

Community based rehabilitation: Special issues

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Abstract. The primary goal in the developing field of community based rehabilitation (CBR) for individuals with TBI/ABI is community participation and integration. At present, CBR is less than clearly defined and is represented by a set of interventions with varied types, degrees of clinical support and models of intervention that are conducted for a diverse and complex set of individuals, situations, deficits and settings. Nonetheless, holistic neurorehabilitation programs should be considered both evidence based and a practice standard. This paper attempts to address some of the significant issues relevant to optimizing long term adaptation for persons receiving CBR. The article also addresses the current need for definitions, models, program classifications and comparisons, as well as programmatic methodologies by attempting to integrate some of the best scientifically supported methodologies within an eclectic holistic rehabilitation model that is easily understood and teachable to persons with TBI, families and rehabilitation professionals. This model and associated methodologies are intended to inform best practices while offering a framework for hypothesis generation, clinical decision-making, evaluation of treatment outcomes and direction of future research.

Keywords: Post-acute rehabilitation, community care, brain injury, biopsychosocial, community based rehabilitation, community reintegration

1. Introduction

The ultimate goal of rehabilitation after traumatic or acquired brain injury (TBI/ABI) is community reintegration. Community reintegration refers to participation in society. The growing trend towards post acute community-based rehabilitation (CBR) for individuals with TBI can be traced to at least several important sources: (1) Expanding evidence that demonstrates more effective learning and increased gains in independence and productivity in the natural settings where individuals must adapt; (2) Evidence that positive supports produce these gains that can usually be obtained for even the most challenging clients and impair-

ments [26,27,67,108] (Malec, pending publication); (3) Global trends toward community based rehabilitation and social support and integration and equalization of opportunities and participation for persons with disabilities [43]; (4) Specific national trends toward community based rehabilitation for persons with TBI in response to both increasing awareness of needs of the growing TBI population and recent TBI legislation. In the US, major legislative and policy influences have included the TBI Act and TBI Act reauthorization, Olmstead decision and others [5,123].

At present, CBR is less than clearly defined and is represented by a varied set of post-acute brain injury interventions with varying types and degrees of clinical supports that are conducted for a diverse and complex set of individuals, situations, deficits and settings. The potential range of CBR settings is broad and may include: neurobehavioral, residential and supported programs, as well as outpatient, day treatment and home

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based programs. As such, CBR does not lend itself well to the rigors of randomized clinical trials and is only beginning to be systematically defined and evaluated [14, 29,30,91].

As pointed out by Sander et al. [91], there are significant gaps in our understanding of factors that impact community reintegration. They point out three challenging needs that must be addressed to advance interventions and research in the area of CBR: (1) A comprehensive definition of community integration that includes perspective and preferences of persons with TBI; (2) Cultural competence in measurement and intervention; (3) A thorough assessment of environmental factors impacting participation that is incorporated into treatment planning and research.

Given the paucity of writings about the challenges of working with survivors of TBI in post acute settings, we address some of the important issues in the context of analyzing biopsychosocial aspects of optimizing long term care for persons with TBI in the community. Equally, if not more importantly, the current need for definitions, models, program classifications and comparisons and programmatic methodologies [30] will be addressed by attempting to integrate some of the best scientifically supported methodologies within an eclectic holistic rehabilitation model that is easily understood and teachable to persons with TBI, families and rehabilitation professionals.

2. An integrated, holistic model for CBR after TBI

Persistent biological (medical), cognitive, emotional, behavioral and social dysfunction following brain injury can present with formidable neurorehabilitation challenges. Recent reviews and accumulating empirical evidence regarding remediation of cognitive, behavioral and psychosocial disorders following acquired brain injury (TBI) indicate the greatest overall improvement from programs that involve a paradigm of complex, sophisticated and integrated, or 'holistic' interventions [15,26,75]. Such programs focus on psychosocial/emotional aspects of recovery, address many impairments and disabilities and strive to support participation, independence and self managed adaptation and adaptive strategy use for all aspects of life in the real world. Holistic programs can be considered not only evidence based, but also a treatment standard [14, 95].

A summary of the theoretical and empirical underpinnings and the best empirically supported method-

ologies integrated in the Holistic Habit and Self Rehabilitation (HHSR) model are included in Table 1.

In the HHSR model, three primary, interdependent, essential ingredients for relearning and rehabilitation are emphasized, the three *P*'s: *Plan* or prescriptive rehabilitative strategy and design, usually task analysis based for stepwise relearning of deficient behavioral skills; *Practice*, the structured repetition component of habit re-manufacturing; *Promoting* motivation and effort necessary for sustained practice (prerequisite to habit acquisition) via replacing debilitating emotions and attitudes (e.g., incremental expectancies and reinforcement, adaptive reinterpretation and redirection of any significant anger, frustration, depression, fear, pessimism, feelings of victimization, self pity, hopelessness, low grade chronic despair, etc.), where these emotional responses are considered the greatest obstacles to rehabilitation [36,71,73,81,119]. Considerable anecdotal and observational data and unpublished case reports collected by the authors, along with research reports in related areas [26,92,102–104] indicate that the gains that can follow resolution of the persistent maladaptive emotional reactions, when combined with potent retraining strategies, can convert into impressive improvements in functional status and adaptation even many years post injury.

