

CHAPTER 1

General Introduction

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“Neuropsychological rehabilitation” is a process whereby people who have sustained insults to the brain are helped to achieve their optimum physical, emotional, psychological, and vocational well-being (McLellan, 1991). The main purposes of such rehabilitation are to support people with disabilities resulting from brain insults in achieving their optimum level of well-being, to reduce the impact of their problems in everyday life, and to help them return to their own most appropriate environments. Rehabilitation is not about teaching clients to score better on tests, to learn lists of words, or to be faster at detecting stimuli. The focus of treatment is on improving aspects of everyday life; rehabilitation therefore needs to involve personally meaningful themes, activities, settings, and interactions (Ylvisaker & Feeney, 2000).

PRINCIPLES OF REHABILITATION

This workbook has grown out of the psychoeducation groups run for clients with acquired brain injury (ABI) who attend The Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation in Ely, Cambridgeshire, United Kingdom. The rehabilitation program at OZC is based on six core components that the staff members believe illustrate the principles of good clinical practice, and that underpin the material offered in this book:

1. *Therapeutic milieu*. A concept derived from the work of Ben-Yishay (1996), the “therapeutic milieu” in holistic rehabilitation refers to the organization of all aspects of the environment to provide maximum support in the process of adjustment and increased social participation. The milieu embodies a strong sense of mutual cooperation and trust—a sense that underpins the working alliances between clients and clinicians.

2. *Meaningful goals.* Care is taken to make the goals set with clients meaningful and functionally relevant. By “meaningful functional activity,” we are referring to all daily activities that form the basis for social participation. These can be categorized into vocational, educational, recreational, social, and independent living activities. It is through participation in these areas that we all gain a sense of purpose and meaning in our lives. Although we may not think about this consciously in everyday life, these types of activities enable us to achieve certain aims or ambitions that are personally significant to us and thereby contribute to our sense of identity.

3. *Shared understanding.* In a rehabilitation context, this term refers to mutual understanding among clients, families, and staff. The notion comes from the use of “formulation” in clinical practice (Butler, 1998). As explained in more detail below, a formulation is a map or guide to intervention that combines a model derived from established theories and best evidence from the client’s and family’s own personal views, experiences, and stories. This concept should be applied to all individual clinical work, and should influence the way the rehabilitation experience is organized as a whole. It includes a team philosophy that incorporates a shared team vision, explicit values, and goals. Additional characteristics of shared understanding include assimilation of research and theory; participation in knowledge and experience with other professionals and families; peer audit of the services provided; and absorption of the views and contributions of past clients.

4. *Psychological interventions.* These are based upon certain ways of understanding feelings and behavior. Specific psychological models are applied to guide work, depending upon each individual’s specific needs. Approaches from these models provide ways for team members to engage clients in positive change and to tackle specific problems.

5. *Compensatory strategies and retraining.* These are the two principal approaches to managing cognitive impairments. “Compensatory strategies” are alternative ways to enable individuals to achieve a desired objective when an underlying function of the brain is not operating effectively; many of these are outlined in this workbook. “Retraining” is undertaken to improve performance of a specific brain function or to improve performance on a particular task or activity. Retraining also helps to address skills lost through lack of use (e.g., through not being at work since an injury occurred).

6. *Families and caregivers.* Rehabilitation involves working closely with families and caregivers, who sometimes report that they feel like “afterthoughts” in rehabilitation. Recent government policies within the United Kingdom highlight the fact that families and caregivers experience significant burden following ABI, and provision of support for them is recommended.

At OZC, we follow a holistic approach to brain injury rehabilitation, pioneered by Diller (1976), Ben-Yishay (1978), and Prigatano (1986). Such an approach “consists of well-integrated interventions that exceed in scope, as well as in kind, those highly specific and circumscribed interventions which are usually subsumed under the term ‘cognitive remediation’” (Ben-Yishay & Prigatano, 1990, p. 400). Perhaps the main philosophy of the holistic approach is the insistence that it is futile to separate the cognitive, social, emotional, and

functional aspects of brain injury. Given that emotions affect human behavior, including how people think, remember, communicate, and solve problems, we need to acknowledge that these functions are interconnected and often hard to separate; all of them need to be dealt with in rehabilitation.

