

A Patient-Centered Research Agenda for Improving Moderate to Severe Traumatic Brain Injury  
Healthcare and Wellbeing Across the Lifespan

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## **Acknowledgements**

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This material is based upon work supported through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (#39908-UCD). The opinions, interpretations, and conclusions presented in this work are solely the responsibility of the authors and do not necessarily represent the views of the PCORI and are not necessarily endorsed by Department of Veterans Affairs.

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## Introduction

With over 5 million Americans living with traumatic brain injury (TBI)-related disability, TBI represents a major public health issue.<sup>1</sup> Conservative estimates suggest that, annually, 2.5 million TBIs occur in the United States.<sup>2</sup> Every year, approximately 116,000 individuals over the age of 15 are discharged from a hospital after sustaining a moderate to severe TBI.<sup>3</sup> Individuals with a history of moderate to severe TBI often live with chronic cognitive, sensory, and physical impairments. Moreover, findings suggest that those living with a history of moderate to severe TBI have decreased participation in all areas of life.<sup>4</sup> As such, it is not surprising that members of this cohort have not been sufficiently involved in the process of identifying TBI-related research priorities.

Until fairly recently (e.g., following implementation of the 911 call system, advances in critical care medicine) those with more severe injuries did not live after sustaining the injury. As the first cohorts of those who survived such injuries age, TBI is now being re-conceptualized as a chronic condition. Chronic TBI carries with it life-long health implications for those living with a history of injury, as well as their caregivers. In specific, research suggests that TBI outcomes change dynamically over the lifespan post-injury.<sup>5</sup> In particular, function and quality of life (QOL) can decline over time, as a result of progressive neurodegeneration, comorbid physical and mental health conditions, aging, and psychosocial challenges.<sup>5</sup> Secondary health conditions can arise such as pain, fatigue, obesity, isolation, and depression.<sup>6</sup> Over the course of a lifetime, secondary conditions can also negatively impact function and participation in daily activities, as well as increase dependence on others, and decrease QOL.<sup>7</sup> Acknowledging TBI as a chronic health condition also highlights the need to identify evidence-based strategies to facilitate lifelong management of associated symptoms.<sup>5</sup>

In a metasynthesis of qualitative studies, Levack, Kayes, and Fadyl identified seven recurring themes which characterize the experiences of those living with a history of TBI: “1) mind/body disconnect; 2) disconnect with pre-injury identity; 3) social disconnect; 4) emotional sequelae; 5) internal and external resources; 6) reconstruction of self-identity; 7) reconstruction of a place in the world; 8) reconstruction of personhood.”<sup>8</sup> Further, in a study by Brenner (Co-Investigator) and colleagues, TBI survivors identified loss of sense of self, cognitive impairment, and emotional and psychiatric disturbances as critical risk factors for suicide post-TBI. On the other hand, participants also noted the following protective factors, which supported the mental and emotional wellbeing of individuals living with TBI: social support, sense of purpose, religion/spirituality, and access to mental health treatment.<sup>9</sup> From a patient-centered perspective, social wellbeing following a TBI is primarily dependent on making friends and a sense of being acknowledged.<sup>10</sup> However, research-based community integration efforts emphasize independent living and return to work post-injury, both of which can lead to increased isolation and social fatigue from the perspective of individuals living with TBI-related social and cognitive impairment.<sup>10</sup>

Research is needed to identify effective interventions for supporting the long-term outcomes of TBI survivors as defined by those living with the injuries and their families. The need to identify effective interventions for supporting the long-term outcomes of TBI survivors as defined by those living with the injuries and their families is the focus of The Coalition for Recovery and Innovation in Traumatic Brain Injury Care Across the Lifespan (CRITICAL). The CRITICAL brought together patients with TBI and their caregivers with clinicians, researchers, and advocates to collaborate regarding TBI-focused research. CRITICAL members were tasked

with developing a patient-centered national research agenda to improve moderate to severe TBI care across the lifespan. This paper presents the research agenda developed by the CRITICAL.

## **Method**

### **Participants**

Eight TBI survivors and caregivers, including three men and three women living with a moderate to severe traumatic brain injury and two women who are caregivers of severe TBI survivors, were recruited via recommendations from TBI clinicians, researchers, and advocates. A Co-Investigator of the study conducted telephone screening interviews with survivors and caregivers to make sure they met the following criteria proposed by Hibbard et al<sup>11</sup>: (1) a willingness to volunteer time and energy needed for the workshops and between meeting assignments; (2) a motivation to “help others” and “give back something”; (3) successful personal adjustment to the challenges of living with a TBI; (4) adequate insight into personal limitations and strengths; (5) an absence of current serious psychiatric problems; (6) an ability to listen; and (7) an ability to inhibit personal responses and views or opinions when necessary. Eight TBI professionals (five women and three men) were recruited through existing partnerships with the US Veterans Health Administration (VHA), TBI Model Systems programs, American Psychological Association Division 22 Rehabilitation Psychology, the Brain Injury Program at Craig Hospital, the Colorado Brain Injury Program, and the Brain Injury Alliance of Colorado. They were recruited based on their ability to link the coalition’s discussions and results to national TBI research, education, and clinical care networks. Six of the CRITICAL members were from outside Colorado and 10 were from the local Colorado region.

