

Toward an Optimal Healing Environment in Pediatric Rehabilitation

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ABSTRACT

Although recent scientific advances have enabled us to minimize disability and improve the quality of life for people with disabilities and their families, cure is still not possible for many rehabilitation patients. This inability to cure renders the field of rehabilitation medicine particularly well-suited to the philosophy of healing. In contrast to curing, which is aimed at removing or reversing a disease process, both rehabilitation and healing are meant to enhance all aspects of well-being, restore integrity to the person, and facilitate the creation of meaning. Pediatric rehabilitation represents the interface of rehabilitation medicine and pediatrics, and is associated with unique characteristics that provide a natural context for exploring the optimal healing environment. This paper describes those characteristics and argues for the systematic integration and evaluation of healing interventions among children with developmental disabilities and their caregivers (parents, health care practitioners, and teachers). The ultimate aim of these interventions would be to improve all levels of the children's functioning in their homes, schools, and community environments by reducing impairment and increasing activity and participation. The paper concludes with a discussion of research priorities and the challenges imposed by different research strategies.

Rehabilitation of persons with catastrophic illnesses or injuries is a complex, labor-intensive interaction between patients and caregivers. Experiences of overwhelming loss and suffering evoke strong emotions that shape the behavior of both patients and staff during the rehabilitation process. In response to each patient's unique experience, compassion, caring and other humanistic qualities of the effective caregiver help create a healing environment.

—L. S. Halstead¹

THE CONTEXT OF REHABILITATION MEDICINE

Scientific and social advances

Over the past three decades, there have been significant scientific advances in the field of rehabilitation medicine. Biomedical knowledge has grown exponentially, par-

ticularly in the areas of genetics, neuroscience, and developmental neurobiology thereby affecting our understanding of neurodevelopmental and related disabilities. Whole new classes of disease have been delineated in the past 10 years. Major interventions in medical, surgical, behavioral, and technological sciences have resulted in a much broader choice of therapeutic options, with increasing scientific support for the efficacy of certain interventions. Investigators

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continue to build on the accomplishments of their predecessors.

Societal changes in the past 30 years have been equally striking. We have witnessed a major movement toward accepting people with disabilities and respecting their integrity and wholeness. This is reflected, in part, by the almost complete disappearance of terms such as “cripple,” “imbecile,” “deaf and dumb,” and a rejection of the phrase “disabled people” in favor of “people with disabilities.” In addition, the taxonomy used to describe the functional limitations associated with disability and assess the progress of people with disabilities was modified. In the late 1990s, the World Health Organization (WHO) ICDH-2 International Classification of Functioning and Disability (ICFD) changed the categories “disability” and “handicap” to “activity” and “participation.”² These modifications reflect a more positive, optimistic, and holistic orientation toward the evaluation process.

In addition, society has moved from an institutional model of care toward community-based models of care. Federal mandates ensure that people with disabilities have adequate health coverage and full access to their work and community environments, and families are increasingly being seen as partners in the care of their loved ones with disabilities. The Americans with Disabilities Act (ADA) of 1990 provides civil rights protections to people with disabilities.³ Since 1975, and the implementation of the Education of the Handicapped Act (in 1990 renamed IDEA—Individuals with Disabilities Education Act), many rehabilitation services required for the child to participate in the educational setting are provided within the school system, and typically in the classroom, with educational funding.⁴ Although our ability to minimize disability and improve the quality of life for people with disabilities and their families is impressive, cure is still not possible for many rehabilitation patients. This inability to cure renders the field of rehabilitation medicine particularly well-suited to achieving a balance between scientific and humanistic medicine, and highly receptive to the development and implementation of an optimal healing environment (OHE).⁵

The relationship between rehabilitation and healing

The definition of rehabilitation is remarkably similar to the definition of healing. Jennings⁶ defines rehabilitation as the restoration of the power or capacity for living, where living does not signify mere biologic life and function. It is the qualitative dimension of living well and living meaningfully that rehabilitation seeks to restore. Healing is defined as: “those physical, mental, social or spiritual processes of recovery, repair, renewal, and transformation that increase wholeness, and often but not invariably, order and coherence.”⁷ In contrast to curing, which is aimed at removing or reversing a disease process, both rehabilitation and healing are meant to enhance all aspects of well-being

and facilitate the creation of meaning. Jennings⁶ argues that in rehabilitation, disease or disability cannot be seen as an external enemy to be defeated with the assistance of medical technology and expertise. Nor is the “sick role” the proper lens through which to view the situation of the person with a long-term disability. Instead, the appropriate goals of rehabilitation are the restoration of integrity to the person and the preservation of a meaningful life and self-identity.”⁶

The transformative process that occurs in the context of rehabilitation is borne of caring rather than curing. In the face of disability or disabling injury, transformation can only take place in and through relationships of mutual giving and interdependence. In addition to tending to the physical needs and limitations of their patients, rehabilitation professionals tend to “a wounded human,” a person whose feelings of self-worth are shattered. By tending to these wounds, the caregiver develops an awareness of his or her own grief, loss, and sorrow. Those who are aware of their own wounds, the “wounded healers,” are the most effective healers.⁸ It is this knowing and understanding that empowers and leads to the thousands of undocumented, selfless acts of caring and compassion. This is the caregiver “as witness” who allows the patient to say, “If you can accept me in all the ways that I am wounded, then maybe, just maybe, I can accept myself.”¹