The HHSR model promotes the attitude and activity routines necessary for structured, consistently repeated behaviors for reestablishing effective behavioral skill habits. The reader is referred to Martelli, Nicholson, Zasler [73] and the villamartelli.com (<http://villamartelli.com>) website for additional reading. In HHSR, resolving persistent catastrophic emotional reactions involves three integrated components: 1) Confronting deficits in an incremental manner to prevent being overwhelmed by distressful emotion (e.g., graduated exposure, cognitive restructuring); 2) A supportive conceptual framework and rehabilitation methodology that fosters hope and includes self-instruction to reinforce graduated successes in very incremental stages that progress toward desired goals (e.g., The Five Commandments of Rehabilitation; (see Table 2)); 3) A rehabilitation methodology that emphasizes errorless learning and task analyses in order to simultaneously simplify reacquisition and habitualization of many basic adaptational skills while minimizing learning disruptive distressful emotions.

2.1. Enhancing learning in CBR

The errorless learning (EL) literature is a growing body of research consistently demonstrating the ef-

Table 1

A summary of the theoretical and empirical underpinnings and best empirically supported methodologies integrated in the Holistic Habit and Self Rehabilitation (HHSR) model

HHSR:

- (1) Conceptualizes brain injury sequelae in terms of disruption of previously established hierarchical, interdependent habits that underlie all efficient, adaptive living skills. Retraining them is the challenge of rehabilitation;
 - (2) Is a biopsychosocial model that synthesizes the literature on catastrophic Reaction [36] and adaptational disability and literature on neuroplasticity [38] learned helplessness [97] and learned non-use/constraint induced movement therapy [63,102–104]
 - (3) Further combines research on learning [77], anxiety and anxiety-related avoidance after brain injury [86] and cognitive behavioral therapy [93] and positive behavioral interventions and supports [26,49] to demonstrate that negative emotional reactions, learning and expectancy are extremely powerful determinants of functional disability and rehabilitation barriers that can be remediated to improve health;
 - (4) Aims to simplify and integrate core psychotherapeutic and learning principles as rehabilitation process ingredients necessary for optimal facilitation of skills retraining [73,75];
 - (5) Generates practical, utilitarian strategies for retraining adaptive cognitive, emotional, behavioral and social skills, as well as strategies for overcoming common obstacles to utilizing methods that promote effective skills acquisition;
 - (6) Is founded upon and integrates: (a) learning literature [93] and especially the literature on “automatic learning” and “errorless learning” following brain injury [57]; (b) a widely applicable task analytic approach to designing relevant skills retraining protocols; (c) analysis of organic, reactive, developmental, and characterological obstacles to strategy utilization and relearning and generation of effective therapeutic interventions; (d) procedures for promoting rehabilitative strategy use adapted to acute and chronic neurologic losses, an individual’s inherent reinforcement preferences and coping style, and naturalistic reinforcers that highlight relationships to functional goals, utilize social networks;
 - (7) employs a simple and appealing cognitive attitudinal/ motivational system and set of procedures consistent with cognitive behavioral psychotherapy [71,73,77].
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fectiveness of EL training methods for teaching skills to individuals with neurologic impairments who have been poorly responsive to trial and error (or “effortful”) teaching. Success with EL treatment has been demonstrated for persons with severe memory impairments after brain injury/disease, learning disabilities, dementia, aphasia, Parkinson’s disease, schizophrenia, autism, mental retardation, post-encephalitic amnesia, mild cognitive impairment, and other neurologic and neuropsychiatric disorders. This work has also extended to complex social problem-solving skills in work rehabilitation, learning in amnesics with mild executive deficits and acquisition of multicomponent concepts in amnesic children [21,33–35,42,54–57,64,74,78,83,93,94,100,110]. Assistive cues are offered in the form of task analytically derived checklists or verbal instruction. For example, in the “method of vanishing cues”, maximum cues are provided initially and progressively withdrawn only when no longer needed for completely successful task performance.

Task Analysis (TA) is a learning procedure that breaks tasks or complex procedures into single, simple, logically sequenced steps, checklist style, to guide performance through each sequential step. Functional TA’s simplify and optimize task initiation, sequencing, completion and follow-up, help mitigate difficulties associated with fatigue and can assist with a wide range of neurocognitive difficulties [51,68,69,73]. TA’S provide an errorless learning format that can be supplemented with any needed direct instruction or supervision,

while ensuring a simplified learning process, successful task completion, learning of only successful procedures, reduced competing memory traces and elimination of frustration and distressful emotional reactions that can be especially inhibitory to memory and learning performance in persons with TBI. TA’s can be beneficial for both basic and complex behaviors, ranging from simple tasks to complete daily routines, to help re-establish the efficient habit routines that comprise everyday human behavior and activity.

Graduated Exposure (GE), a highly effective behavioral therapy procedure for anxiety desensitization, involves slowly and incrementally increasing a patient’s exposure to a feared, distressful or challenging situation [77,87,99]. In addition to clinical anxiety, GE has application for a wide range of distressful emotional, sensory and physiologic symptoms. GE has been used by these authors and others to produce significant functional improvements for persons with disablement from driving anxiety, fatigue, dizziness, and vestibulopathies. We have used GE protocols to improve post-traumatic and other problems with visual endurance, reading tolerance, concentrating in presence of persistent headache, dizziness, social avoidance responses following TBI and SCI, and, in combination with graduated activity exercises, to reduce maladaptive avoidance responses associated with fear of pain and headache [72,73].