Ben-Yishay and Prigatano (1990) provide a model of hierarchical stages in the holistic approach through which a client must work (either implicitly or explicitly) in rehabilitation:

- *Engagement*: Increasing the individual's awareness of what has happened to him or her.
- *Awareness*: Increasing the person's understanding of what has happened.
- *Mastery*: The provision of strategies or techniques to reduce cognitive problems.
- *Control*: The development of compensatory skills.
- *Acceptance*.
- *Identity*: Provision of vocational and other counseling.

It can be argued that the holistic approach is less of a model and more of a series of beliefs or principles (Prigatano, 1999). Nevertheless, the holistic model makes clinical sense—and in the long term it is probably cost-effective, despite its apparent expense (Cope, Cole, Hali, & Barkan, 1991; Mehlbye & Larsen, 1994; Wilson, 1997; Wilson & Evans, 2002).

In fact, there is mounting evidence that rehabilitation reduces the effects of cognitive, psychosocial, and emotional problems, leading to greater independence and eventual employability for many persons with brain injuries, as well as reductions in family stress (Cicerone et al., 2005; Wilson, Gracey, Evans, & Bateman, 2009). Cicerone, Mott, Azulay, Sharlow-Galella, Ellmo, et al. (2008) and Cicerone, Langenbahn, Braden, Malec, Berquist, et al. (2011) endorse the effectiveness of holistic approaches for traumatic brain injury (TBI): “Comprehensive holistic neuropsychological rehabilitation is recommended to improve post-acute participation and quality of life after moderate or severe TBI” (2011, p. 526).

Although the holistic approach is possibly best for the majority of people with brain injury, it is probably true to say that holistic programs can be improved through the incorporation of ideas and applications from learning theory, including task analysis, baseline recording, and monitoring. Other improvements can come from the implementation of single-case experimental designs within individual treatment programs. Further refinements can be encouraged by the use of cognitive neuropsychological models; such models enable us to identify cognitive strengths and weaknesses in more detail, to explain observed phenomena, and to make predictions about cognitive functioning.

THIS BOOK'S INTENDED AUDIENCE

While the myriad difficulties faced by survivors of brain injury—which can range from word-finding difficulties to memory problems to anger outbursts—require support from an experienced interdisciplinary team of speech and language therapists, occupational therapists, and clinical psychologists, few clients have such a team at their disposal. Many

therapists and psychologists are working alone and may see clients at most on a weekly basis in a hospital or clinic. They may be seeing people at home, or they may be using Skype or other Internet-based methods of service provision, and they will probably not be working in a brain injury rehabilitation center. It is for these professionals that we have published this book. We envisage that it will be used primarily by occupational therapists, speech and language therapists, clinical psychologists, and neuropsychologists, as well as others working with survivors of TBI, stroke, encephalitis, hypoxic brain damage, and other kinds of nonprogressive brain injury. The workbook can be used in a hospital or clinic setting, but can also be used when therapists are visiting clients at home.

The resources provided in the book are aimed at supporting therapists' work across professional boundaries, using core skills to address clients' needs holistically. Please be aware that our intention is not to imply that occupational therapists can be clinical psychologists, or vice versa. It is important for professionals to be aware of their own disciplinary limitations, and to refer clients to appropriately qualified service providers when doing so is appropriate.

ISSUES IN REHABILITATION

Assessment

Before any treatment can begin, a careful assessment is necessary. Although Sundberg and Tyler (1962) best defined "assessment" over 50 years ago when they described the process as involving the systematic collection, organization, and interpretation of information about a person and his or her situation, assessment is also concerned with the prediction of behavior in new situations. The way this information is collected, organized, and interpreted will depend on the purpose of the assessment. Answering a theoretical question such as "Are there double dissociations between long-term and short-term memory deficits?" requires a particular approach to assessment. In this book, our aim is to help provide practical answers to practical questions, such as "How do the memory deficits manifest themselves in everyday life?"; this aim requires a completely different mode of assessment.