In pediatric rehabilitation, self-acceptance is vital to recovery for both the child and the parent. There are different strategies for promoting self-acceptance; some are mainstream and some are unconventional.⁹ However, fundamental to all such strategies is the importance of becoming more mindful about and focused on the present. Mindfulness is defined as moment to moment nonjudgmental awareness.¹⁰ By being in present time, participants can remain hopeful without attachment to or expectation of a particular outcome. It is this balance between hope and expectation that is likely to facilitate the healing process. Yet, in rehabilitation, it is easy for patients and their support circle to ignore or forget about the present while they nostalgically remember the past or long for a better future. Caregivers can help family members and the child learn to accept the child exactly as he or she is.^{11,12} Making use of the present moment and acceptance have healing qualities not because they reduce a disability, but because they impart a sense of worth, deepen hopes, and honor the personhood of each patient.¹³

In addition to the inherently transformative nature of rehabilitation, there are several quite tangible characteristics of the inpatient rehabilitation setting that promote healing. First, the process of rehabilitation is highly physical, helping to diminish a sense of physical isolation that can be brought on by disability.¹ Patients get up early every morning, they shower and dress, and follow an active schedule and meet with several different therapists in one day. They have to move from their rooms to the therapy areas. Some of the therapies take place in groups and some are individual. Either way, there are always one or more individ-

uals who encourage the patient. Moreover, throughout the day there is a considerable amount of touching and body contact. Unlike the physical contact that takes place in acute care medical settings, which is usually centering around physical examinations, withdrawal of body fluids, administration of medication or painful procedures, much of the physical interaction in rehabilitation involves “being held.”

Another factor that facilitates healing in rehabilitation is that care is highly individualized and interdisciplinary. Because deficits resulting from multisystem neurologic disease or injury are medical, physical, functional, communicative, behavioral, cognitive and social, therapeutic interventions aimed at all of these areas necessitate having a team of professionals available. This team includes, at a minimum, pediatricians, physiatrists, physical therapists (PT), occupational therapists (OT), speech–language pathologists, psychologists, and social workers.

All of these factors—an interdisciplinary team, a vibrant and supportive environment, a focus on the present moment—may have a healing effect not only on the patients but on the caregivers themselves. It is highly plausible that the levels of burnout, so prevalent among health professionals in other settings, are not as commonly observed among clinicians in rehabilitation settings. Unfortunately, the national data that exist on staff retention, burnout and turnover rates are either flawed by low response rates or categorized by type of professional (e.g., PT, OT.), rather than type of setting.¹⁴ Therefore, they are not helpful in answering this question.

Special characteristics of pediatric rehabilitation

Pediatric rehabilitation represents the interface of rehabilitation medicine and pediatrics, the combination of which results in some unique characteristics. First, the goal in pediatric rehabilitation is not simply to restore the child to premorbid levels of functioning, but rather “to facilitate development for the remainder of childhood and attain optimal functioning and quality of life in adulthood.”¹⁵ The Commission on Accreditation of Rehabilitation Facilities (CARF) describes pediatric rehabilitation as family centered, culturally sensitive, interdisciplinary, coordinated, and outcome oriented, where the outcomes are focused on “preventing further impairment, reducing activity limitations, and minimizing participation restrictions while maximizing growth and development.”¹⁶ The achievement of these goals will depend on the nature of the child’s disease or disability.

The second unique characteristic relates to the population served by pediatric rehabilitation, most of whom are children with neurologic deficits. Within neurorehabilitation, there are predominately three distinct groups of children. In the first group are children with developmental disorders. Some of these disorders are clearly congenital, such as spina

bifida and Down’s syndrome. Others, such as cerebral palsy, may be congenital or acquired during the perinatal period. Still others, such as autism, may not be apparent until the preschool years and will have lifelong consequences. The services provided to children with developmental disabilities are described as habilitative. They are focused not on regaining lost skills, but on learning ways to foster developmentally appropriate skills with whatever impairment or activity limitation the children might have.

In the second group, children are born healthy and grow up normally until they experience a traumatic event such as a brain or spinal cord injury. These events completely disrupt family life as it was previously known. Services provided to children with acquired injury are focused on regaining lost skills. This goal fits the truest sense of rehabilitation. Nevertheless, according to Ylvisaker,¹⁷ meaningful rehabilitation for a child after brain injury extends far beyond the treatments, equipment, and restorative exercises of medical rehabilitation: “Long-term success in a child’s life, years after the injury, is in large measure a function of supports provided in family, school and social contexts, and of the child’s skill and knowledge acquired in and applied to the many specific settings, tasks and activities that children encounter over the course of their development.”

The third population of children, less prevalent than the other two, are those who have degenerative disorders. These children seem to develop normally for a period of time. Then they begin to lose skills and eventually die at an earlier than expected age. Degenerative disorders include muscular dystrophy, Rett syndrome, and adreno-leukodystrophy. Rehabilitation for these children focuses on slowing the loss of function and helping the child and family cope with the disease process.

The nature of the child’s disorder, whether developmental, acquired, or degenerative, is likely to influence the child’s and/or the primary caretaker’s level of hope and expectation. For example, a 12-year-old child with cerebral palsy has only known himself or herself that way. Although the child still may have hopes of being different, the child has no lived experience of how else life could be. By contrast, a child with an acquired brain injury or degenerative disorder has an image of himself or herself without any impairments and, therefore, a set of expectations about returning to that previous state. Similarly, a parent of a child with an acquired injury may have more difficulty letting go of the image they had for their child’s future than a parent who gives birth to a child with a developmental disability.¹⁸ In the latter case, after grieving the loss of the child they did not have, these parents can focus on the as yet unknown potential of the infant and developing child they do have. Interventions aimed at developing an OHE therefore need to take account of the nature of the child’s disorder and its impact on hope and expectation.