### **Materials and Procedure**

The CRITICAL followed three steps to develop the research agenda: 1) question development, 2) question prioritization, and 3) agenda setting.

**Question development.** Question development began with a two-day, in-person workshop attended by the stakeholders and research team members. TBI survivors and caregivers were asked to provide input on their experiences, interests, and priorities related to long-term TBI recovery and care through large group discussion and by pairing up with TBI professionals in a reflective listening exercise. We modeled the workshop agenda and discussion questions after the search conference method of participatory decision making and planning.<sup>12</sup> We modified the search conference methods to be more focused on our specific topic of TBI and support individuals with cognitive impairments. As with search conferences, we started our discussion very broad and narrowed in to identify specific gaps and needs in patient-centered outcomes research to support TBI survivors across the lifespan post-injury. Our discussion questions and phases of the workshop are detailed below in Table 1. During the workshop we took extensive notes, which we compiled and analyzed using qualitative descriptive coding.<sup>13,14</sup> Through descriptive coding, we identified several themes from responses within each discussion question.

We then transformed the raw notes into descriptive meeting notes organized by the themes we identified and sent them out as an online survey in REDCap. CRITICAL members rated how accurately the themes reflected what was said in the workshop, how accurately the themes reflected their own beliefs, and the level of importance each theme had for TBI research and care. A slider scale was used for questions and endpoints for the two questions addressing accuracy were “not at all accurate” and “very accurate.” Endpoints for the question addressing importance in research and care were “not at all important” and “very important.” We also held

phone calls with each of the TBI survivors and caregivers following the workshop in order to gather additional qualitative information from partners about their experience at the workshop.

We analyzed data from the online survey and phone calls were analyzed and identified five themes that emerged as most important. Subsequently, we conducted preliminary literature reviews on each of the five themes. For this literature review we conducted a review of published systematic reviews and clinical guidelines. These thematic literature reviews are presented below in the results section.

**Question prioritization.** The CRITICAL then met approximately four and a half months following the first workshop for a second day-long workshop (five hours, followed by a social gathering). At this workshop, we introduced stakeholders to the Problems, Interventions, Comparators, and Outcomes (PICO) formulation for defining an answerable research question. We also reviewed with stakeholder the results from the online survey, phone interviews, and preliminary literature reviews.

Following this set-up and review, we conducted a Nominal Group Technique (NGT) process.<sup>15</sup> First, we created breakout groups of four CRITICAL members in each group. The groups were asked to brainstorm and develop questions and topics related to one of the five themes—with each group assigned one theme. Because we had five themes and participants for four groups, we combined the QOL of Caregiver and Identity of Caregiver themes into one discussion group. Each discussion group then shared the research questions and topics they came up. We recorded the research questions and topics on flip charts under their respective themes. We then provided 10 stickers to each CRITICAL member and asked the members to place their dots on those research questions and topics they felt were most important. Stakeholders were allowed to use up to three dots on a single research question.

Following the workshop, the research team reviewed the proposed questions and topics and transformed them into 26 answerable research questions/aims. Two online surveys were then developed (one for TBI survivors and caregivers and one for TBI professionals) to further prioritize the answerable research questions. We included only research questions and topics that received greater than three votes during the NGT exercise at workshop two. The patient partner survey asked respondents to rank questions and aims on a five-point Likert scale for the following questions: *1) How important is this question/aim to you? 2) How much do you think answering this question/aim will improve your health or well-being? 3) How relevant is this question/aim to the health care of individuals living with TBI? 4) How relevant is this question/aim to caregivers' engagement in the health care of individuals living with TBI?* TBI professionals were asked to rank the questions and aims on a five-point Likert scale for the following questions: *1) How clinically important is this question/aim? 2) To what extent does this question/aim represent a new or emerging area of TBI research? 3) To what extent could research into this topic address an important evidence gap? 4) What is the likelihood of relevant findings on this topic being implemented into practice?*

**Agenda setting.** At the third and final in-person workshop, which was held six months after the second workshop, the CRITICAL identified a consensus on the research agenda priorities and structure. We facilitated the discussion following a consensus decision making method, employing seven basic steps: introduction, clarifying questions, discussion, establish basic direction, synthesize or modify proposal, call for consensus, and record.<sup>16</sup> We held small group discussions via teleconference prior to the meeting to review results of the research agenda and ensure all CRITICAL members regardless of cognitive impairment had read and understood the survey results. To start the workshop, we first reviewed the project to date and results of the



online survey (*introduction*). We then asked participants to share their thoughts and reactions with the group (*clarifying questions*). Third, we had breakout group discussions (*discussion*), with the following discussion questions for groups: *Do the results reflect what is most important to you? Where do you think the results are correct and where are they incorrect? What questions do the results raise?* Fourth, we facilitated a discussion where each group shared the discussion they had and the group developed a general direction for the content of the research agenda (*establish basic direction*). During this phase, the CRITICAL members began to coalesce around three priority research areas. Fifth, we reviewed a proposed structure for the research agenda incorporating the three priority topic areas (*synthesize or modify proposal*). Sixth, we called for consensus first on the structure of the research agenda and then on the three priority research areas to include (*call for consensus*). Finally, we recorded these decisions on and discussion on flips charts, compiled all notes post-workshop, and developed official meeting minutes detailing the CRITICAL decisions (*record*).