In clinical practice, there are two main types of assessment procedures: those where standardized assessment tools are employed, and those where more functional or behavioral measures are used. These distinctive types of assessment enable us to answer different questions. Standardized tests can tell us how a client compares to others of the same age or the same diagnosis. They can determine the cognitive strengths and weaknesses of the person being assessed; for instance, they can help us decide whether a client has a pure memory deficit or more widespread cognitive difficulties. They can also enable us to estimate the probability of clinical depression and so forth. Standardized assessment procedures, however, are less good at answering other questions important in rehabilitation, such as how the client's family is coping; what the client sees as his or her major problems; what compensatory strategies have been tried; whether this person is able to return home or return to work; or what learning strategies should be employed in teaching the client new information. These questions aim to understand practical problems the individual may face in real life. Ultimately, they are aimed at making daily living better for both the client

and family. In another book, I (Wilson, 2009) provide further discussion of assessment and the characteristics of different kinds of assessment procedures; advice on assessment is also offered in each chapter of this book.

Formulation

When the assessment procedures have been completed, we can derive hypotheses regarding the nature, causes, and factors influencing a client's current situation and problems. In other words, we can come up with a "formulation." Formulation takes into account the multitude of possible influences on an individual's level of functioning and psychological state. It also helps the team, the individual therapist(s), and the client to understand the problems. In an interdisciplinary rehabilitation team, where a range of assessments (and interventions) may be carried out by different professionals, formulation helps bring together the results of these assessments into a single coherent whole. Included in the formulation should be a consideration of preinjury factors, such as the client's personality, occupation, and family support; the nature and type of injury, such as a life-threatening TBI; the extent of any losses, such as hemiplegia, memory impairment, and word-finding difficulties; and coping and adjustment issues. In the formulation process, cognitive, emotional, and behavioral consequences of the brain injury will be addressed, together with threats to identity and how the person makes sense of what has happened to him or her. Finally, the formulation should consider family and other social networks. Presenting this formulation visually, through a chart or graph, may help summarize the information and promote shared understanding (see Handout 1.1*).

A good clinical formulation should lead to appropriate and relevant interventions. We (Wilson, Robertson, & Mole, 2015) describe how formulation was used to set psychological therapy goals for Claire, who, following encephalitis, presented with anxiety symptoms that were formulated in terms of the threat to her identity. She had been a caring mother, wife, friend, and nurse. After the illness, however, she felt unable to run her household or take care of her children. Her anxiety symptoms further reduced her confidence in carrying out her household duties. Claire perceived a discrepancy between who she was before her illness and how she was defined after the illness. She had impairments in autobiographical memory and poor consolidation of new information. This, together with the perceived discrepancy, led her to do things to make herself feel "more like me" by the application of old, inflexible rules, and thus protect herself from this threat to her identity. The development of mood goals for her psychological therapy was based on this formulation.

Goal Setting

Goal setting has been used in rehabilitation for a number of years with various diagnostic groups, including people with cerebral palsy, spinal injuries, developmental learning difficulties, and ABI (McMillan & Sparkes, 1999). Because goal setting is simple, focuses on practical everyday problems, is tailored to individual needs, and avoids the artificial

*At the end of the chapter.

distinction between many outcome measures and real-life functioning, it is used increasingly in rehabilitation programs. Goal setting provides direction for rehabilitation, identifies priorities for intervention, evaluates progress, compartmentalizes treatment into achievable steps, promotes team functioning and cooperation, and results in better outcomes (Nair & Wade, 2003).

As mentioned above, it is important for rehabilitation to focus on the achievement of meaningful and functionally relevant goals. Levack et al. (2015) state, “There is general agreement that goal setting is a hallmark of contemporary rehabilitation and that skills in goal setting characterize those health professionals who work in this field” (p. 4). When we negotiate goals with our clients, their families, and the members of their rehabilitation teams, we are looking for something that the clients *will* do and *want* to do; these targets should reflect the clients’ longer-term goals and be steps toward achieving them. Goals are important regulators and motivators of human performance and action (Austin & Vancouver, 1996); ultimately, they are a desired outcome by which progress can be measured.