The third distinguishing characteristic is the role of the parent/caretaker and other significant family members in all

aspects of care delivery. Children with disabilities, like all children, are dependent on others in their world to provide care and direction during their developing years. Although family members are usually involved in other areas of pediatric medicine, in pediatric rehabilitation, designated family members, usually self-selected, become the healers and are taught to carry out the therapeutic program in everyday life. In contrast to the dyadic nature of the healing relationships in the context of clinical nursing practice¹⁹ or clinical medicine,²⁰ caregiving in pediatric rehabilitation is always three-way. Ylvisaker and Feeney²¹ refer to an unpublished study in Brazil where indirect rehabilitation services carried out by well-trained parents produced superior outcomes to those carried out by rehabilitation specialists. Family members not only influence the well-being of the child with a disability, but having a child with a disability in the family can influence the well-being of family members.²² Some families, particularly those with deep religious faith, may feel “blessed” to have a child with a disability²³; others may not. Some research indicates that divorce and stress on siblings are more prevalent in this group of families.²⁴

Fourth is the longitudinal nature of much of pediatric rehabilitation, especially for children with developmental disabilities. In any pediatric population, the need for and intensity of services will change over time as the child develops. In the pediatric rehabilitation population, because many children are not “cured,” they need attention throughout their lifetimes. However, the type and intensity of service must change to reflect not only where the child is in life, but the particular needs of the child’s condition and the interaction between the two. Moreover, the needs of the family change over time. For example, a parent at the time a child is diagnosed with cerebral palsy has very different needs than that same parent as the child is making the transition from school to work. Less is known about the needs of parents during the latter stages of a child’s recovery from traumatic injury.²⁵ This is an important time point to evaluate because it coincides with a decreased access to rehabilitation professionals, and because the adult studies have suggested that parents’ unmet needs may increase over time.

Fifth, not only do needs change throughout development, but so also do the team players. For example, teachers become increasingly important in the child’s life because he will spend the majority of his waking hours in the school setting. The longitudinal nature of pediatric rehabilitation also influences the delivery of health care in two distinct but related ways. The first has to do with the inevitable involvement of sites other than the hospital where rehabilitation may be conducted or continues after discharge from the hospital such as medical day program, outpatient, and home-based services. The second implication concerns the continuity of care. Some children may continue to see their hospital-based team of therapists on an outpatient basis. Most children, however, will “transition” to a new community outpatient or school-based team. Although significant efforts

are made to make this transition as seamless as possible by identifying the new team prior to discharge, ensuring communication between caregivers at different sites and encouraging adoption of the same treatment approach and style in the new setting, challenges associated with transfer of training are well documented.²⁶ Less well-documented are the implications of transition on the healing relationships that family members have formed with the inpatient team of therapists and/or with a particular therapist in an outpatient setting.

A sixth variable, always present in the rehabilitation process, is the degree of resilience that the specific child brings with him or her. Because of the developing nature of the child, his or her strengths and weaknesses are not as “set in stone” as they might be with an adult. Resilience is broadly defined as a dynamic process encompassing positive adaptation within the context of significant adversity.²⁷ The resilience literature has focused on the identification of underlying protective factors that mediate children’s reaction to stressful experiences and chronic adversity. These factors may be within the individual (temperament, self-esteem, locus of control), within the family environment (e.g., caregiving styles or parenting) or within the community (e.g., a strong role model or a supportive friend).²⁸ It is not known whether resilience or adaptability is an immutable personality trait, or whether it can be modified or enhanced by a healing environment.

One of the potential obstacles to positive adaptation, and another common characteristic of pediatric rehabilitation, is the tendency toward “learned helplessness.” Ylvisaker and Feeney²¹ argue that, “in a rehabilitation context, clinicians and parents are disposed to intensify their control over children and adolescents with neurologic impairment, thereby potentially increasing the probability that the children will become increasingly helpless . . . rehabilitation programs in which clinicians fail to work collaboratively with and empower parents, and in contrast direct the parents in a unilateral manner, may unwittingly promote learned helplessness in the parents.”²¹ Learned optimism is the antidote to learned helplessness and provides a useful outcome against which to measure the impact of a healing intervention.

INVESTIGATING THE IMPACT OF OHE IN PEDIATRIC REHABILITATION

Rehabilitation literature in support of healing research

The conventional rehabilitation literature is calling for several major changes in priority that are aligned with the goals of healing research. First, in its statement of research priorities, the National Center for Medical Rehabilitation Research (NCMRR) calls for a shift in the focus of research from cause and cure to functional limitations. The NCMRR task force argues that, “the scientific enterprise needs to turn

its attention to the functioning of the whole person within our society. The goal of improving independent living for people with disabilities depends on the development of a science that recognizes that the whole is greater than the sum of individual parts.²⁹ Two of NCMRR's seven research priorities, behavioral adaptation and whole-body response, include factors that are directly related to components of an OHE.⁵ For example, NCMRR suggests that future behavioral adaptation research explore ways to facilitate the process of positive adjustment and full participation including community integration of both children and adults with disabilities. Similarly, NCMRR encourages a research focus on whole body adaptive mechanisms developed in response to chronic pain and an exploration of the body's ability to heal from within.²⁹

Second, the NCMRR also has identified the need to develop standardized measures of subjective well-being.²⁹ Some existing scales developed in other fields examine subjective well-being, but the sensitivity of such scales in rehabilitation in general, and pediatric rehabilitation in particular, requires exploration. For example, the concept of quality of life (QoL), which is defined as the perceived differences between an individual's hopes and expectations and their present experience,³⁰ is directly relevant to pediatric rehabilitation. However, most QoL research has focused on illness rather than disability, and hospitalized children rather than children in the community. Furthermore, although measures of QoL, resilience,²⁸ and self-efficacy³¹ have been used in the context of pediatric rehabilitation research, the distinctions between some of these concepts are not clear.²⁸ Pediatric rehabilitation provides an ideal setting in which to conduct the exploratory methodological work necessary to disaggregate such constructs (discriminant validity).