## **Results**

### **Topic Development**

Results of the descriptive coding of notes from the first workshop led the research team identify seven discussion questions, which generated the richest and most relevant responses for research agenda shaping (see Table 2). There were 28 total themes identified across the seven discussion questions. For example, one discussion question was “What is the state of the world for people with TBI and other disabilities?” Some themes that arose from the discussion were “it is isolating,” “it is stressful,” “identity matters,” and “caregivers face tremendous responsibility.” Though the research team selected only half of the discussion questions for in depth analysis,

there was significant overlap between responses from the selected questions and responses from the non-selected questions.

The research team met to discuss the 28 themes and arrive at a consensus on and define five broad thematic categories that encompassed a majority of content. The five thematic categories were: social/engagement, quality of life of survivor, identity of survivor, quality of life of caregiver, and identity of caregiver.

**Social/engagement.** Loneliness is well documented in the literature as having negative effects on mental health and a variety of chronic conditions.<sup>17,18</sup> Social functioning (including functional status, employment, and relationships) is negatively affected following moderate to severe traumatic brain injury.<sup>19</sup> Strong social support for TBI survivors is related to increased well-being.<sup>20</sup> A study on public perceptions of TBI revealed that the public endorses many misconceptions and negative attitudes about TBI.<sup>21</sup> These misconceptions further exacerbate isolation for TBI survivors. Several articles were found regarding interventions for participation, loneliness, and related factors. Proposed interventions found in the literature include multidisciplinary rehabilitation programs, peer support, videoconferencing/telehealth, metacognitive strategy training and psychoeducation.<sup>17,22-25</sup> The possibility of successful interventions in decreasing things like loneliness and isolation while increasing things like participation post-injury are promising in the context of long-term recovery and rehabilitation. All articles conclude with saying some or all of the following; that the evidence for interventions is limited and that well-designed studies with comparable and clear outcomes are needed.

**QOL of survivors.** A 1998 systematic review found a major issue with the way studies attempted to define QOL and which domains were included.<sup>26</sup> A systematic review on how health-related quality of life (HRQL) is measured found large variation in its measurement but

overall found that HRQL decreased after injury with deficits persisting long-term (especially in physical, social, and emotional domains).<sup>27</sup> The authors note that a TBI specific health-related QOL measure (the QOLIBRI) developed in 2010 appears to be a promising measure.<sup>27</sup> Stocchetti and Zanier<sup>28</sup> confirm similar findings in QOL post-injury, with mental health, emotions, and social functioning showing particular declines. Certain measures are less accurate or sensitive for severe TBI so caution should be exercised when using HRQL measures to assess this population. Use of the SF-36 in conjunction with a TBI-specific measure like the QOLIBRI is suggested.<sup>27</sup> An additional suggestion is that more research focus on long-term outcomes and also note the importance of decreasing tissue damage post injury which poses multiple problems long-term following injury.<sup>28</sup>

**Identity of survivors.** Two reviews found that there is a loss of or negative impact on self-identity post-injury.<sup>29,30</sup> Some studies found positive changes in self-concept post-injury like increased perceived maturity and appreciation.<sup>30</sup> Return to work (RTW) also contributes to identity and while a large discrepancy exists between RTW rates found in the literature, RTW is difficult post-injury with self-awareness and severity of injury playing a large role in RTW.<sup>31</sup> Bryson-Campbell et al<sup>29</sup> emphasize the importance of redeveloping self-identity following injury which can be facilitated in part by having strong support networks, allowing time to grieve and cope after injury, redeveloping community roles, and the use of Acceptance and Commitment Therapy which is a therapy that utilizes CBT. Improving RTW suggestions include rehabilitation which addresses increasing self-awareness, motivation, and includes supported employment. A need exists for research to be conducted specifically on occupational identity loss post-injury and on practical solutions for the redevelopment of identity post-injury. Other research needs in this

area are consistent self-identity measurement (10 different measures were used in their analysis of 15 studies) in addition to prospective longitudinal studies.<sup>30</sup>

