping Strategies**

Example quotes of coping strategies
Music is always my immediate go-to and instant relief.
When I looked at the pictures, I was able to settle down and just, center myself again and kind of go on about my day.
It's not images for me, it's vocal or music or someone else voice... something like [an alert that says,] "You're okay."
To be honest, I think scents are stronger than images.

the alert was successful in mitigating a full-blown triggering experience.

The potential of refocusing anxiety through an image or other sensory exposure was a comforting thought to many, noting that this type of a device could be empowering and offer a sense of control when navigating daily routines. One participant shared the confidence that came from experiencing a different outcome as a result of using calming strategies, and how the new strategies helped “not hang on to the conversation for too long”, which helped instill a sense of confidence and success. Another participant discussed the typical pharmacological strategies that are available, but thought it was important to have other non-pharmacological, behavioral-based tools and strategies when medications may not be compatible with patient preference -- “*Unfortunately, we're overly medicated, we turn to medicine first. I actually turn to medicine last*”.

Although the study focused on investigating the power of recovery cues on emotional and physiological response, many participants shared the importance of relationships and connecting to a support network when experiencing cue-induced distress, noting that a device could encourage a person to connect with others when a natural default would be toward isolation.

**Sensory Cues and Experiences**

Participants shared unique ways of coping using recovery-relevant sensory cues, reinforcing the importance of

tailored assessment. Strategies included music, pictures, and a comforting voice (Table 3). One participant, who continues to experience distress in situations mimicking the original motor vehicle crash, shared that audio inspirational passages from a literary source, a supportive family member’s voice, and particular types of preferred music helps bring the participant back to safety and emotional stability.

**Innovation Insights**

Participants made important content contributions to aid in device development. Some felt that although personalization of the device would be important, offering a library or menu of options might be helpful as a place to start before customization (Table 4). Participant suggestions varied, and included : 1) a person’s own recording of their calming heart beat – when they are most regulated – that could be activated through the device; 2) a buzz or vibration suggesting, “*it's okay to breathe* [and to] *help pull you out of that space*”; 3) smell, call (voice), text, pre-recording, or video of self when coping well; 4) a feature that digitally captures a tactile experience, such as petting a dog, and delivering the sensation through the device, and 5) an in-vivo plan when an experience is disorienting.