Third, there has been a shift in emphasis within the standard classification system established by the WHO's ICDH-2.² This system identifies and describes three levels of functioning: impairment, activity and participation. Impairment focuses on the loss or deviation of body function (e.g., paralysis or spasticity of an extremity). Activity refers to functional tasks that one needs to perform on a daily basis, such as walking and eating. Participation refers to one's ability to engage in daily life situations such as going to school, work, or church, or whatever other activities are a meaningful part of that individual's life. In recent years, the focus of rehabilitation research has changed from an emphasis on measures of impairment and activity to measures of participation. This shift was motivated by the need to capture the highly individualized nature of rehabilitation. For example, two individuals could have the same impairment and activity restriction (e.g., leg paralysis and inability to walk unassisted) and yet have different levels of participation. One could use a wheelchair and fully participate in a meaningful life, and the other could choose not to do so. When assessing the impact of an OHE, one should consider whether the intervention is appropriately targeting the level

of participation. Moreover, more sensitive measures of participation may need to be developed because identifying and assessing the components of participation, motivation, passion and interest is challenging. This focus on societal participation has also been identified as a research priority for the American Occupational Therapy Foundation.³²

Fourth, both the American and the Canadian occupational therapy literature highlight the importance of caring, hope, and spirituality in OTs' relationships with patients. Although spirituality has been a part of the Canadian written practice guidelines since 1983, it remains unclear how this translates into practice.³³ Survey research among American OTs also demonstrates uncertainty about the role of spirituality in practice and a lack of educational training in this area,³⁴⁻³⁶ as well as concern about whether caring oversteps appropriate patient boundaries.³⁷ More research is needed to explore rehabilitation therapists' attitudes, beliefs and practices regarding caring,³⁸ hope,¹¹ and spirituality.

Although each of the other specialties (physical therapy, speech-language pathology, physiatry, etc.) has a robust literature describing interventions and outcomes among specific populations in pediatric rehabilitation, most of this research does not shed light on the components of an OHE. The research literature in less conventional specialties that are not consistently part of the rehabilitation team, such as music and art therapy, suggests significant alignment with the goals of optimal healing. Music therapy has been shown to be effective in meeting the diverse needs of the child involved in rehabilitation, regardless of the level of functioning.^{39,40} Impairment and activity levels can be altered by playing musical instruments that encourages use of both arms, reach, grasp, coordination, strength of upper limbs and shoulder stability. Similarly, rhythmic auditory stimulation (RAS) can facilitate long-term gait training in patients with traumatic brain injuries.⁴¹ Techniques such as song-writing and improvisation can influence the child's level of participation by providing opportunities for children to express their feelings, communicate appropriately and identify strengths that restore a sense of self-worth and dignity and improve self-esteem.

Design and measurement considerations

The design of research to assess the impact of an OHE in the setting of pediatric rehabilitation must consider the unique characteristics of this particular context. The multiplicity of relationships in pediatric rehabilitation presents the greatest challenge for healing research. This challenge takes two forms: the identification of which population and/or relationship to target, and controlling for the impact of other relationships on the outcome being measured. Figure 1 depicts the primacy of the relationship between the parent and the child, as well as the other relationships that are meaningful to the parent-child dyad. Because the relative influence of other relationships will vary throughout the child's

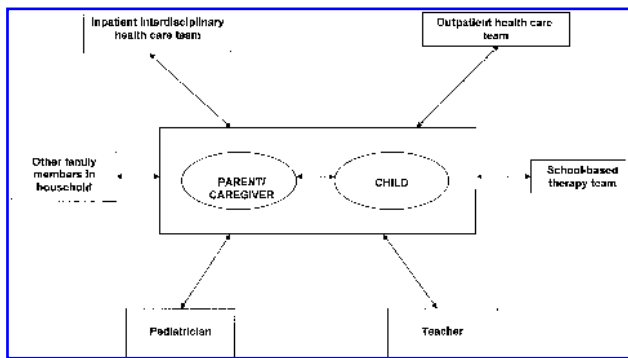


FIG. 1. Multiplicity of relationships influencing the parent-child dyad.

life, proposed research should consider the assessment of changes over time. The longitudinality of care that characterizes pediatric rehabilitation requires that studies be as comprehensive and “naturalistic” as possible.

If the target of the intervention is the child, appropriate research designs, questions, and methods must take into account the age of the child, the nature and severity of the disability, what the goal of the intervention is and where the child receives services. For example, school-age children with traumatic brain injury (TBI) will likely experience intensive inpatient services followed by transition to outpatient and school-based services all in a relatively short time. By contrast, children with developmental disabilities such as cerebral palsy, except when/if they are hospitalized for an acute rehabilitative need, will experience a more stable team of caregivers. Therefore, the design of studies involving children with TBI must consider the most appropriate location and duration of the intervention in order to maximize feasibility and minimize the influence of several uncontrolled variables. Another measurement challenge when studying children with TBI is how to differentiate normal developmental variations from functional manifestations of disability.⁴² With cerebral palsy and autism, classification of severity poses significant research challenges that do not typically exist with spinal cord injury or spina bifida.

Interventions will sometimes be more appropriately targeted to the parent. In this case, the design of healing-oriented research needs to consider the nature and timing of the intervention. For example, when children are newly diagnosed, parents are likely to be in a state of crisis. Depending on the nature of the intervention, this may or may not be an appropriate time to involve parents in research. To the extent that parents are in crisis, and that unmet parental needs²⁵ and poor family functioning⁴³ influence the outcome for children with TBI and other neurologic disorders, an appropriate intervention might be aimed at healing the parent and the family. Whether the target of the intervention is the parent or another of the child’s healers (e.g., clinician or teacher), the goal of such an intervention might

be to enhance self-care and wholeness. In this case, appropriate and highly sensitive outcome measures, such as improvement in, or balance of, energy, would have to be developed.