**QOL and identity of caregivers.** A scoping systematic review found 62 studies specific to TBI caregivers with 51 of those reporting negative outcomes and 11 reporting positive outcomes.<sup>32</sup> High caregiver burden, poor family functioning, and poor mental health/high emotional distress were the top 3 factors associated with negative caregiving outcomes. Qadeer et al<sup>33</sup> found similar trends (specifying anxiety and depression for mental health problems) and found that lack of caregiver personal time is a main complaint. Baker et al<sup>32</sup> reviewed 21 interventions, finding that interventions targeting the caregiver directly were found to be more effective than those targeting the care receiver. Common principles of the interventions included education, empowerment, peer mentoring and peer support. All 11 studies showed caregiver improvement on one or more outcomes right after the intervention. Social support was cited by both papers as key to lessening the effects of caregiver burden and improving outcomes. Caregivers are an important part of the recovery process and their wellbeing is crucial to positive recovery outcomes and to the relationship between caregiver and care receiver. Problem-solving training for caregivers is a promising area deserving of more research<sup>32,33</sup> as well as more focus on positive caregiver outcomes.<sup>32</sup>

### **Question Development**

Out of the discussion of the five thematic categories, CRITICAL members identified and prioritized 26 research topics with three or more votes during the NGT exercise, which were then further narrowed down through an online survey. A full list of research topics and questions can be found on the CRITICAL website:

<http://www.ucdenver.edu/academics/colleges/medicalschoo/department/pmr/Research/Pages/CRITICAL.aspx>.

### **Question Prioritization**

Table 3 shows those research topics and their associated answerable questions that were prioritized in the final online survey as the top ten by TBI professionals, TBI survivors and caregivers, or both. Figures 1 and 2 show the top 10 research priorities for each group (top 11 for TBI survivors and caregivers due to a tie) along with their summary scores. The scores were calculated by summing responses of the 8 respondents in each group for each of the 4 questions (e.g. How relevant is this question/aim to the health care of individuals living with TBI?) and converting the sums to a 100-point scale. Scores were then averaged across the four questions to get a final summary score. Figures 1 and 2 show that overall, TBI survivors and caregivers rated all questions as higher than TBI professionals (20 was the lowest possible score and 100 was the highest possible). Four questions/aims were in the top 10 for both groups: 1) Can interventions focused on increasing relationship stability support those with a history of moderate to severe TBI reestablish their post-injury identity? 2) How can “thriving” be developed at a patient centered outcome for those living with a history of moderate to severe TBI? 3) Can sensitive and specific QOL-related outcomes be developed for moderate to severe TBI survivors at different stages of rehabilitation? 4) What services can improve the QOL of individuals who care for survivors of moderate to severe TBI?

Several discrepancies arose between groups. One discrepancy that stood out to TBI survivors and caregivers was that secondary health conditions was not among the top 10 ranked for TBI professionals. A discussion was held at the 3<sup>rd</sup> workshop to address this. At least one of the major reasons for discrepancies like this was how the questions were framed differently for

each group. For example, TBI professionals were asked to rank topics regarding evidence gaps and the degree to which they addressed an emerging area of TBI research. On the other hand, TBI survivors and caregivers were asked to rank topics on how much a topic would improve their health and how relevant it is to the healthcare of those living with TBI. When taking the secondary health conditions question into account, TBI professionals explained that significant research already exists on the topic and that, therefore, it is not an emerging area of research despite being clearly important to the long-term health of TBI survivors.

During the final consensus workshop, the discussion of the prioritized research areas revealed a pattern. Numerous prioritized topics were highly related to each other. For example, social communication interventions and relationship stability were identified as ultimately the same topic—how support social and relationship quality for TBI survivors. Likewise daily respite and services for caregivers were grouped as addressing the same need—identifying needs of caregivers and developing services to support them. Through the consensus decision making process, the CRITICAL agreed to reframe the research agenda into three priority topic areas: Relationship Quality, Caregiver Needs, and Thriving. The final recommendations of the CRITICAL are provided below in the presentation and discussion of the research agenda.

## **Research Agenda**

### **Relationship Quality**

Partners agreed that relationships broadly are of foundational importance to the long-term health and recovery of TBI survivors and caregivers alike. Building off the groups' earlier prioritization of identifying effective interventions to promote relationship stability as one of the most important research questions, the CRITICAL members clarified and expanded this priority area during the consensus discussion. **Members agreed that the priority need is for research**

**to develop and compare interventions to improve long-term relationships quality for TBI survivors and caregivers.**

Although physical impairments can improve quickly after injury, challenges with cognitive and psychosocial functioning may persist for years.<sup>34</sup> These impairments often negatively impact relationships.<sup>35,36</sup> Challenges in relationships and social functioning are often cited by TBI survivors as the most significant long-term challenge they face and are related to diminished emotional and psychological wellbeing.<sup>37</sup> Relationships are crucial for TBI survivors as they can increase participation in home or community activities, promote better self-care, and are associated with adaptive emotional functioning.<sup>35,38,39</sup> However, measurement of relationships as an outcome is limited and frequently focuses on marital stability. Instead, **CRITICAL members emphasized the importance of relationship quality and consideration of the diverse types of relationships in one's life** ranging from casual acquaintances to intimate person relationships.

CRITICAL members agreed that stable relationships don't necessarily equate to good relationships. Therefore, they agree that relationship quality more broadly is central to the health and quality of life of TBI survivors. **Relationship quality includes the ability to have meaningful conversations, reciprocal empathy, fun/social connectedness, belongingness, and social capital.** CRITICAL members acknowledged that friends may naturally come and go, so the ability to maintain positive relationships includes the ability to be flexible and adjust as one's life, friends, and other circumstances change.