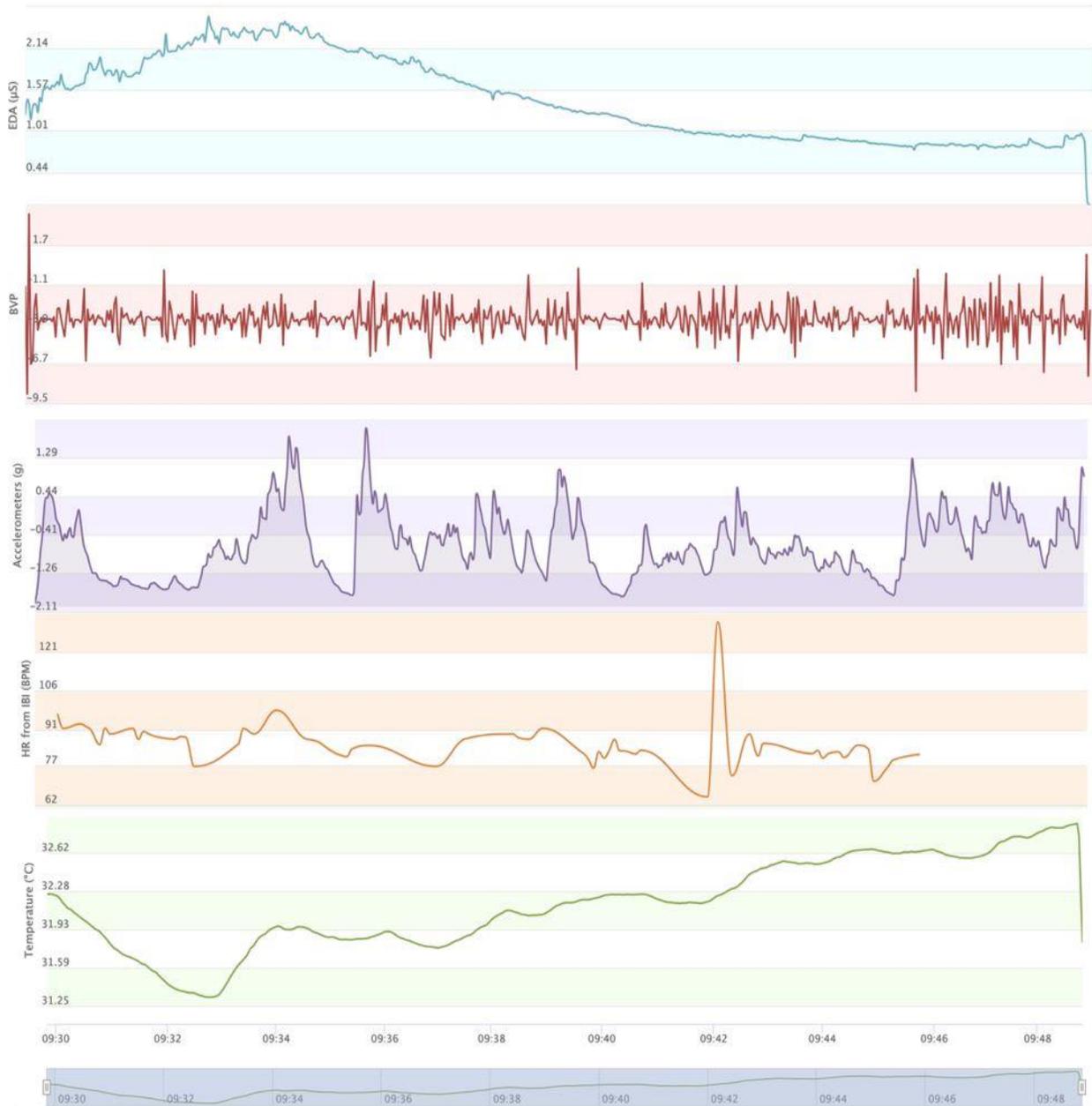
**Physiological Response to Cues**

Our secondary aim was to begin collecting data and examine trends on cue presentation and corresponding physiological response. Participants wore a sensor wristband that acquired real-time physiological data on:

**Table 4. Suggestions for Device Innovation**

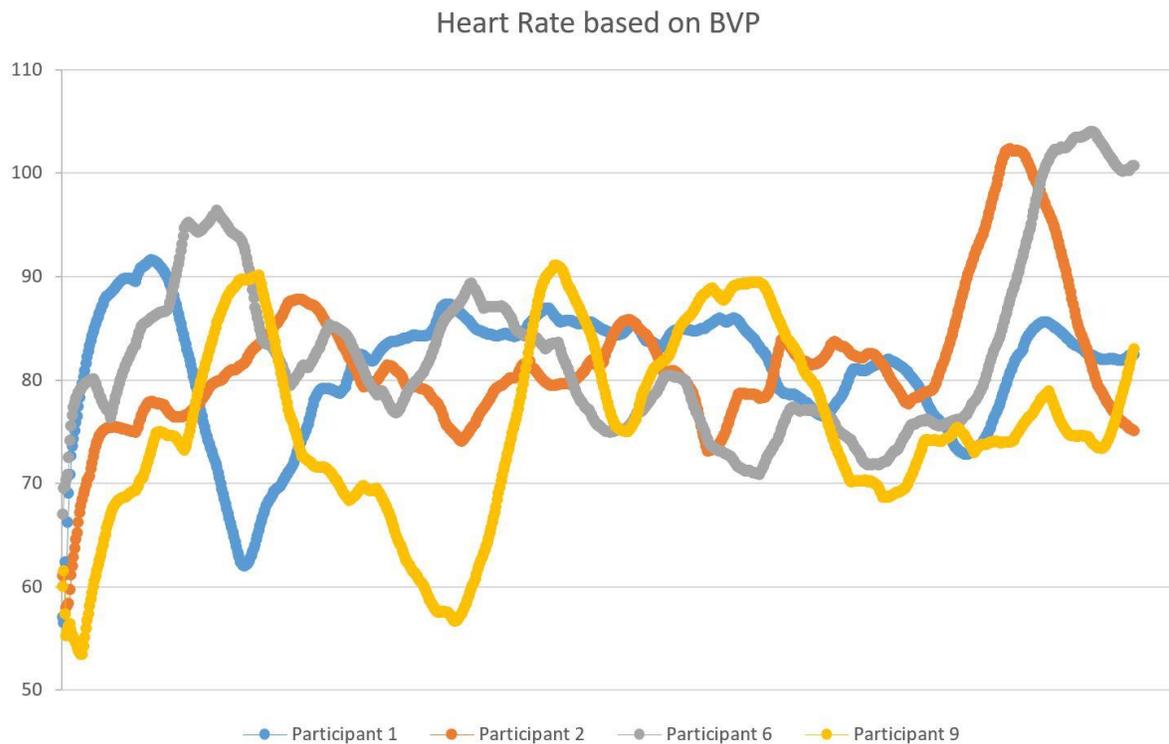
Example quotes of suggestions for innovation
Make it easy to start. Preloaded can be helpful to start [e.g., meditation app], but then the ability to personalize later is good. Having preloaded and own images is important. Building my tool chest in the beginning can be challenging. Even if you can't have it specific to each person at first, maybe having different categories that you can choose from. Like, soothing sounds...
I think if it had the screen, and if the device would alert you, 'you're starting to struggle, you're starting to have a trigger,' and maybe the screen would have a list with your plan ... it might be that quick cue to give you that reminder that this is what you need to do. Because when you're in that moment ... it can be really difficult to think about what you should do.
It would help if they were in a watch or an app or something. It'd be nice if I could access it from my watch. It would be better to be on my body...It's easier if you're wearing it.
I like the idea of having a non-human response to something, because sometimes for trauma survivors, it can be difficult for us to reach out to people because you don't want to burden them.