In general, the extant empirical literature on pediatric rehabilitation suffers from methodological problems in the definition and measurement of recovery and outcome.^{44,45} In addition, many of the validated instruments to assess the child’s activity and participation levels have been designed for parents. Children, themselves, have not often been part of the assessment process. In light of evidence that proxy responses by parents and teachers correlate poorly with the perceptions of the child they represent,⁴⁶ attention is now being paid to the exploration of new approaches that include children, as well as approaches that focus on environmental influences including and beyond the family.⁴²

Several well-validated measures do exist that address global health outcomes in children. Some of these measures are designed for very young children and some are intended for use with older children. As shown in Table 1, the ICIDH-2 serves as a useful framework for differentiating measurement by dimensions of the disabling process.⁴²

For example, the WeeFIM was developed to measure and track development of functional independence in children with disabilities, and is the most widely-used tool to assess the “impairment” and “activity” components of the ICIDH-2.⁴⁷ Instruments used to assess the “participation” component include the Rand Health Status Measure for Children (HMSC),⁴⁸ the Pediatric Evaluation of Disability Inventory (PEDI),⁴⁹ the Child Health and Illness Profile (CHIP)—Adolescent Edition,⁵⁰ the Child Health Questionnaire (CHQ),⁵¹ the Youth Quality of Life Instrument—Research Version (YQOL-S),⁵² and the School Function Assessment (SFA).⁵³ These instruments, along with measures of self-efficacy,³¹ learned optimism,²¹ the Grief Experience Inven-

TABLE 1. GLOBAL MEASURES BY DIMENSIONS OF DISABILITY

Measure	Impairment	Activity	Participation
HMSC		X	X
QWB	X	X	
WeeFIM	X	X	
PEDI		X	X
CHIP-AE		X	X
CHQ		X	X
YQOL-S		X	X
ABILITIES	X	X	
POSNA	X	X	
SFA		X	X

HMSC, Rand Health Status Measure for Children, QWB, Quality of Well-Being Scale; WeeFIM, Functional Independence Measure for Children; PEDI, Pediatric Evaluation of Disability Inventory; CHIP-AE, Child Health and Illness Profile—Adolescent Edition; CHQ, Child Health Questionnaire; YQOL-S, Youth Quality of Life Instrument-Research Version; ABILITIES; POSNA; SFA, School Function Assessment. From Ref. 42.

tory (GEI),¹⁸ the Motivational Assessment Scale,⁵⁴ and the Family Impact of Childhood Disability Scale (FICD)⁵⁵ would have greatest utility in assessing the impact of healing interventions on children with disabilities and their parents. These objective measures should be used in conjunction with more subjective measures since, according to the four-quadrant model proposed by Quinn et al.,¹⁹ subjective and objective measures provide different kinds of information and are best suited to different types of methodologies.

Proposed research

In our view, research priority should be given to the intrapersonal and interpersonal elements of an OHE and assessments of their impact on a child's level of participation. Intention, wholeness and compassionate, trusting relationships between children and their caregivers and among caregivers, form the basis of any transformative, healing experience. A comprehensive research plan would include two levels/types of research that can be conducted simultaneously.

Exploratory research

One type of research would involve the development of new and more sensitive instruments to complement the validated instruments listed above. For example, efforts to assess intention might benefit from a measure that discriminates between different types of expectation and their relationship to hope. Positive expectation is one of the critical attributes of hope,⁵⁶ but the difference between "positive expectation" and what we would consider a destructive type of expectation (i.e., "attachment to a particular outcome") is not understood. Similarly, in order to assess "wholeness and energy" it might be helpful to modify and validate the Mindful Attention Awareness Scale¹⁰ originally developed for use with patients' parents as a measure of "living in the moment." Measures of the healing relationship might tap assessments of partnership, physical contact, continuity in transition, child empowerment or level of "ease" between the parent and child. Exploratory, observational studies, "triangulated with qualitative inquiry,"¹⁹ provide the most appropriate starting point for the development of new measurement tools that would then be followed by rigorous quantitative assessments of reliability and validity.

In addition to exploratory qualitative research, exploratory basic research can be conducted to demonstrate physical mechanism or causality. Pilot studies can be carried out to determine the feasibility and sensitivity of neuroimaging studies,⁵⁷ and/or gas discharge visualization (GDV) bioelectrography,⁵⁸ to measure energy fields.