**Research should consider the impact of all types of relationships—that is, romantic partnerships and marriage, family, friends, and co-workers.** Friendships should not be limited only to close friends that can empathize and provide emotional support, but also include

friendships that provide primarily a social outlet for having fun without needing deeper friendship (e.g., friends you go out with to watch a game, but would not be the first person you would call in a time of distress). Of these relationships, the relationship with one's primary caregiver is of particular importance and impacts the wellbeing of both the TBI survivor and the caregiver. Therefore, research into relationship quality should assess the impact of interventions on the health and wellbeing of both survivor and caregiver.

**Challenges with social skills post TBI is the central issue and barrier to relationship stability, formation, and maintenance.**<sup>36</sup> Social functioning is central to formation and maintenance of meaningful relationships, and is negatively impacted by a number of cognitive and physical limitations that can be caused by TBI.<sup>37</sup> Of the interventions hypothesized to improve social functioning and relationship stability, training in social and communication skills are the most studied. Other interventions hypothesized to improve social functioning and relationships include relationship skills training, self-regulation training, peer mentoring, mental health treatment, and technology.<sup>37</sup> Over the course of the CRITICAL project, members discussed all of these potential interventions, but emphasized social skills training for survivors and teaching family and friends about TBI survivors' social skills and communication styles. Educating friends and family reduces the burden for survivors and contributes to an environment of understanding between the survivor and those they interact with. Additionally, CRITICAL members recommended considering the potential benefit of technological solutions, such as friend finder apps and meet ups for facilitation of social interaction and fostering community.

**Relationships are critical to wellbeing, thriving, and long-term health and quality of life for TBI survivors and their caregivers.** During the final consensus workshop, CRITICAL members strongly agreed that all three of the priority research areas are closely interlinked.



Relationship quality is central to supporting caregivers and TBI survivors alike, and essential to any conceptualization and measurement of thriving or wellbeing. Given the existing state of knowledge on the link between post TBI relationships and survivor and caregiver quality of life, the final recommendation of CRITICAL is for an increase in comparative effectiveness research of interventions to improve social skills, family and friends' communication training and education, and technology for establishing post-TBI relationships. Secondly, CRITICAL recommends that relationship quality be defined broadly to include formation and maintenance of all types of relationships.

### **Caregiver Needs**

Throughout the CRITICAL process, the group identified caregiver needs as important to address. Initially, this was broken into two buckets—caregiver quality of life and caregiver identity. During the question prioritization stage, both patient and TBI professionals prioritized the question, “What services can improve the quality of life (QOL) of individuals who care for survivors of moderate to severe TBI?” Likewise, patient and TBI professionals identified other caregiver research questions as important. These other questions, such as developing a daily respite program, were more specific instances of the broader question on services to support caregiver QOL. Therefore, at the final consensus meeting, CRITICAL members agreed that there is a broad need for more research into the health and wellbeing of TBI caregivers. **The primary research need with respect to caregivers is the development of theory and testable models to guide future research into interventions for improving caregiver wellbeing.**

QOL for caregivers of individuals with TBI is significantly impacted due to changes in responsibility loads which lead to loss of personal time<sup>40</sup> and unmet needs.<sup>41</sup> Although there are unmet needs for caregivers, very few studies evaluate services provided for TBI carers.<sup>42</sup>

Caregivers may experience barriers to services and express need for more information.<sup>43,44</sup> A study on caregivers of individuals with TBIs found that providing them with trainings on navigating the health system decreased their depression symptoms.<sup>45</sup> However, caregiver distress and burden may continue years post-injury supporting the need to evaluate long term services.<sup>46</sup>

CRITICAL TBI professionals, in particular those professionally involved in TBI research, emphasized that there is very little extant research on the long-term needs of TBI caregivers, the impact of caregiving, and the reciprocal relationship between caregiver and survivor wellbeing on each other's health. Findings from a few studies suggest that lack of free time and hours spent caregiving are major components to caregiver QOL and unmet needs.<sup>40,47,48</sup> Decreasing the number of informal care hours through a combination of providing in-home respite, services, and daily assistance may have a positive impact.<sup>49,50</sup> However, services may need to be individualized due to the high variability in unmet needs for caregivers.<sup>41</sup> The limited, yet emerging knowledge on caregiver needs only further emphasizes the conclusions of CRITICAL. Namely, **research is needed across all stages—from theory to intervention testing—if we are to identify effective supports and services for caregivers.**

There is a tendency to think of caregivers homogenously, but **CRITICAL members emphasized that there are many different kinds of caregivers, with different needs.** Research will need to conceptualize caregiver needs in a person-centered fashion that emphasizes and accounts for variability in needs. Caregiver role definition and role change or reassignment post injury should be investigated, and testable theories developed on the psychological process and health impacts of role definition and change. Caregiver research will need to consider the impact of the personality of the caregiver, including their response to the caregiver role.