**Figure 1. Cue Trend Data**



- blood volume pulse (BVP) from which heart rate variability can be derived
- galvanic skin response (GSR) biofeedback which measures constantly fluctuating changes in certain electrical properties of the skin,
- a three-axis accelerometer reading that captures motion-based activity
- peripheral skin temperature

Data output collected for one participant is illustrated below (Figure 1), with data streaming beginning around 9:30am and continuing for about 18 minutes in consultation. The trauma cue presentation occurred three minutes into the session and then 9 minutes from then, the recovery cue presentation started. The trends for this participant seem to suggest that during the initiation of trauma- and recovery cues, there is a change in the heart rate as expected. What was interesting is that the EDA or Electrodermal activity changes along with the trend in the temperature. This was also observed for other participants

**Figure 2. Heart Rate Comparisons**

in the study as well. Each participant started the session at different times and similar data was collected for each participant.

Figure 2 is an illustration of the comparison on heart rate obtained from the BVP for four different participants plotted on the same time scale. The trauma and recovery cues correspond to the different peaks for each participant. This is only preliminary data which provides encouragement to move forward in this area with additional data collection

## Conclusion

Results from participant interviews have informed further development of our mobile sensory support system model in significant ways, giving evidence to the importance of three components, all of which must be included: 1) Recovery cues; 2) Relationships (being able to connect to supportive network); and 3) Regulation (neurophysiological regulation and behavioral risk reduction). Participants suggested that monitoring neurophysiological behavioral risk, activating recovery cues, and helping individuals connect to their relational support network, are all important features that would need to be included in a mobile recovery support system. A signature theme noted among participants was the restoration of control, especially when triggers impacted

functioning unexpectedly. Participants shared how helpless they felt after the trauma and how powerful it is to get some of that control back over their physiological and emotional responses. Participants seemed to value this type of recovery system as an effective supplement to therapy and/or pharmacology or, in some cases, a replacement for those, but that there may need to be other strategies and supports in that tool chest as well.

In future work, we aim to examine the utility of using virtual reality (VR) technology as a method to calibrate patient-specific behavioral risk and recovery-regulation set-points. VR technology can be used to simulate patient-specific trauma cue-triggering experiences that allows for calibration of a personalized neurophysiological reactivity set-point, captured in-session using fNIRS (Functional Near-Infrared Spectroscopy) and physiological sensors (smartwatch Empatica E4) worn during the scenario. In addition, simulation of recovery-regulation experiences using patient-specific virtually-generated supportive relationships, trauma recovery-enhanced environmental conditions, and trauma recovery-associated sensory cues, could allow for the calibration of a recovery-regulated neurophysiological set-point, captured by the same in-session neurophysiological sensor systems. Over time, the device could calibrate a neurophysiological recovery profile based on activation and non-use patterning.

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## Appendix A

### Session 2:

- What is the biggest area of concern or struggle for you, currently?
- How do you currently handle/manage the problems/struggles?
- What training/education/treatment have you had to help you manage your problems/struggles?
- Describe the process of generating your recovery cue intervention (prompts: e.g, what came to mind first, were visual images or audio or something different more important to you? Were people involved? Were special places involved? Were other sensory experiences important in helping you orient to recovery – e.g., textures, colors, etc.?)
- How is the Recovery System intervention (exposure to your recovery cues) we practiced today different/similar to your previous training and/or your typical response to distress or anxiety?
- What potential does this mobile device/recovery system have to improve the wellbeing of those struggling with [name their problem/struggles]?
- How might a device like the one described in this study be used to connect family or other social supports in meaningful ways?
- What would make you likely to use this kind of mobile device/recovery system (what would motivate you)?
- How confident are you that you'll be able to use this recovery system this week?
  - What makes you so confident/lack confidence? What would make you more confident (if low)

### Session 3:

- Did you have a chance to use the recovery system this week? How many times? What prompted your use each time?
- Tell me about the times you used your visual images/audio (how you felt before, which images/audio you used/how long/how you felt afterward).
- [If subject practiced just one time] What would have made you more likely to [use the system] a second or third time?
- [If the subject practiced more than once] What made you [use the system] a second (or third, etc) time?
- What potential does this mobile device/recovery system have to improve the wellbeing of those struggling with [name their problem/struggles]?
- How confident are you that you'll be able to use this recovery system in the future?
  - What makes you so confident/lack confidence? What would make you more confident (if low)