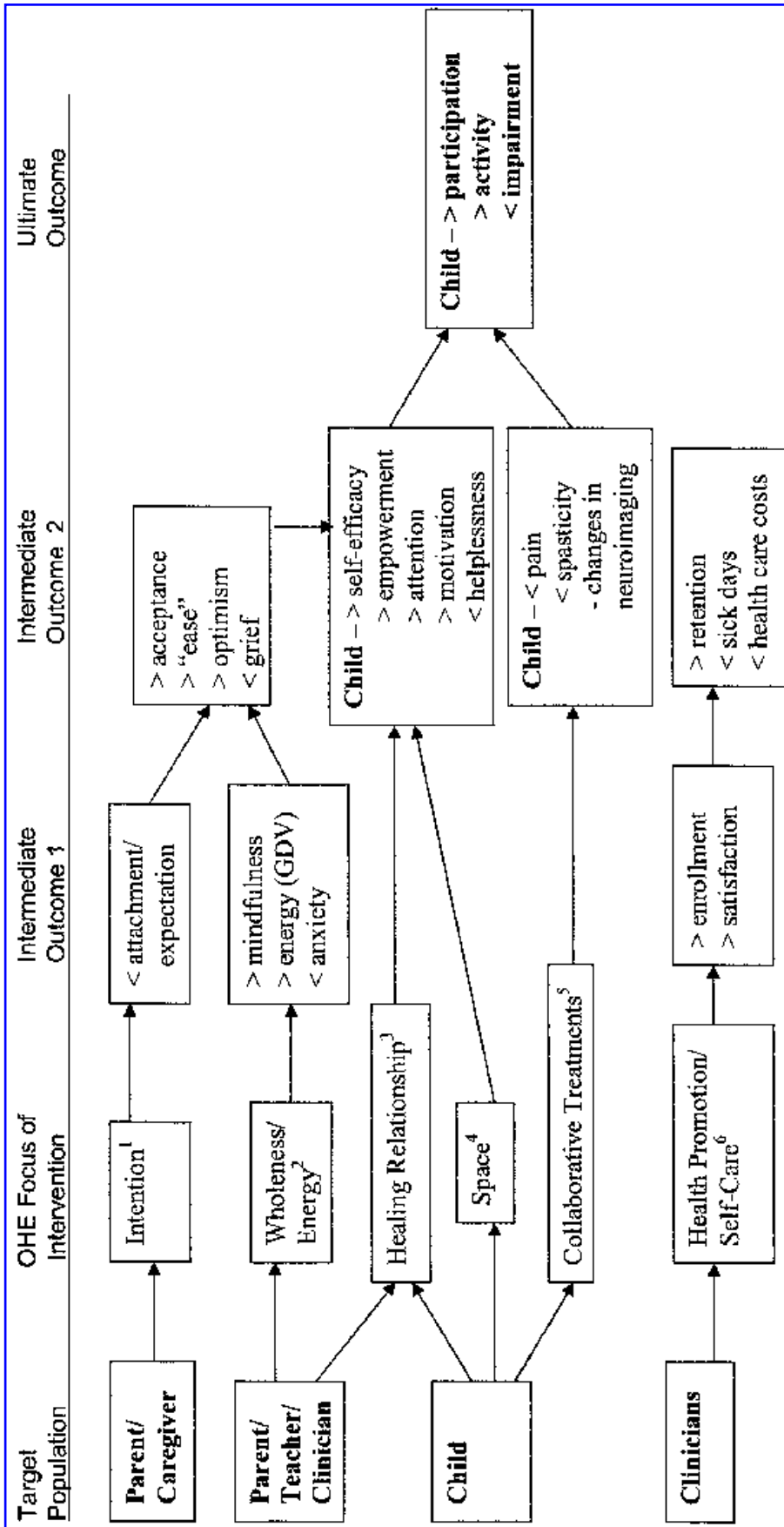
Outcomes research

Several interventions could easily be implemented within each healing component using measurement tools that al-

ready exist as above or are newly developed. Figure 2 provides a graphic representation of various target populations, healing interventions, research questions, and intermediate outcomes that can be envisioned as part of an OHE research plan. All of the proposed interventions have a common ultimate outcome: improving all levels of the child's functioning in the home, school and community environments by reducing impairment and increasing activity and participation. Healing interventions are more likely to have an impact on activity and participation levels than on levels of impairment. However, the ultimate outcome is preceded by several intermediate goals (process outcomes) that can be measured along the way. Depending on the particular hypotheses being tested, these intermediate measures could be considered independent or dependent variables. As shown in Figure 2, certain target populations are better suited for certain interventions, and the nature of the intermediate outcomes will vary according to type of intervention.

Healing intention and awareness. Because healing is an inherent goal of rehabilitation, we assume that rehabilitation therapists and teachers intend to be "healers," albeit to varying degrees. Therefore, an intervention in this category may be most powerfully aimed at the parent or significant caretaker. Such an intervention might focus on assisting parents to "let go" of expectations where expectation is defined as attachment to a particular outcome, and determining whether a shift in participants' hope and expectation creates greater "ease" between parent and child. Change in "ease" might be operationalized by a change in the nature of the "stories" parents tell about their children, or by developing a validated instrument. The effect of such an intervention might vary depending on the type and severity of the child's disability.

With certain disabilities, particularly acquired injury or degenerative disease, the parent may be so devastated that the child may become the most likely focus of an intervention to enhance healing intention. Such an intervention might be designed very differently. Ylvisaker et al.⁵⁹ describe a very individualized model for working with children following brain injury that focuses on positive supports, empowering the child and real-life participation. For example, one can imagine designing a community service-oriented study in which the child-participant assumes the role of "healer" by systematically providing gifts or services to those individuals who are most important in the child's life. Such a study could take the form of a randomized clinical trial, although the highly individualized nature of the child's lived experience as "healer" might be lost without the addition of qualitative methodologies. Outcomes may be increased self-efficacy, greater initiation (particularly meaningful in children with frontal-lobe injuries), and increased attention to task and participation in school. Any research that targets the child would have to consider the age of the child. We propose that because young children of less than



Proposal Research Questions

- ¹What is the impact of an intervention aimed at shifting parental hope and expectation in the level of ease in the relationship between parent and child; on the child's attention; level; on parental grief and acceptance; on the child's motivation and participation in school?
- ²What is the impact of offering *qigong*, yoga or drumming to parents, teachers and/or clinicians on their energy levels and balance (measured objectively) and mindfulness; on the child's level of participation?
- ³What is the impact of offering parents, teachers and/or clinicians an educational intervention about the healing relationship on the child empowerment/self-efficacy; on the child's motivation and participation in school?
- ⁴What is the impact of a healing environment (e.g., designing patient or treatment rooms according to *feng shui* principles) on treatment outcome; level of participation in therapy?
- ⁵What is the impact of offering energy healing or acupuncture to children on their pain/spasticity? On their functional magnetic resonance imaging; on their levels of participation?
- ⁶What is the impact of seated massage, *qigong*, or yoga for clinical staff on their use of sick days/annual health care costs?