The most common way of thinking about caregivers is as part of the nuclear family of the survivor, such as the spouse or parents providing support. However, **research will need to expand the definition of caregiver to include other types of caregivers like friends of the survivor, the multiple roles caregivers maintain beyond being a caregiver, and the ecological context of caregiving.** Caregivers also include those who support TBI survivors that don't need a constant caregiver. Therefore, caregiving in research should refer broadly to those who provide caring and support long-term post injury, to varying degrees. Furthermore, caregivers need to be regarded not just as caregivers, but acknowledged as having other roles and associated needs—for example, research will need to take into account spouse needs separate from their caregiver role. Finally, we will need other ways of thinking about caregiver environment to include the role of individual context, a social-ecological conceptualization of caregiving, and cultural environment.

One important area to include in caregiver research is the role of networking on wellbeing. In particular, CRITICAL caregiver members discussed the role of connecting with other caregivers that “get it,” in addition to having individuals in their social network that can provide companionship and fun without needing to be intimately familiar with what it's like to be a caregiver. Therefore, **research should investigate how social connection with peers – both counterpart caregivers and non-caregivers - supports caregiver wellbeing.**

**Basic health and psychological research on caregiving is needed in addition to services to improve caregiver wellbeing and caregiving ability.** Other areas of disability research that are further along in studying caregiving may provide guidance on theory development and effective programs. Current research lacks a clear articulation of how

caregiving impacts TBI survivors and caregivers alike. Development of theory is necessary to develop testable models, specify measures, and develop interventions.

## **Thriving**

Whereas CRITICAL members agreed that relationship quality and caregiver needs are clear priorities, the research priority for thriving is more of a challenge in that **we need to find a new language, which will thereby shift both how we talk about long-term TBI outcomes and how we measure and assess interventions.** The problem inherent in the concept of thriving is lack of clarity as to how an individual may define thriving. This problem is highlighted by an unresolvable disagreement that occurred while discussing the topic. Some of the CRITICAL members argued that they are not thriving and could never define their life as thriving anymore because of the injury. On the other hand, some argued that given their injury they feel like they are thriving. In either case, each individual referenced the injury to demonstrate that they are or are not thriving—some as a before and after comparison, others as to show how far they have come and continue to grow post-injury.

Brown et al<sup>51</sup> note the absence in consensus on the definition of thriving. And although there have been attempts to define and measure thriving, CRITICAL members agreed that it is easier to agree on negative outcomes than on positive ones. **As one member stated, “We can all agree what is a poor outcome, but we have completely different ideas of how to define the positive outcomes like thriving.”** The clinical providers emphasized that terms like thriving have historically existed due to the need for some metric to assess how well their services are working. Interventions and TBI support programs often use the term “thriving,” or are required to demonstrate how they improve thriving. The goal of measuring thriving is to find a way to evaluate service on positive gains not just deficit reduction.

**The CRITICAL, therefore, calls for a shift in thinking, and asks of researchers and providers to reconsider whether the popular concept of thriving is even the correct term.**

We were unable to find a singular definition that we feel there could be consensus on. As such, thriving, or its replacement, must be based on individual and person-centered orientation.

Because we each have different definitions of what is a positive outcome or goal in life, we must likewise assess each individual's progress towards a personally meaningful positive outcome.

The metric must likewise be applicable to anyone, and not be specific to TBI. Lastly, it is not an end-state, but is a quality that ebbs and flows over time—depending on what is occurring in one's life it may be up or down at any given moment. As such, it is one options that meets some of CRITICAL's priorities for an outcomes.

One CRITICAL member asked everyone to consider the Flourishing Scale as a substitute for how we have been talking about thriving. This scale measures self-perceived success in important areas such as relationships, self-esteem, purpose, and optimism.<sup>52</sup> The flourishing scale is relational in that relationships and social connections are applicable to anyone, and they are not TBI or health condition specific. Some other terms the members suggested instead of thriving include success, resilience, wellbeing, and person-centered meaningfulness.

Yet, even more fundamentally, **the CRITICAL members agreed that the primary research priority is developing a new conceptual model for the long-term wellbeing of TBI survivors.** Beyond terms and measures, we need to better understand how health and wellbeing interact across caregivers and survivors. That is, research on caregiver needs is an intimate part of post-TBI thriving. So too, relationship quality is a critical element of thriving. The importance of the concept of thriving, therefore, is the emphasis on pushing the research agenda beyond just

symptom reduction and focusing on positives. **Thriving, or the topic formerly known as thriving, remains a priority for the future of TBI research in order to:**

- 1) understand the reciprocal linkages between survivor and caregiver wellbeing;**
- 2) understand how improved relationship quality leads to a sense of thriving; and**
- 3) ensure that patient-centered research on TBI create and/or use measures of person-centered outcomes of wellbeing, not just deficit reduction.**

### **Conclusion**

The CRITICAL's research agenda orients towards three high priority research areas, each with different stages of requisite research. Within the area of relationship quality, research is needed to identify the most effective intervention strategies, including expanding the measurement of relationship outcomes and conducting comparative effectiveness studies of existing or in-development interventions. For caregiver needs, on the other hand, substantial conceptual work is needed alongside intervention development. There is a substantial dearth of theory and research on TBI caregiving; therefore, researchers should focus on theory development and formative and qualitative research to map needs. Lastly, the CRITICAL began to discuss thriving as the "topic formerly known as thriving" in recognition of a primary need to develop a new model for measuring and talking about long-term wellbeing among TBI survivors. A central facet of the thriving research needs is the development of new outcomes measures or more frequent use of existing measures such as the flourishing scale that are person centered.

