

Chapter 2

Families' Early Sessions, Emotional Status, and Treatment Themes

2.1 The Initial Consultation

Emotional support for family members is usually the by-product of the provision of neurorehabilitation therapies for their loved ones, especially in the acute aftermath of the injury, while the patient is hospitalized. As depicted in phases 1 through 3 of the Family Experiential Model (FEM) of Recovery, the primary caregiver's and close relatives', as well as the support networks' total preoccupation is with the crisis of the patient's injury, especially given the gravity of the news and the uncertainty of his or her survival (see Chap. 1, Sect. 1.5; Klonoff and Koberstein 2010; Klonoff et al. 2008; Turner et al. 2007). Understandably, the relatives want the emphasis to be on the best care for their loved one; they ignore and may even resent any emphasis by the health-care professionals on their own psychological needs. Although the primary caregiver and overall family may initially rebuff support, once the patient is discharged home, they begin to glean some appreciation of the magnitude of their responsibilities. They now may gain an inkling of how overwhelmed and grief-stricken they are, whether by their own self-appraisal or through input from others around them. Their feelings of helplessness and dismay may then propel them to seek at least some level of professional input and support. However, their principal motivation to do so is most often because they are seeking more help for their loved one.

In an outpatient treatment environment, it often comes as a surprise to the patient and caregivers that the family will be so central to the neurorehabilitation process. Typically, the first contact with family members is the joint interview with the psychotherapist, with their loved one present. Usually, it is the primary caregiver who attends the appointment and the patient (if capable) signs the appropriate medical release form to allow the family member to participate in the appointment. Components of the initial consultation with patients have been reviewed previously (Klonoff 2010). This includes the necessary physician referral, appropriate medical records and neuropsychological test results, as well as domains of inquiry (demographics, social history, medical history, injury-related data, patients' subjective reports of postinjury status, and current medical treatment; Klonoff 2010). Here, the primary emphasis is on the patient; the family member's function is to provide other associated history and input, especially if the patient is unable to recall relevant pre- and/or

postinjury information. Although the family may feel their role is perfunctory, the astute clinician will use the consultation as an opportunity to introduce the integral role and importance of the caregiver (i.e., tier 1), second-order family members or friends (i.e., tier 2), and broader support network (i.e., tier 3) for the loved one and each other. The therapist can also gather meaningful early observations about the primary caregiver's mood, demeanor, and psychological health through his or her clinical presentation, as well as the interaction patterns between the family member and the loved one (Klonoff 2010).

A fundamental aspect of the first session is to clarify the role of the psychotherapist in treating the family. The therapist needs to clarify who the identified patient is; in outpatient neurorehabilitation settings, it is the individual who has suffered the brain injury. The family members represent the concerned third parties in a collateral relationship, who are present to receive emotional support and education in order to maximize the harmony in the family relationships, so as to facilitate the best recovery for their loved one. They do not have a patient–doctor relationship; therefore, the information they share is not considered private or privileged. Outside of the neurorehabilitation setting for the patient with the brain injury (e.g., a separate private practice setting or clinic), family members may seek psychotherapy for themselves; in this case, they are the identified patient and their communications are considered privileged between themselves and their identified treater. In this latter scenario, the family members' overall psychological needs and interests are paramount and they may or may not coincide with the requirements and goals for the individual with the brain injury. In fact, the patient may not even be a participant in the sessions. Often-times, this type of therapy is undertaken when the relative (e.g., spouse) has some ambivalence about the future of the relationship or would benefit from his or her own psychotherapeutic relationship, secondary to the level of distress or other psychological needs. Therefore, it is imperative to obtain the family member's expectations of the therapy process, both for himself or herself and his or her loved one. If the boundaries of the therapeutic relationships involving the patient and family members are not clear, the psychotherapist has the ethical obligation to take the necessary time to define this, so that all parties are aware of the intent of the psychotherapeutic process.

In addition, written materials which describe the treatment process should be available at the commencement of psychotherapy. These should clearly delineate how family members are integrated into the treatment setting, including a review of the expected types of documentation related to the family's involvement and treatment. Figure 2.1 provides a sample explanation whereby the family members are receiving support and education as part of a holistic approach, but where the identified patient is the loved one who has sustained a brain injury.

2.2 Early Sessions

Once a mutual decision is made by the psychotherapist, patient, and family members to continue the psychotherapy process, a more in-depth assessment of the relatives' knowledge base, subjective impressions, emotional status, challenges, and needs

Neurorehabilitation Program Requirements:

Family Members:

Our clinical experience and program research indicates that the recovery and rehabilitation of your loved one is strongly related to the working alliance and education we provide to you. In addition, your experience and input is vital to our team efforts to understand and effectively treat your loved one.

Of note, your loved one is considered the identified patient in this setting. We will, of course, obtain the necessary medical releases from him or her to enable us to have open dialogue with you. Our role in working with you is to provide emotional support and instruction to enhance your loved one's adjustment, as well as his or her family relationships and community reintegration. As part of our documentation about your loved one's rehabilitation progress and challenges, you should expect that there will be content related to the treatment interventions being provided to you, as family members, also including relevant recommendations to support and educate you. Of note, as you are not the identified patient, there is no expectation of a patient-doctor relationship. Nonetheless, your involvement and focus on improving your awareness, acceptance, and realism about your loved one's brain injury is of paramount importance to the therapists in this setting and to your loved one.