FIG. 2. Proposed target populations, research questions, and outcomes for optimal health environment research in pediatric rehabilitation.

5 years of age cognitively are very dependent on others for their life functions, they are less likely to be active participants in research than the older child who has many independent skills.

Wholeness and energy. As with healing intention, the most likely target population for an intervention to enhance wholeness and energy could be the parent or other caretakers like clinicians and teachers. Often the parent is depleted of energy from his or her ongoing role as caretaker of a family who also has a child with special needs, the sudden trauma of “losing” a child as they know him/her or coping with the knowledge that their child is going to die. An intervention such as yoga or *qigong* might be implemented and evaluated in terms of changes in mindfulness or presence when with the child. Such changes could be documented qualitatively by coding videotapes or narratives, and/or quantitatively through the use of validated instruments such as the Maastricht History and Advice Checklist or scales that measure optimism or anxiety, or physiologic devices that measure changes in energy fields such as GDV. These same interventions and outcome measures may be applied to the older child.

Healing relationships. In pediatric rehabilitation, all the relationships are potentially important, with the parent–child relationship the most consistent and intensive over time. Healing relationships are very much dependent upon the intention and wholeness that each individual brings to the partnership. Interventions aimed at enhancing the healing relationship should be targeted to both parent and child. Outcome measures might focus on changes in the child’s self-efficacy, empowerment, attention, motivation, and optimism. Perhaps less of a priority, but important nevertheless, are interventions aimed at improving the physical environment, enhancing healing collaborations and promoting health.

Healing spaces. Changes to the physical environment that support and stimulate recovery and repair processes, such as the visual esthetics, sound, music, smell, taste, lighting, air, art, water, horticulture and architecture, would most likely be made to the child’s space. The purpose of such research would be to assess the impact of designing patient treatment or classrooms according to, for example, *feng shui* principles, on the child’s attention and motivation, and ultimately on his/her level of participation in therapy.

Healing collaborations. Collaborative treatment interventions would most likely be geared toward the child. For example, one might consider adding energy healing or acupuncture to traditional pharmaceutical management of pain. Pain management scales, prominent measures in more conventional research, could be readily used to evaluate the impact of such interventions, although measures of subjective experience, as well as assessment of changes in neuroimaging studies could be used as well.⁶⁰

Health promotion

Although health promotion interventions would be appropriate for any target population, high priority should be given to implementing self-care and health promotion strategies for clinicians and teachers, as well as parents. Often the responsibilities of caretaking interfere with self-care activities. Initial surveys should be conducted to assess the amount and type of self-care activities in which clinicians and teachers are engaged, to provide a baseline against which to measure change. Then, interventions such as massage, yoga, and other stress management techniques could be implemented, and the impact of those interventions measured by changes in staff turnover, number of sick days taken, and health care utilization rates. Another population that might benefit from health promotion interventions is teenagers with disabilities who are at increased risk of substance use and addiction.⁶¹

In summary, research designed to influence any of the components of an OHE in the context of pediatric rehabilitation must give careful consideration to the choice of target population, the appropriateness of the intervention and the sensitivity of the outcome measures. The Kennedy Krieger Institute has implemented several of these interventions (see Appendix), and intends to evaluate their impact in the years to come.

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APPENDIX. THE KENNEDY KRIEGER INSTITUTE (KKI): A CASE EXAMPLE OF AN EVOLVING HEALING ENVIRONMENT

The Kennedy Krieger Institute (KKI), located in Baltimore, MD, is an internationally recognized pediatric rehabilitation organization known for its excellence in patient care, research, training and community outreach. The Institute's mission is to "help children and adolescents with disorders of the brain achieve their potential and participate as fully as possible in family, school and community life." Founded in 1937, the KKI has grown to an organization of more than 2000 employees serving 10,000 children annually. These children are primarily from the greater Baltimore area, but also are referred from elsewhere in the United States and throughout the world. Many of them are poor and minority. Clinical services are provided on an inpatient rehabilitation unit, in over 40 outpatient clinics and in the community. The Institute also has a school serving 500 children annually.

What follows is a summary of various "healing" initiatives implemented over the past several years at KKI. We have divided them into five time periods that correspond to shifts in healing intention within the Institute.

Prior to July 1, 1997: As described above, many healing characteristics are inherent to the rehabilitation context. By virtue of being an interdisciplinary pediatric rehabilitation facility, KKI has always had many of these characteristics in place including the intention of caring, kindness, hopefulness and wellness. Care has always been family-centered, and patient and family education has always been emphasized. These characteristics remain present today.

Prior to 1997, there was no explicit intention to create a healing environment at KKI, but there were some organizational structures in place that were compatible with a healing environment. For example, intake for outpatient clinics was decentralized allowing for personalized attention to families in arranging for appointments, matching clinician skills with specific patients and in responding to inquiries. The staff making appointments knew the clinicians well and got to know families well.

July 1, 1997–June 30, 1999: During this time period, Medicaid in Maryland transitioned to managed care. Medicaid is a significant payor for the KKI and, in preparation for this shift, the KKI moved to a model of centralized clinical operations to meet the new requirements/challenges of managed care. Although this shift reaped many benefits, the diminished personalized contact with families adversely affected the healing environment of the Institute. During this period of transition, authorization for services was often interrupted, therapists were not as well matched with their patients, some patients were no longer able to receive services at the KKI, and emphasis was placed on higher productivity. Staff morale was low in large part because there was less time available for individual patient-related activities. In general, this transition to managed care only affected the health care segment of the Institute; there was little effect noticed by the school and research staff.