From the earliest days of goal setting in brain injury rehabilitation (Houts & Scott, 1975; McMillan & Sparkes, 1999), several principles of this approach to rehabilitation have been recognized. First, each client should (as far as possible) be involved in setting his or her own goals. Second, the goals should be reasonable and client-centered. Third, they should describe the client’s behavior when a goal is reached. Fourth, they should spell out the methods to be used in achieving the goals, in such a manner that anyone reading the plan would know what to do. McMillan and Sparkes (1999) summarize the principles of Houts and Scott (1975) and add to them by suggesting that goals should (1) be realistic and potentially attainable during admission, (2) be clear and specific, (3) have a definite time deadline, and (4) be measurable. These recommendations have been used to provide an acronym that reminds us that goals should be SMART (Specific, Measurable, Achievable, Realistic, and Timely; McMillan & Sparkes, 1999; Evans, 2012). Others have added an extra ER to make SMARTER goals, the last two letters referring (depending on the authors) to Evaluate and Revise (Yemm, 2013), Ethical and Recorded (Haughey, 2011), or Evolving and Relation-centered (Sherratt, Worrall, Hersh, Howe, & Davidson, 2015).

Kersten, McPherson, Kayes, Theadom, and McCambridge (2015) suggest some limitations of the SMART approach, but the main point is that the goals set for individuals in brain injury rehabilitation programs should be meaningful and purposeful for those individuals.

Long-term goals target disabilities in order to improve day-to-day functioning and should be achievable by the time of discharge from a rehabilitation program, whereas *short-term goals* are the steps set each week or two to achieve the long-term goals. Collicutt McGrath (2008) captures the essence of goal-setting philosophy when she states that ideally rehabilitation should be “patient centered *not* profession centered; participation/role based *not* impairment or activities based; interdisciplinary *not* multidisciplinary; goal directed *not* problem focused; individualized *not* programmatic” (p. 41; emphasis in original).

Awareness

“Awareness” is a term that can mean different things to different people. Broadly speaking, it is knowledge of a perception or a fact, but it can be interpreted in a number of ways.

Another term used regularly in neuropsychology is “anosognosia.” The term was originally coined by Babinski (1914) to describe people who denied their hemiplegia, but is now more generally used to mean denial or lack of awareness of illness (Wilson, 2012). It can be differentiated from “anosodiaphoria,” in which clients do not deny their illness but are unconcerned by their problems. The latter is associated with right-hemisphere lesions (Wilson, 2012). Also associated with right-hemisphere damage is “unilateral neglect” (a failure to report, respond to, or attend to stimuli on one side of space, usually the left; Heilman, Watson, Valenstein, & Goldberg, 1987).

When we talk about awareness after brain injury, however, we are usually referring to a person’s knowledge and appreciation of his or her problems. It can be argued that rehabilitation is hampered when clients are unaware of their difficulties. This may be true in part, but lack of awareness does not preclude improvement in rehabilitation. After all, we can teach simple tasks to people in coma (Shiel, Wilson, Horn, Watson, & McLellan, 1993), and children with severe developmental learning difficulties can learn skills (Cullen, 1976); yet neither of these groups have good awareness. Nevertheless, those who have reasonable awareness of their difficulties are indeed more likely to benefit from rehabilitation. Ownsworth, McFarland, and McYoung (2000) describe a number of studies showing that individuals who have a good outcome after ABI are typically those who recognize and appreciate their limitations, set realistic goals, and actively participate in rehabilitation (Bergquist & Jackets, 1993; Deaton, 1986; Lam, McMahon, Priddy, & Gehred-Schultz, 1988; Prigatano, 1986). One of the main purposes of a holistic program—and this book—is to help people with brain injury become more aware of, and develop a better understanding of, the changes that have occurred as a result of the damage they have sustained (Trexler, Eberle, & Zappalá, 2000).