The CRITICAL research agenda stresses the interrelated aspects of the three topic areas, with advancement in each are impacting the other. Improvement in relationship quality of TBI survivors will simultaneously result in addressing some needs of caregivers and promote thriving or flourishing for TBI survivors. Improved definition and measurement of thriving or a related

outcome, will provide a means of assessing the impact of relationship quality and the ability to meet caregiver needs on TBI survivor wellbeing. And the ability to better meet the needs of caregivers will support improved relationship quality between caregivers and TBI survivors as well as promote thriving among TBI survivors.

The CRITICAL formed and met over the course of two years, 2017-2018, bringing together TBI survivors, caregivers, and professionals to identify a new research agenda. The focus of the CRITICAL's work and research agenda is on identifying patient-centered research priorities to improve the long-term health and wellbeing of TBI survivors and caregivers. This focus on long-term is specific to address a gap in the literature on patient-centered needs across the lifespan post-acute rehabilitation. That is, in recognition of TBI as a chronic condition with lifetime consequences, the CRITICAL developed an agenda to specify the long-term Patient Centered Outcomes Research needs of TBI survivor and caregivers. The work of the CRITICAL provides a road map for future researchers to identify new and emerging areas of clinical research to improve the health and wellbeing of both TBI survivors and caregivers.

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**Table 1.** Workshop 1 Discussion Questions

Workshop Phase	Discussion Method	Discussion Questions
Learning About Our World	Large group	<ul style="list-style-type: none"> <li>• What is state of the world for people with TBI and other disabilities?</li> <li>• What important changes do you see happening around you?</li> <li>• Where do we see the world heading?</li> </ul>
	Discussion Pairs	<ul style="list-style-type: none"> <li>• What is the <i>desirable</i> future world for people with TBI?</li> <li>• What do you want to see in the world for people with TBI?</li> </ul>
Learning About Our System	Large Group	<ul style="list-style-type: none"> <li>• What are the contextual factors that impact TBI survivors?</li> <li>• What exists for acute TBI care?</li> <li>• What exists for TBI rehab?</li> <li>• What exists for long-term TBI care (“the rest of your life”)?</li> </ul>
Learning About Research Needs	Large Group	<ul style="list-style-type: none"> <li>• What are priority areas for research and care?</li> <li>• Where have we not focused enough resources?</li> <li>• What are the most important patient-centered outcomes that we need to focus future research on?</li> </ul>
	Discussion pairs	<ul style="list-style-type: none"> <li>• The most <i>achievable</i> future (2-5 years) of our system for TBI survivors and caregivers?</li> <li>• What TBI patient-centered outcomes are most important to improve the system of support for?</li> </ul>

**Table 2.** Identified Themes from Workshop 1

Discussion Question	Theme
What is the state of the world for people with TBI and other disabilities?	It is isolating
	It is stressful
	Money matters
	Identity matters
	Health care needs to be improved
What important changes do you see happening around you?	Caregivers face tremendous responsibility
	Discrimination and individualism on the rise
Where do you see the world heading?	Technology is a helpful aid but also poses challenges
	More information and technology
What is the desirable future world for people with TBI?	Polarization of attitudes
	Improvements in institutions
	Change in attitudes and a continued sense of hope
	Improvements in dissemination of knowledge
	Improvements in medicine
What is the achievable future world for people with TBI?	Improved quality of life and inclusion
	A healthier environment
	Improved institutions and policies
	Improved dissemination of knowledge
	Improved technology
What's missing?	Personal and interpersonal improvements
	Improvements in medicine and medical community
	Dissemination of knowledge
	There is much room for medicine and health to be
What are priority areas for research and care?	Social capital and social connections
	Purpose
	Social/engagement
	Identity and quality of life for survivor
	Identity and quality of life for caregiver