GE has been utilized to positively modulate disability perceptions and to improve resumption of functional

Table 2
Summary HHSR component posters

<p>Holistic Habit Rehabilitation Ingredients: The 3 P's</p> <ul style="list-style-type: none"> - Plan: Strategy or design for stepwise progress toward desired outcome. . . Usually based on task analyses (TA's). Specific, concrete, and obvious steps are indicated. - Practice: Repetition (the cement of learning) of TA's make performance of complex, cumbersome & boring tasks more automatic, effortless, habitual. Habits allow performance of tasks without special effort, energy, concentration, memory, etc. - Promoting Attitude: The facilitative attitude provides motivation & fuels persistence & mobilization of energy necessary for accomplishment of a progressive series of desirable but challenging goals. <p>Task Analysis: The Building Block of LEARNing TA's:</p> <ul style="list-style-type: none"> - Break tasks into single, logically sequenced steps & recording in a Checklist & checking off each step as completed. - Make task initiation, completion & follow through much easier; greatly improve performance despite limitations in memory, attention, energy, initiative, ability to sustain performance, organization, other impairments. - Reduce demand & energy consumed by reasoning & problem solving associated with planning, organizing, recall, decision making, prioritizing of appropriate steps, sequences for basic & complex tasks. - Provide benefit of errorless learning and motor learning. - (Rre)establish efficient habit routines that make up normal everyday activity. Greater impairments require more repetitions to produce automatic habits. - In HHSR, ingredients for (re)building automatic habits are the 3 P's: Plan (relying on TA), Practice, Promoting Attitude. Result is (re)habilitation, or increased life efficiency accomplished by removing obstacles to independence. <p>The Five Commandments of Rehabilitation: <i>Incorporating Cognitive Behavioral Psychotherapy to Conquer the Catastrophic Reaction</i></p> <ul style="list-style-type: none"> - Thou Shall Make Only Accurate Comparisons. <i>Thou shall not make false comparisons.</i> - Thou Shall Learn New Ways to Do Old Things. - Thou Shall Not Beat Thyself Up . . . Instead, Thou Shall Build Thyself Up! - Thou Shall View Progress as a Series of Small Steps - Thou Shall Expect Challenge & Strive to Beat IT 	<p>4 R's: Relationship, Rationale, Ritual, Reinforcement</p> <ul style="list-style-type: none"> - Relationship: A strong, positive and trusting therapeutic Relationship is required to facilitate emotional trust while calming anxieties and emotional distress, and inspiring hope and collaborative effort. - Rationale: A credible Rationale is required to offer a believable treatment model and logically convincing procedure that sets pre-requisite positive expectancies. - Ritual: A credible methodology & set of procedural interventions that produces measurable successes to confirm expectations & reinforce hope & continued efforts. - Reinforcement: The consistent application of rewards such as verbal praise, smiles and positive gestures, etc., to SHAPE, highlight and increase desirable goal directed achievements. <p>FIRSTS: Planned First Time Accomplishments (FTA's)</p> <ul style="list-style-type: none"> - Indicate Progress; Promote Hope & Positive Self Expectancies - Promote Persistent Goal Related Effort; Discourage "Quitting", "Giving up" - Facilitate Incremental Expectancies - Promote Adaptive Self Assessment/Comparison's & Adaptive Self Reinforcement - Promote Practice Through Promotional Attitude <p>Measures of Rehabilitation Quality (HHRS): P, R, F Model (3P's, 4R's, Firsts)</p> <ul style="list-style-type: none"> - # of P's <ul style="list-style-type: none"> * 1 or 2 P's: Suboptimal * 3 P's: Holistic - # of R's <ul style="list-style-type: none"> * 0-3: Suboptimal * 4: Holistic - # of "Firsts" <ul style="list-style-type: none"> * Some: Less effective * Many: More effective
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and work related activities [7,8,68,70,72,73,122]. The technique of GE has in the aforementioned contexts also been successful in persons recalcitrant to previous treatments and/or with poorly delineated symptom generators. GE programs can be implemented in both home and community based interventions with designs for assisted, partial or mostly independent implementation. GE has been one of the most powerful and frequently used strategies in our rehabilitation arsenal. GE combination interventions should be part of the primary psychotherapeutic and rehabilitation retraining strategies in the HHSR model of neurorehabilitation.

HHSR recognizes that the overwhelming conclusion of all major reviews of psychotherapy data [11,31-34, 46,82,112] indicate that therapist relationship factors play a much more important role in outcome than treatment approaches. The model borrows [73] and prescribes strategies for facilitating potent therapy via rehabilitation delivery that can be summarized by the 4 R's: A strong, positive therapeutic *Relationship* facilitates emotional trust while calming distress, and inspiring hope and collaborative effort. The *Rationale* offers a believable treatment schema that sets positive expectancies. The *Ritual* or interventions produce individualized, specific opportunities to experience and

measure validity of the therapy. Finally, *Reinforcement* confirms hope and expectations and strengthens continued efforts and must be shaped to optimize accurate incremental assessment and internal satisfaction. In HHSR, first time accomplishments (FTA's; always emphasized and often strategically planned) are a primary reinforcing progress indicator and promoter of hope, positive incremental expectancies and persistent goal related effort.

2.2. The self and behavior

The second HHSR Rehab Commandment specifically addresses adaptively learning new ways to do old things. This extends to the most important "old" thing, which is a sense of self. Self or personality is the enduring pattern of thinking, feeling and behaving, or interpreting and acting, that characterizes humans. Post injury impairments and life disruption and increased stress can block and distort the Self. Per HHSR, the most important "old thing" to learn a new way to do is "Be You". When injury distorts it, it must be relearned, through practice, just like other habits.