The starting point for rehabilitation is always to establish a client’s level of awareness. The Crosson et al. (1989) pyramid model conceptualizes awareness by proposing three hierarchical levels: “intellectual,” “emergent,” and “anticipatory” awareness. Intellectual awareness involves recognition of deficits and an intellectual understanding of the implications of these deficits in everyday life; most clients will have some intellectual awareness of their difficulties on entering rehabilitation. Emergent awareness refers to an “in-the-moment” awareness, whereby individuals can recognize their difficulties as they occur. Finally, anticipatory awareness—regarded as the highest level of awareness—refers to an individual’s ability to anticipate when difficulties may be experienced in the future (Barco, Crosson, Bolesta, Werts, & Stout, 1991). Once a client’s initial level of awareness has been identified, interventions are targeted at moving up through these levels if possible.

In our experience, formal assessment has some contribution to building awareness. If the assessment is explained throughout and the client is aware of what each assessment is investigating, then the results can certainly contribute to developing intellectual awareness. Some assessments with good ecological validity (e.g., the Functional Assessment of Verbal Reasoning and Executive Skills; MacDonald, 1998) can imitate real-life tasks and allow someone to relate any struggles in the assessment to real-life experiences.

Questionnaires that explore a client’s perceptions of difficulties can also offer valuable insights. The effect is cumulative if a measure is replicated with the client’s significant other. For example, the La Trobe Communication Questionnaire (Douglas, O’Flaherty, & Snow,

2000) assesses both the client's and significant other's perceptions of the client's communication skills; the Patient Competency Rating Scale (Prigatano, 1986) asks clients to rate (on a scale of 1–5) how good they are at preparing their own meals, dressing themselves, keeping appointments, and so forth. An independent rater also completes the scale for each client, and this rating is used to determine whether the client has good or poor awareness of problems. Provided that the client's sense of safety is maintained, the feedback from the co-respondent can offer valuable insights. Video feedback can also be immensely valuable (see Keohane & Prince, Chapter 6, this volume).

Case Complexity

The content of any rehabilitation program provided is going to depend on a number of issues. These include the nature and severity of the brain damage sustained, the age of the person when seen, the person's age at the time of insult, and the status of the undamaged areas of the brain, as well as the person's premorbid cognitive functioning, personality, previous occupation, previous rehabilitation received, motivation, and family support. No client, however, is untreatable. Even those in a vegetative or minimally conscious state can benefit from rehabilitation (Wilson, Dhamapurkar, & Rose, 2016). Such clients cannot negotiate the goals, of course, but family members and other care providers working in the clients' best interests can consult as to the best way forward.

Robertson and Murre (1999) believe that the severity of brain damage determines whether or not rehabilitation is warranted. They suggest that those with mild lesions will recover spontaneously, that those with moderate lesions benefit from a retraining approach, and that those with severe lesions will require a compensatory approach. Although there may be some elements of truth in this belief, our opinion is that it is too simplistic and superficial. For example, the location of the lesion almost certainly plays a role in rehabilitation. Thus people with mild lesions in the frontal lobes may be more disadvantaged than people with severe lesions in the left anterior temporal lobe. The former group may have attention, planning, and organization problems precluding them from gaining the maximum benefit from the rehabilitation on offer, whereas the latter group, with language problems, may show considerable plasticity by transferring some of the language functions to the right hemisphere.

In addition, some people with a mild brain injury (defined as a confused state or loss of consciousness of less than 30 minutes, an initial Glasgow Coma Scale score of 13–15, and posttraumatic amnesia lasting less than 24 hours) can experience long-lasting problems. Ponsford et al. (2002) say that survivors of mild TBI can experience headache, dizziness, insomnia, reduced speed of thinking, concentration and memory problems, fatigue, irritability, anxiety, and depression, just like those with moderate or severe TBI. Furthermore, Ponsford et al. suggest that some symptoms may persist for years because of the stress of coping with reduced information-processing capacity.