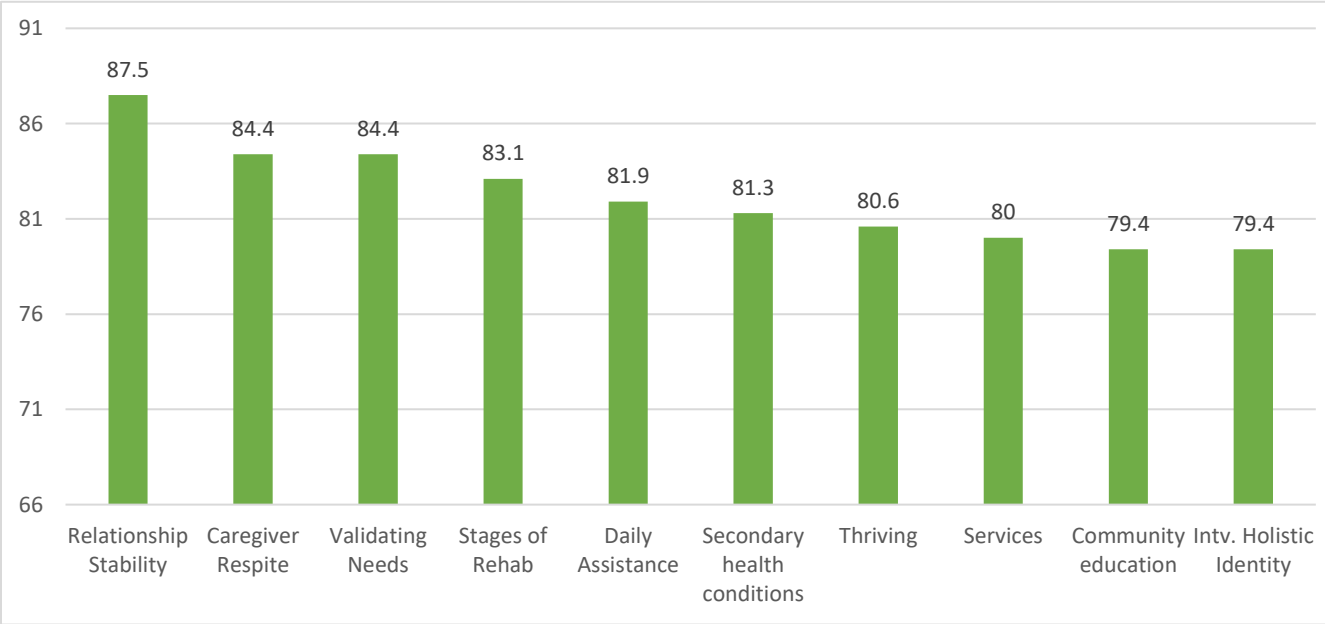


**Table 3.** Codes and Transformed Answerable Research Questions/Aims of Top Questions from Workshop 2

<b>Code</b>	<b>Question from Workshop 2</b>	<b>Transformed Answerable Research Questions/Aims</b>	<b>Ranked as Top 10 By</b>
Cue social skills	Teach family and friends to cue social skills	Can teaching family and friends to cue social skills improve social engagement among those with a history of moderate to severe TBI?	TBI professionals
Social comm. intv.	Does participating in a social communication intervention increase social engagement among those with a history of moderate to severe TBI?		TBI professionals
Relationship stability	relationship stability	Can interventions focused on increasing relationship stability support those with a history of moderate to severe TBI reestablish their post-injury identity?	Both
Peer support – ID surv.	identify alternative methods for peer support—beyond support groups and peer mentoring	Research Aim: To identify more effective methods of peer support	TBI professionals
Tech solutions – soc. eng.	using technology to facilitate social engagement	Can technological solutions (e.g., phone-based applications) be used to facilitate social engagement among those with a history of moderate to severe TBI?	TBI professionals
Daily assistance	more help and respite (caregiver centered)	What types of daily assistance are the most beneficial to the QOL of individuals who care for survivors of moderate to severe TBI?	TBI survivors and caregivers
Services	services available for caregivers (e.g., yoga)	What services can improve the QOL of individuals who care for survivors of moderate to severe TBI?	Both
Peer support - ID careg.	alternate methods for peer support - are there other/new models?	What alternate methods of peer support, other than peer groups and peer mentoring, are beneficial to caregivers?	TBI professionals
Wellness programs	services available for caregivers (e.g., yoga)	What can wellness programs (such as, exercise, yoga, mediation) improve the QOL for caregivers of those living with moderate to severe TBI?	TBI professionals
Caregiver respite	more help and respite (caregiver centered)	What is the impact of caregiver respite on QOL?	Patient Partners
Validating needs	explicitly listening to and validating caregiver	How does explicitly listening to and validating caregiver needs impact caregiver identity?	Patient Partners
Thriving	how to measure “thriving”?	How can “thriving” be developed at a patient centered outcome for those living with a history of moderate to severe TBI?	Both

Secondary health conditions	How do secondary health conditions create barriers to social and community engagement for those living with moderate to severe TBI?		Patient Partners
Tech solutions – vol.	using technology to promote volunteering	Can technological solutions be utilized to promote volunteering among those with a history of moderate to severe TBI?	TBI professionals
Intv. holistic identity	reestablishing identity – support identity beyond TBI survivor	Can interventions be developed to help individuals with a history TBI reestablishing a holistic identity?	Patient Partners
Stages of rehab	how to assess outcomes when starting point is different	Can sensitive and specific QOL-related outcomes be developed for moderate to severe TBI survivors at different stages of rehabilitation?	Both

**Figure 1.** Top Ten Important Research Questions/Aims for TBI survivors and caregivers



**Figure 2.** Top Ten Important Research Questions/Aims for TBI professionals