One strategy for rebuilding "self" includes interviewing family and friends via meetings or questionnaire to solicit favorite or prominent pre-injury memories. Historical records are reviewed if possible. From descriptions, a summary list of characteristics of an enduring, historically defined and enduring sense of "self"/personality traits is organized (usually into an acronym for easy recall). These descriptions are subsequently included in a "Me versus Not Me" self definitional/directional poster that is used to shape increasing expressions of "Me" traits (especially as replacements, competitors for less desirable post-injury thoughts and behaviors). "Me" versus "Not Me" conceptual posters are individually, collaboratively and creatively designed and anointed with graphics and even music or popular movie clips in a structured flexibility format that can be integrated into positive behavioral supports in relevant settings [26]. Clients are shaped to use this individualized, explicit, logically compelling and affectively motivating "self-direction" earlier and earlier in the sequence of thoughts and actions, especially with attention to more challenging behaviors.

Another protocol for achieving a more stable and satisfactory self and life involves graphically constructing a list of important life areas, delineated by symbol categories of love, work and play [84]. Satisfaction is rated for each goal and an average overall score (com-

posite life and self satisfaction) and a range of possible rehabilitation outcomes are delineated (goal attainment scaling) for each. Then, a sequence of objectives for improvement in each targeted goal area are collaboratively designed with serial monitoring of interventions and progress in order to reinforce incremental accomplishments in goal areas and in general self and life satisfaction.

HHSR offers an uncomplicated and intuitively appealing model and methodology for devising and individualizing specific retraining protocols. It integrates and synchronizes potent neurorehabilitation-specific learning and psychotherapeutic strategies to offer integrated protocols for rehabilitationists, families and clients. HHSR offers skill reacquisition protocol templates developed for a broad range of even the most challenging areas, while also integrating reconstruction of a positive and guiding sense of self. HHSR, as an optimistic model, aims to expand "neuropsychotherapeutic" rehabilitation beyond enhancing emotional adjustment and functional compensation to include promotion of neuroplastic based rehabilitation of cognitive, behavioral and physical capabilities.

The HHSR model continues to be developed, refined and applied in various clinical treatment settings. Illustrative case studies are available ([73]; <http://villamartelli.com>). An introduction to building rehabilitation protocols using the "3 P's" approach can be found at: <http://villamartelli.com>. Online protocol segments illustrate samples of application of task analytic derived, errorless learning based skills building protocols (the Plan), individually adapted reinforcement via a palatable cognitive attitudinal approach for countering inherent resistances to strategy utilization and practice, and promoting incremented goal achievement and reinforcement from graduated successes (i.e. the Practice and Promotional attitude components).

Finally, an extremely important component of biopsychosocial and holistic post-acute rehabilitation programs is combination treatment employing a true integration of medical, physical, cognitive, neurobehavioral, linguistic and psychosocial treatments. Scope and space limitations restrict adequate coverage of this broad topic beyond basic references and referral to additional readings [3,124].

3. Social, avocational and vocational reentry in CBR

Community integration has been traditionally defined by three main areas: social activity, indepen-

dent living and employment or other productive activity [91]. Independence and meaningful relationships and activities, or “having something to do, somewhere to live, and someone to love” [49] mark the most important needs of persons after TBI. From the writings of Freud to Meninger, work, love and play constitute the primary components of human individuality, activity and psychological health. Prigatano [84] also identified the aforementioned trilogy as the major symbols to guide recovery of individual identity and wholeness after brain injury.

3.1. Social reentry

A great deal of rehabilitation focuses on returning the person with a brain injury to work or to some type of productive activity. Love and play, in contrast, are too often neglected as critical elements for feelings of purposefulness and productivity necessary for self and life satisfaction [2]. This is despite the fact that for many persons with TBI, return to work may not be possible or practical, cannot approach pre-injury levels of function, or may not be valued as highly as needs to assume or resume social roles and function. Limited employment-focused views of productivity neglect the critically important and meaningful roles of productive avocational activities and leisure, family roles and productive relationships, community service and learning and education [107]. Importantly, Willer and Corrigan [118] accurately defined successful integration as active participation in a broad range of community involvements and not just a narrow series of opportunities (e.g., employment or independent living).

The social consequences of a catastrophic injury are often more persistently devastating and more challenging to remediate than the physical and cognitive consequences [101]. Removed from jobs and social contacts and routines, reduced in functional capacity and more reliant on others for care, persons with TBI too frequently find their friendships and social supports and networks drastically reduced. The psychosocial problems of decreased social contact and opportunities, depression, and loneliness, as well as changes in internal and external coping resources further complicate and contribute to social network evaporation and complication of efforts at community re-entry. In their review, Morton and Wehman [79] presciently offered their most compelling recommendation that community rehabilitationists focus significantly more energies and resources upon the psychosocial health of clients with TBI as a rising obstacle to community adaptation.

Increasing evidence supports the efficacy of rehabilitation interventions for improving vocational re-entry with a necessary emphasis being on sustainable results. Clearly, rehabilitation programs that focus on social support and integration are effective in promoting gains in independence and productivity in persons with TBI (ERABI). However, there are few studies showing improvements in social integration and satisfaction [47, 117]. There is some evidence for the positive effects of community-based rehabilitation programs that use a peer or supported relationship model of intervention, although inconsistent results are reported and social reintegration improvements are usually not obtained.