Fig. 2.1 Sample explanation of the family members' role in holistic treatment

can be obtained through a separate follow-up meeting without the patient present. This form of inquiry is appropriate for both the primary caregiver(s) and the second tier of family supports, although generally it is the primary caregiver(s) who attends the first and early sessions. The patient is aware of this process and he/she has given written permission for this follow-up dialogue. As referenced in Chap. 1 (see Fig. 1.1), the family members' personality, emotions, and behavior "set the stage" for their interventions, and of course, a parallel process unfolds with their loved one. Table 2.1 depicts a list of important and common emotional and behavioral observations, which the psychotherapist can garner based on these initial interactions with the caregiver(s). Based on these first impressions, the psychotherapist can then formulate early working hypotheses, which are later refined based on follow-up contact. Of note, the family members' emotions and behaviors are fluid and can oscillate between many or all of these within one or more early sessions.

With respect to other salient factors, some clinicians prefer to utilize questionnaires or structured interviews to amass pertinent historical and practical information about the patient/family unit, based on the family member(s)' self-report(s), including caregiver burden (Nabors et al. 2002; see Saban et al. 2010, for a review; see Visser-Meily et al. 2004, for a review). However, I prefer a semi-structured approach, which covers topics using open-ended questions. Deviation from a scripted approach facilitates dialogue and is a more fluid outlet for family members to describe their

Table 2.1 Family members' presenting behaviors and the therapist's working hypotheses

Behaviors	Working hypotheses
Tearful, pessimistic, overwhelmed	Is the caregiver depressed and/or burned out?
Frustrated, angry, blaming, demanding	Has the caregiver had negative experiences with the health-care system prior to this interaction?
Anxious, passive, helpless	Is the caregiver in the "yellow warning" zone of coping? Does the caregiver have any of the necessary tools and/or psychoeducation to help himself/herself and the loved one?
Lonely, resentful, aloof	Does the caregiver have a wider support system helping himself/herself?
Composed, inquisitive, caring, attuned	Has this family member already had access to helpful resources? Does this family member have a "green adaptive" coping style?

unique perspectives and experiences. Again, the questions are applicable to the primary caregiver(s) and the broader family support system, based on whoever attends the beginning sessions. The topics and sample questions are presented in Table 2.2 and include germane aspects of their social history prior to their loved one's injuries. Many of these subject domains relate to the relatives' contextual realities, as defined in Fig. 1.1, namely their history, culture, environment, social context, psychodynamics, values, spirituality, and accomplishments.

As illustrated in Table 2.2, the interview also affords the opportunity for the psychotherapist to appraise the family members' current functional and psychological status (based on their personal account of the injury-related events); perception of their loved one's injury consequences and course of recovery; the relatives' current daily activities, stressors, and coping paradigms; the relatives' priorities, goals, and aspirations for their loved one and themselves; and the family's support system. This last factor is noteworthy, as it begins to frame the overall support system, based on the tier 1 (i.e., main caregiver(s)), tier 2 (family and friends who are actively involved), and tier 3 (relatives, friends, and community contacts with adjunct roles). With all of this input and material, the psychotherapist can now better collaborate with the patient and family to devise the next steps in the psychotherapy process, namely to ascertain their baseline level of awareness, acceptance, and realism.

2.2.1 A Baseline Determination of the Family's Awareness, Acceptance, and Realism

As a gauge of the direction of psychotherapy, the psychotherapist should obtain an overview of the family members' beginning level of awareness, acceptance, and realism about: (a) their loved one's injury sequelae and (b) their own situation, challenges, and needs. *Self-awareness* has been defined as "the understanding and acknowledgement of postinjury neurological strengths and difficulties, as well as their functional implications" (Klonoff 2010, p. 46). *Acceptance* is the individual's "ability and willingness to cope with his or her new reality and identity" (Klonoff 2010,