As well as the nature and extent of the brain damage, we need to consider the influence of other factors on whether a person does well after a brain injury. Strong motivation, good family support systems, and the quality of rehabilitation available are likely to enhance success, whereas premorbid health problems, lack of social relationships, and reluctance to use

strategies in the belief that this is somehow “cheating” or will prevent natural recovery may lead to limited improvement.

Group or Individual Work?

The importance of working with individuals is inherent in the rehabilitation program at OZC. We need to address each client’s personal problems, involve him or her in the negotiation of goals, and find the best learning strategies for that individual. Nevertheless, all holistic treatment programs, including the one offered at OZC, provide both group and individual therapy (Trexler et al., 2000). We are all members of groups, be they family, work colleagues, social, political, religious, or leisure groups. Groups provide us with shared identities, roles, and peer support. We know that after brain injury many people experience a loss of roles and purpose, and experience a sense of isolation (Malley, Bateman, & Gracey, 2009); groups can help overcome this isolation. Many of the chapters in this book not only discuss individual work, but also suggest group work where this is possible.

Haslam et al. (2008) looked at individuals’ memberships in multiple groups prior to stroke and found that continuity of social identity (maintenance of group membership after stroke) predicted well-being. In the authors’ words, “Life satisfaction was associated both with multiple group memberships prior to stroke, and with maintenance of those group memberships” (p. 671).

In addition, therapists are invariably short of time, and one way of dealing with this is to treat people in groups rather than individually. It is also cheaper to treat several people at a time. A more important reason is that survivors of brain injury may benefit from interaction with others having similar problems. Sometimes they fear they are losing their sanity, and this fear may be alleviated by observing others with similar problems. Groups can reduce anxiety and distress. They can instill hope and show clients that they are not alone. It is often easier to accept advice from peers than from therapists, or to use strategies that peers are using rather than strategies recommended by the professional staff, so groups may lead to better learning of appropriate behavior. They may even result in altruism, such as supporting less able people within the group.

Group members may form friendships and reduce the feelings of social isolation. There is a saying that “nothing succeeds like success,” so staff members running groups can ensure success within them by making the tasks appropriate to each member’s ability level. This can further enhance members’ self-esteem.

Groups also have face validity. That is, clients and families can see the point of groups and *believe* they are a good thing; this belief, in turn, can improve motivation to participate. Finally, groups are educative for the therapists running them. Considerable information can be gained by noting each client’s responses to different strategies and observing which tasks are enjoyed or not enjoyed. Particular problems that arise can be observed and dealt with accordingly. In short, groups are a valuable treatment resource; they are important for people in distressing or demanding circumstances; and group acceptance and mutual support may bring about important clinical changes (Wilson, 2009).

We recognize that it is not always possible to run groups. This is especially likely to be true if therapists are working alone in the community. It may be possible to link with other

local services to form support groups; alternatively, clients and caregivers can be encouraged to use online forums to share experiences.

CONCLUSIONS

By way of introduction to this workbook, this chapter has outlined the philosophy and core components of the OZC holistic rehabilitation program, on which the book is based. The chapter has described the principles of rehabilitation and stressed that the program's main purposes are to improve clients' functioning in everyday life and to help them reconstruct their identities. It has also looked at the principles of assessment and acknowledged the need to employ both standardized tests and behavioral or functional measures when therapists are evaluating a person's strengths and weaknesses. The chapter has acknowledged the importance of goal setting to plan rehabilitation and the value of making the goals meaningful and relevant to each client. Consideration has been given as well to the concept of awareness, which can mean different things to different people, and to how different types of awareness (or lack of it) might affect the design of a rehabilitation program. The chapter has taken a brief look at case complexity and the factors that can influence response to rehabilitation. Finally, it has addressed the importance of providing group as well as individual therapy.

My colleagues and I hope that this book will provide resources to support the rehabilitation of survivors of brain injury, and will provide information and understanding to their families, caregivers, and employers—especially in cases where survivors and their helpers may not be able to access the services of a specialist team.

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