One investigated approach to enhancing community reintegration after TBI has been social peer mentoring programs. Stuchen, Davis, Bogaards et al. [101] matched trained social peer mentors to partners with TBI to foster skill-building in social activities planning and social communication through phone contacts and joint participation in community social events over a three month period. High satisfaction was reported along with improvements in perceived social support and trends toward increased social life satisfaction. However, increased depressive symptoms with no improvements in social activity level and social network size were noted. Similarly mixed results were previously obtained by Hibbard, Cantor, Charatz et al. [44]. In a group based approach, Dahlberg, Cusick, Hawley et al. [20] employed a group social communication skills training to demonstrate improved social communication skills and overall life satisfaction after TBI with results maintained at follow-up. Clearly additional research is needed. However, consistent with evidence from efforts to remediate social isolation in other populations, better results are obtained for group versus individual based interventions (e.g. [105]).

As strongly argued by Sander [89], and embodied in the mission statement of The Institute for Rehabilitation Research (TIRR: <http://www.tbicomunity.org>), all areas of community integration, including traditionally under-emphasized areas such as friendships, intimacy, and creative expression, should be addressed in the context of community reintegration. The need for novel therapeutic approaches clearly represents one of the most important aspects and greatest needs in community based rehabilitation.

Some novel approaches to social integration for persons with TBI are described by Sanders and colleagues [89–91,101]. One includes an intervention for training family members as paraprofessionals which is ideally suited to the many persons with TBI/ABI who

lack proximate or financial access to rehabilitation services and/or who rely on family members as the sole source of support. It involves training that focuses on the real world environment and tasks with persons who are most familiar with functional needs and environmental obstacles and/or supports. It can be flexibly delivered through a distance learning program for families in remote locations or limited travelling options. A unique model for a cognitive-behavioral intervention with family members to optimize the family environment to support community reintegration is offered; this may be especially useful in mitigating negative impact of dysfunctional family coping (also see [62]). Another approach is a social peer support intervention aimed at improving and sustaining social integration. The primary role of social peer mentor is expanding the social network and social activity level of the person with TBI. Options for supported employment are offered that include peer supports in place of traditional job coaches for purposes of adding focus to facilitating social integration in the workplace. Emphasizing training in a 'big picture' format, facilitating informal ongoing social interactions occurring at work, including co-workers in the process of training and fading, using other employees to "show the ropes", taking breaks with other employees and working in proximity to co-workers performing similar or overlapping duties are some of the strategies that can facilitate social acceptance and facilitation and minimize "stigma" from being perceived as different. This approach can even include increasing community social activities as a means of using social channels to obtain jobs. A model of peer support intervention is nicely explicated in the paper in this issue by Dr. Kolakowsky-Hayner and colleagues.

Incorporating developmental disabilities and special education interventions, Ylvisaker and Feeney [26,27] have focused on utilization of social supports, cognitive strategies, and assistive technologies to promote a successful community-based "positive behavioral support" approach to community integration. Some of their tools have included: 1) training of family caregivers, educators, and employers as support personnel; 2) shaping adaptive antecedent behaviors to promote productive behaviors and preempt maladaptive behaviors; 3) shaping of self-awareness and goal setting; and 4) utilizing assistive technologies as task-sequencing and memory orthotics.

In the HHSR model, the numerous changes associated with brain injury are conceptualized as combining to essentially produce a debranching of the individuals' social connections/network. The typical result is

a sub-community of socially disconnected and lonely individuals who are overly reliant on family and social agencies for greatly reduced levels of "analogue" social engagement and activity. Analogously, each individual is like a tree trunk that has had its branches stripped away. The purpose of community based rehabilitation is to re-connect these individuals to the community, to re-establish branches of meaningful social contacts with both other individuals sharing similar or complementary situations or interests, as well as the existing heterogeneous community relationships. TBI support groups such as the ones for which state organizations of the Brain Injury Association of America (BIAV.org) advocate and facilitate through resources and guideline manuals, are consistent with both this philosophy and the established tradition of promoting education, support and enhancement in all areas of community integration for other minority and disability groups.

As argued for by Angel [1], empowerment, justice and equalization of opportunities in special populations must begin with collective awareness and mobilization. In an early progressive approach to social reintegration, Condeluci [17–19] prescribes an 'interdependent' paradigm. In contrast to integration that involves changing and fitting in, principles of inclusion and self-determination offer ways for empowering people with brain injuries to be included in their communities as they are. Condeluci offers practical guides for employing community activist advocacy strategies. He also offers guides for promoting the mutually reinforcing interactions between persons getting and persons giving assistance that are deemed prerequisites for meaningful rehabilitation outcomes, satisfaction and for creation of interdependent communities.

3.2. *Avocational reentry*

Avocational reentry has historically involved recreational and leisure activities. Hobbies, volunteer activities and taking educational classes are also frequently relevant. These are important components of human individuality and psychological health that play critical but typically under-emphasized roles in recovery of identity and self and life satisfaction after brain injury [12]. Especially because return to work is often not achievable, recreation and leisure and other avocational pursuits become increasingly important as sources of productivity, enjoyment, and reinforcement. They can also serve to build self-esteem and discharge stress. Such activities offer a safe, low stress and enjoyable means of practicing social and other skills than can

bridge the return to increasing community and social participation and integration.

The social benefits of leisure and volunteer and educational activities include the development and maintenance of social support networks, social identity, social interaction skills and the expression of creativity [48]. Leisure choices may be influenced by ability and cultural value judgments. They may support occupational balance and influence hope, motivation and optimism. An inability to maintain previous leisure occupations may reinforce uncertainty about the future and lead to negative redefinition of the person's sense of self, roles, and goals. Hence, leisure satisfaction can be a predictor of quality of life and be associated with adjustment to disability and well-being.