July 1, 1999–June 30, 2001: Having survived the Medicaid transition to managed care, staff were ready for a change. A strong grassroots initiative, the Service Excellence Program, emerged at this time to improve staff morale and enhance customer service. Approximately 50 staff members from all parts of the Institute, including the school and research sections, met and identified organizational strengths and challenges related to providing excellent relationship-centered care to individuals both internally (e.g., staff) and externally (e.g., patients/students and their families). Priorities were identified with input from all departments, and task groups were formed. Three staff members, representing nursing, social work and guest relations were chosen to lead these activities and became the Service Excellence Steering Group. This group has an identified senior administration liaison and reports to a senior staff advisory committee, which includes representatives from senior management, human resources, nursing, and clinical administration.

At the same time that the Service Excellence movement was beginning, a KKI board member introduced a world-renowned energy healer to the senior management team. The board member's stated intention was to unite an excellent healer and an excellent organization and see what possibilities emerge as a result of this collaboration. Through the efforts of the board member, private foundation funds were secured that enabled KKI to establish a center for complementary and alternative medicine (CAM), and allowed the energy healer to come to the Institute three times per year for 2 weeks to offer energy healing and conduct energy research. During this time, interested staff were trained in energy healing theory and techniques, staff and parent education focused on "healing the healer" was conducted, energy healing research was begun and children were treated with energy therapy in addition to traditional treatment regimens. During this

time, the operational procedures at KKI were changed back to a decentralized operations model to allow for more personalized patient/family interaction.

July 1, 2001–June 30, 2003: During this period, visits by the energy healer continued with more staff joining the training group. Service Excellence activities expanded including the addition of a second day to new staff orientation focused on customer service. This second day consists of five modules that were all developed and taught by grass-roots level staff.

The board member who had introduced the energy healer to the senior management team now introduced the president of the Tai Sophia Institute, a Maryland-based graduate educational institution dedicated to teaching healing principles and to the integration of complementary medicine into the health care system. A number of initiatives resulted from this collaboration including onsite training for KKI staff on the creation of healing relationships, the offering of seated massage and yoga to inpatient staff and parents, and the enrollment of seven KKI staff members in a masters degree program in the applied healing arts offered at Tai Sophia.

Perhaps not coincidentally, other intentional actions occurred during this time. Weekly family dinners were initiated for parents of inpatients, seven KKI staff were certified in energy healing, including a senior administrator (coauthor), Lana Warren, Ed.D., O.T.R./L, F.A.O.T.A.). Dr. Warren also enrolled in the Applied Healing Arts Masters Program. Through the establishment of a regular schedule of meetings, Dr. Warren became the liaison between the KKI and the president of the Tai Sophia Institute.

July 1, 2003–Present: Pockets of interest in healing activities began to grow in the Institute. During this time period, the assistant vicepresident of the school enrolled all of her supervisory staff in a training program on the development of healing relationships. Her staff is presently forming a task group to explore ways to create more healing and collaborative conversations with parents. The director of the autism program (also one of the seven trained energy healers, a principal investigator [PI] on one of the energy research studies, and trained in healing relationships) is leading her staff in an innovative training model that is intended to offer healing activities to the parents so that they may be more available to their children. One of the autism program staff, a student in the Applied Healing Arts program, has initiated the creation of a healing room for parents in the autism program.

Recently an onsite acupuncture and massage clinic for staff has been created in collaboration with the Tai Sophia Institute. One of the KKI's offsite programs successfully rallied to get acupuncture offered at their location and to have the healing relationship course offered to their staff. The Senior Administrative liaison has begun teaching mini healing courses to staff throughout the Institute upon request. The remaining centralized care centers are all in the process of decentralizing as they were prior to managed care.

Next steps

Over the next 5 years, training on the healing relationship will be offered to inpatient staff, new outpatient space will be completely gutted and renovated to ensure that healing qualities are present, plans will begin to build a new, state-of-the-art inpatient hospital the design of which will incorporate healing principles, trained energy healers will offer energy healing on a regular basis to eligible inpatients, neuroimaging studies regarding the impact of energy healing and other CAM modalities will continue, using the KKI's dedicated functional magnetic resonance imaging (fMRI) machine, and continuing efforts will be made to nurture the autism and school projects. For example, plans are underway for a "kids as healers" project in which they bake cookies, design message cards, and distribute the cookies to someone who is making a difference in their lives. This will be an extension of the KKI's Take One Share One (TOSO) initiative in which all new employees are given a bag of two TOSO cookies with a note inscribed as follows: "Thanks for choosing KKI. You make a difference. Enjoy a cookie and share the other with someone you feel is making a difference."

Summary

The KKI had a number of healing characteristics already in place due to the nature of pediatric rehabilitation. Following the stressful transition of Maryland Medicaid to managed care, a grassroots initiative by staff emerged to improve staff morale and service to families. At the same time, several healing initiatives were implemented that have increased over time as new pockets of interest emerge throughout the organization. Now, the intention to create a healing environment is conscious, and thoughtful planning is occurring regarding next steps. Key to this process has been the involvement of all levels of staff in the organization from the board level on down and the involvement of a senior administrative liaison who is in a position to create change.

Evaluation

Despite the implementation of many powerful changes at KKI over time, no systematic attempts have been made to evaluate the impact of these changes. Data already exist at KKI that could be reviewed retrospectively to assess changes over time, as in a “natural experiment.”

1. Staff turnover and retention rates.
2. Annual average health care costs per employee.
3. Patient, family, and referral satisfaction surveys.
4. Feedback from educational sessions.
5. Satisfaction/usefulness of Service Excellence (SE) modules for new employees.
6. Annual employee performance appraisals.
7. Number of formal complaints/concerns.
8. Staff use of onsite acupuncture and massage clinic.
9. Attendance at SE events, seated massage and parent dinners.

However, many of sources of these data are flawed by low response rate and recall bias of respondents. Prospective studies will be implemented over the next 5 years to evaluate the impact of new interventions designed to promote an optimal healing environment.