Exercise, as a recreational activity, may offer a wide range of benefits for individuals with brain injury but is often ignored as an activity due to the frequent challenges of integrating persons with mental and physical challenges into these types of activities [37]. Possible consequences of lack of exercise may include increased body weight, decreased joint range of motion, as well as increased risk of illnesses associated with obesity and/or inactivity including diabetes, hypertension, cardiovascular and cerebrovascular disease. Exercise, when performed sufficiently and regularly, may ameliorate a variety of common mood disorders following TBI including depression and anxiety problems, as well as emotional lability [23,45]. Aerobic exercise may encourage functional neuroplastic changes within the brain, producing positive effects on attention, memory and executive function. Regular exercise, when instituted in the post-acute injury period, may improve muscular strength, endurance, flexibility, body composition, and cardiovascular condition, thereby warding off long term negative effects of decreased activity commonly seen in persons with disability [39]. When incorporating exercise into the treatment of individuals with brain injury, it may be useful to emphasize the individual's abilities, as well as preference, while still offering well-rounded and diverse methods of increasing activity level, e.g. adapted sports, therapeutic horseback riding, or aquatics. The reader is referred to other sources for more detailed information on leisure and recreation issues in CBR and in general [28].

3.3. Vocational reentry

Productivity is crucial for reintegration, self worth, fulfillment and self and life satisfaction. Individuals who achieve some level of employment are consistently

observed to experience the highest levels of psychosocial health and tend to lead more active lives, have higher degrees of acceptance of disability, report greater levels of life satisfaction and have more positive self-esteem [113]. Vocational activities typically represent the highest level of achievement following traumatic brain injury, for both clients and rehabilitation professionals [4,84]. The negative psychosocial and physical health consequences associated with TBI likely amplify the impact of loss of job and unemployment well beyond loss of economic stability.

Although a large majority of persons with mild TBI return to employment, estimates for persons with moderate to severe TBI range from 20% to 80% [67]. For the individual client, goals can range from: community based competitive employment and return to a pre-injury or new job without external supports for fifteen or more hours per week, to transitional employment with temporary supports such as a job coach and training in compensatory strategy and assistive device use, work modifications or involvement in an educational or training program; supported community based work with permanent supports or limited hours or volunteer work; to sheltered workshop situations.

Vocational interventions clearly lead to improved RTW rates for persons with TBI [53]. In a review of the literature, Fadyl and McPherson [25] identified three major vocational rehabilitation models: Program-based vocational rehabilitation; supported employment; and case coordination model. Program based models [10] include three sequential modules: 1) individualized, intensive work skills intervention; 2) guided work trials; 3) assisted job placement with support. Interdisciplinary, group-based interventions target cognitive deficits, awareness, acceptance, motivation and social skills. High post treatment employment rates are reported [85]. Such models are best suited for those with severely impaired awareness, cognition, and social functioning, but high program intensity and costs, as well as poor fit for those with less severe impairments, represent limitations.

Supported employment, adapted for persons with TBI [113,116] represents an individual placement model characterized by limited pre-employment training, quick job placement, individualized on-the-job job coaching, and long-term monitoring. Job coaches help contact potential employers, provide additional training, initially helping perform some job duties, obtaining assistive technology, teach problem-solving and compensatory strategies, and model social skills. This approach also reports high employment rates achieved

with persons with severe deficits incapable of maintaining employment without on-site support. Limitations relate to extensive resource hours sometimes required for adequate job retention and poorer applicability to persons with milder impairments.

The case coordination model is a holistic, flexible, individualized approach where the case coordinator collaborates with person with TBI to assess needed services and appropriate referrals (e.g., vocational counseling, pre-employment training, job placement assistance). Integration of vocational services with other rehabilitation services is emphasized, along with intervention, continuity of care, and assessment and referral for impairments that could impede vocational success. High employment rates achieved within twelve months are reported for persons with mild to severe TBI [13]. Limitations include dependence on skills of rehabilitationists and availability of services in the client's geographic area.

A common denominator in reviews of vocational rehabilitation literature is that the best outcomes occur when specialized support, incremental and progressive planning and intervention, as well as ongoing follow-along are provided. Although more evidence based prospective studies are needed, the overwhelming conclusions thus far indicate that most persons with even severe TBI can work in some capacity, needed supports are cost effective and persons with TBI and those who return to work (RTW) sustain important improvements in non-vocational, psychosocial areas [113]. Importantly, the strategies employed with supported employment models and methods of post-TBI vocational rehabilitation parallel the ones promoted in the HHSR model. For more detailed review of community based vocational rehabilitation please see the paper in this issue by Dr. Tyerman.

4. Additional rehabilitation factors

4.1. Social milieu

Guides that are offered for optimizing the treatment milieu in milieu-based neurorehabilitation programs [60] are relevant for all post-acute interventions that have group based components (e.g., comprehensive outpatient rehabilitation programs, day treatment and clubhouse programs, supported living programs). The milieu is comprised of the personalities, attitudes and behaviors of staff, persons with TBI and support personnel. Admission decisions should take into ac-

count the makeup of the current milieu and potential impact of new persons considered for admission to help shape and maintain a compatible and therapeutic environment.

Ethnic and sociocultural background, socioeconomic status, age, education, alcohol and drug problems and personality disturbances must be considered. For instance, limiting the milieu to more than one or two individuals or even significantly involved family members with significant personality and/or substance abuse disorders and including a mixture of ages and types of impairments, seems to help optimize the therapeutic environment and minimize disruption of overall treatment [62]. Encouraging social interaction through scheduled outings, social events and group therapies can promote a sense of community, treatment facilitation and quality of life [61]. Similarly, staff selection and training are equally important to ensure neurobehaviorally competent and consistent therapeutic interactions in order to optimize patient outcomes [9].

Additional important and often critical issues in rehabilitation and especially community rehabilitation include dysfunctional family dynamics, setting realistically achievable goals, driving, friendship, romance, intimacy and sexuality and quality of life. Addressing these in any detail is well beyond the scope of this paper. However, special resources, including guides, podcasts, online videos, etc., are available and easily downloaded from the websites of the sixteen traumatic brain injury model system centers supported by grants from the National Institute of Disability and Rehabilitation Research (NIDRR; www2.ed.gov/about/offices/list/osers/nidrr). Special focus on community integration is given by The Institute for Rehabilitation Research TIRR), Baylor College of Medicine (<http://www.tbicommunity.org>). From the [tbicommunity.com](http://www.tbicommunity.com) website, many useful training, guides and research resources are available. A brief summary of some of the resources relevant to CBR include:

1. Training of healthcare professionals in the community integration needs of persons with TBI, including general and specific training manuals and podcasts for different professionals (e.g., social workers, psychologists and primary care physicians);
2. Increasing Social Networking Opportunities following TBI, including a social peer mentoring program and manual;
3. Training family members as rehabilitation paraprofessionals, including distance learning tools;

4. A cognitive behavioral intervention for stress management for family members;
5. A brief Educational Intervention for Reducing Substance Abuse after TBI;
6. Intimacy following TBI, including physical, spiritual, emotional, and intellectual aspects;
7. Technology and assistive devices to facilitate functioning in the workplace
8. Ethnic diversity in acceptance of disability, community integration needs, barriers and supports.

4.2. Physical milieu

Typically underappreciated are the multiple possible cognitive, visual, visuoperceptual, other sensory, motor, psychoemotional and/or neurobehavioral impairments associated with ABI that can negatively impact ability to participate and function effectively in the housing and living environments. Reintegration into the home and community requires holistic assessment of the full range of functional abilities and activities that can limit community participation and accessibility. These typically include: bathing, dressing, grooming, toileting, meal preparation, personal household management (i.e. money and medication management), laundry, home maintenance (e.g., cleaning), physical exercise and recreational activities (e.g., television/ gaming, computer). This assessment is important for all aspects of rehabilitation treatment that prepare individuals for home and community reentry, including temporary to longer term post acute treatment in comprehensive milieu and outpatient, day rehabilitation and clubhouse and supported living programs [58].

Whether selecting environmental features, designing accommodations and modifications (e.g., assistive technology) or designing residential homes and/or treatment environments, planning and decision making should be individualized in order to facilitate both home and community reentry. This planning and design should always be done in collaboration with the survivor of TBI and relevant family and/or funding sources and should be driven by the goals of: 1) Optimizing functional independence in (a) the least restrictive living environment and (b) in all relevant environments; 2) Emphasizing independence, inclusion and quality of life. This planning and design should always be done in collaboration with the survivor of TBI and relevant family and/or funding sources. Universal access is one methodology that can facilitate access and remove typical environmental obstacles to access and community integration, especially in the workplace [65]. For additional reading, see Kiser and Zasler [58].

4.3. Maximizing autonomy while avoiding risk

A primary ethical principle that guides clinicians in their work with patients is respect for others. Based on this fundamental respect for people, four core bioethical principles [6] have been described: (1) Autonomy: self-determination; Ability to make healthcare and life decisions independently; (2) Non-maleficence: obligations that treating professionals do no harm; (3) Beneficence: promotion and advocacy of patients best interests; and (4) justice, or requirement for the equitable distribution of the burdens and benefits of care [40].

Hanson and Kerkhoff [41] reviewed the literature to summarize five ethical assumptions in rehabilitation: 1) A primary purpose is helping patients maximize functional independence; 2) Competent patients want to improve function; 3) The rehabilitation team protects patient interests; 4) When capable, patients should be involved in decisions affecting their well being. 5) When limited, resources should be allocated to those who can benefit the most. They further present discussion of the four core bioethical principles as they relate to rehabilitation of persons with TBI. Non-maleficence and beneficence are considered on a continuum: do no harm, prevent harm, remove harm and facilitate good. Thoughtful consideration is required in order to balance multiple and sometimes conflicting obligations simultaneously. A frequent example is balancing respect for autonomy and enhancement and compensation for disabling conditions with risk taking behaviors and the obligation to prevent harm.

Some of the most common challenges occur when client autonomy is expressed in the context of desires for driving, sex, smoking and alcohol. Assessing competence and risk can assist with balancing respect for autonomy and obligations to prevent or remove harm. An additional consideration is the availability of positive behavioral interventions and support as means of reducing risk and preventing or replacing potentially harmful risk taking behaviors. Clearly, application of the four bioethical principles and the five ethical assumptions in rehabilitation can assist with balancing multiple contradictory obligations.

4.4. Aging and TBI

Brain injury impacts on the aging process in a myriad number of ways. The issue of aging with an acquired brain injury represents a major public health issue and places increased demands on survivors, professionals, caregivers and funding sources [114]. On-

going medical follow must consider acute and chronic progressive medical problems, hospitalization and re-hospitalization and increased vulnerability to neuromedical impairments including neurodegenerative disorders. Heightened risk of neuro-orthopedic complications due to tonal aberrations, asymmetric gait patterns and abnormal motor recruitment include chronic musculoskeletal pain disorders such as myofascial pain, early degenerative joint disease and contractures. Other areas of function that may be adversely impacted include sleep, mood and cognition due to many different environmental and social factors. Decline in previously effective coping mechanisms and underlying cognitive and emotional coping resources [50,59] are also not uncommon.

The increased risk for both morbidity and mortality in this population has recently been summarized by Masel and Dewitt [76]: “TBI increases long-term mortality and reduces life expectancy. It is associated with increased incidences of seizures, sleep disorders, neurodegenerative diseases, neuroendocrine dysregulation, and psychiatric diseases, as well as non-neurological disorders such as sexual dysfunction, bladder and bowel incontinence, and systemic metabolic dysregulation that may arise and/or persist for months to years post-injury”. Clearly, aging with brain injury negatively impacts a survivor’s abilities and opportunities for community participation. Moreover, families and support systems, including care providers, are aging right along with survivors. This makes continuing support for community participation more challenging.

The goal after TBI is achieving the most “successful” and morbidity free aging as possible [115]. How brain injury impacts aging per se and additionally how neurodisability, in general, impacts age related morbidity are just starting to be addressed through more formal research efforts. This critical issue is addressed in this special issue in the paper by Drs. Murphy and Carmine.

5. Outcome assessment

The movement of rehabilitation into the community is accompanied by need for development and use of specialized measures of the primary components of community integration. Global concepts such as participation are difficult to assess and are influenced not only by injury severity, but also individual needs and values of clients and families as well as societal limitations and norms.

Although beyond the scope of this paper, there are currently numerous instruments available for assessing most aspects of community integration, from participation to quality of life to return to work [120]. New research and promising outcome instruments continue to emerge. In a review article of community integration assessment instruments used in persons with TBI, Salter et al. [88] evaluated five instruments: Community Integration Questionnaire (CIQ), Craig Handicap Assessment and Reporting Technique (CHART), Reintegration to Normal Living Index (RNLI), Sydney Psychosocial Reintegration Scale (SPRS) and Community Integration Measure (CIM). All instruments were noted to assess the three core elements of community integration: relationships with others, independence in one’s own living situation and meaningful activities. Based on comparative description and psychometrics, they concluded that the CIQ and RNLI appeared the most reliable and valid, but recommended further evaluation regarding measurement characteristics and clinical usefulness.

The PART-O is a new, statistically derived combination instrument that appears promising [121]. The 24-item PART-O has been noted to provide acceptable measurement of objective participation for persons with moderate and severe TBI. In addition, use of more individually tailored instruments, such as Goal Attainment Scaling (GAS: [122]) is on the increase due to its advantages in individualizing outcome tracking data and optimizing the relevance of such data to each specific patient and their life circumstances.

6. Future research directions

The growing number of programs and increasing attention to community based rehabilitation is accompanied by an increasing number of publications on CBR. Theory papers and descriptive studies are over-represented while more intervention studies are needed. Intervention studies addressing important areas such as participation, use of local resources, optimizing family function to support community integration and especially in cases of dysfunctional family dynamics, increasing community awareness of TBI/ABI needs and reducing attitudinal and environmental barriers to community participation are especially needed. While more comprehensive review studies are needed and some are beginning to emerge, the available research literature is fragmented on most aspects of CBR. Systematic research is needed to guide and establish

evidence-based practice. Treatment interventions and assessment instruments that are individualized to patient and family needs and preferences are strongly indicated.

Several important recommendations have been offered with regard to the quality of research in CBR and improving the accumulated evidence in the field [14, 29,30,52,91,108]. These recommendations include:

- 1) More specific descriptions of the content, intensity, duration and detailed intervention characteristics of CBR programs, as well as patient characteristics and inclusion, exclusion criteria. These descriptions, along with increased standardization (e.g., through manualized treatment programs) and controlled outcome research will allow reliable comparisons across studies, as well as identification of prognostic personal factors that may contribute to improvements in treatment efficacy.
- 2) Well-designed controlled studies and preferably RCTs, to more objectively evaluate efficacy of CBR programs. When RCTs are difficult to perform, cohort studies (e.g., with waiting period as a control) should be conducted to provide more evidence on the effectiveness of CBR programs and interventions.
- 3) Outcome measures addressing effectiveness of CBR with validated instruments responsive to individual survivor and family needs.
- 4) As sound evidence of the effectiveness of different CBR treatments and programs becomes available, comparison of treatment mixes and testing differences in treatment duration and intensity to determine cost-effectiveness.
- 5) Use of theoretical neurorehabilitation models that allow classification of CBR can structure the generation of testable hypotheses and allow evaluation and comparison of programs in order to improve treatment efficacy. Less complex, outcome focused models that are individually meaningful for persons, families and policymakers are needed in order to gain wide acceptance.

7. Conclusions

Holistic neurorehabilitation programs should be considered both evidence based and a practice standard [14, 95]. Within these programs, practitioners should attempt to integrate the best scientifically supported

methodologies as proposed best practices for addressing many of the most relevant issues in CBR. The proposed HHSR model attempts to imbed these treatment methods within a framework that is easily understood, teachable and palatable for persons with TBI/ ABI, families and rehabilitation staff.

In the relatively young and developing field of community based rehabilitation, the HHSR model and associated methodologies are intended to inform best practices, offer a framework for clinical decision-making, provide a benchmark for evaluating treatment outcomes and spur research to even better inform clinical practice [80].

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