Table 2.2 Relatives' history and current functioning

<i>Social history</i>	
<i>Topics:</i>	<i>Sample inquiries</i>
Birthplace, family structure, and childhood development	Where were you born? Describe your childhood and family structure
Educational history	How much education do you have? Where were you trained?
Marital status (and prior marriages)	How long have you been married? How many times have you been married? Do you have children from your current marriage? Do you have children from your prior marriage(s)? How much contact did you have with your children prior to the injury?
Preinjury living situation	What was your preinjury living situation? Who was in charge of various household chores and responsibilities?
Preinjury occupational history	What type of work did you do prior to your loved one's injury? Was it full- or part-time? Did you enjoy your work? Was it stressful?
Preinjury financial status	What was your preinjury financial status? Were there any stressors?
Preinjury psychiatric history and treatment	Have you ever seen a psychologist or psychiatrist? For what purpose(s)? Did the treatment help? If so, how?
Preinjury substance use/abuse	Did you drink, smoke, or use street drugs prior to your loved one's injury? Have you ever had a problem with addiction to alcohol or drugs? Did you pursue treatment for this problem? Was the treatment successful?
Preinjury challenges and "traumas"	Have you ever experienced any prior challenges, or life "traumas"? How did you deal with these?
Preinjury relationship with your loved one with the brain injury	What was your preinjury relationship with your loved one who has the brain injury?
Preinjury supports	What values are most essential to you? What was the role of spirituality and faith in your life preinjury?
<i>Subjective report of postinjury status:</i>	
<i>Topics:</i>	<i>Sample inquiries</i>
More detailed exploration of the family's injury-related experiences	Describe the circumstances of your loved one's injury How were you notified and by whom? How would you describe his/her acute care? How has it been since he/she came home?
More detailed exploration of the family member(s)' perception(s) of injury-related sequelae and interface with health professionals	How have you acquired information about your loved one? How has the experience been in interacting with health professionals thus far? Describe the physical, cognitive, emotional, and functional challenges of your loved one

Table 2.2 (continued)

	How have these affected you and your relationship with your loved one?
Perception of their loved one's course of recovery	Which problem(s) affect(s) you the most and why?
Current daily activities (i.e., work, hobbies, and leisure) and finances	What is your sense of your loved one's recovery—is he/she improving, or not?
	How do you spend your day?
	Are you working?
	If yes, how has your work been affected?
	If not working, how is your family supporting itself?
	Do you have time for hobbies or leisure and what are they?
	Do you have time to see friends and socialize?
Overall stressors and coping paradigms	What are your current emotions?
	What is going well for you right now?
	What are your main stressors?
	Are you experiencing changes in your appetite, sleep patterns, or energy level?
	What do you miss the most?
	How are your other family members doing?
	How have you and your other family members coped with the stressors?
Priorities, goals, and aspirations for their loved one	What are your priorities for your loved one?
	What are your aspirations for your loved one?
	Where do you see your loved one in 6 months?
Priorities, goals, and aspirations for themselves	What are your own priorities?
	What are your aspirations?
	Where do you see yourself in 6 months?
More detailed exploration of current supports	How many relatives and friends are involved with the care of your loved one who sustained the injury?
	What types of assistance do they provide?
	Do you feel you are getting sufficient help?

p. 100), typified by embracing and implementing compensations (Klonoff 2010). *Realism* represents the “integration of accumulated internal perceptions and external life experiences to produce healthy judgments and attainable objectives for the future” (Klonoff 2010, p. 198). Table 2.3 contains baseline determinants of the family members’ degree of awareness, acceptance, and realism. These are divided according to “limited” versus “good” indicators. This prototype is helpful, as it can be used with multiple members of the support system, including the primary caregiver(s) as well as associated relatives and friends. It captures the initial breadth and depth of the overall support network’s degree of attunement with the complexities of the injury and its impact on themselves.

2.2.1.1 Awareness

Table 2.3 describes two broad categories of the baseline determinants of awareness in the family members after brain injury. The first grouping relates to questions about the patient, that is, the relatives’ loved one. This pertains to how well the caregiver/family initially understands and acknowledges to the therapist, the nature and extent of

Table 2.3 Baseline determinant of family members' awareness, acceptance, and realism

<i>Limited awareness</i>	<i>Good awareness</i>
<i>Patient-related inquiries:</i>	
1. Spontaneous acknowledgment of physical injury-related changes only, without recognition of cognitive, mood, or psychosocial sequelae based on open-ended questions (what changes have you observed in your loved one?)	1. Spontaneous identification of a broader range of physical, emotional, cognitive, and psychosocial difficulties, based on open-ended questions (e.g., what changes have you observed in your loved one?)
2. Ability to identify one or two rudimentary nonphysical, postinjury difficulties with direct questions (e.g., what thinking changes have you noticed? or how has your loved one's memory/personality changed?)	2. Ability to recognize the saliency of cognitive, personality/mood, and interpersonal difficulties (compared with physical problems) for the loved one's overall adjustment
3. Significant underestimation of the severity of possible deficits based on a rating scale (see Table 2.4: no problem; small, medium, or large problem) compared with objective data (e.g., medical/neuropsychological data) and/or their loved one's subjective self-ratings	3. Deficit ratings on Table 2.4 are "in the ball park" based on collateral objective data (e.g., medical/neuropsychological records) and/or subjective ratings by their loved one
4. Inability to generalize possible injury-related difficulties to community environments (e.g., school or work)	4. Ability to generalize how the injury-related difficulties affect home and community independence as well as productivity
<i>Caregiver/support network topics:</i>	
1. Reluctance or unwillingness to acknowledge possible deleterious or stressful effects of their loved one's neurological event	1. Ability to acknowledge that the neurological event in their loved one has had a life-altering effect, including certain stressors
2. Lack of insight into the need for outside treatment for themselves and therefore reject help	2. Recognize and communicate openly the need for outside professional interventions for themselves
<i>Limited acceptance</i>	
<i>Patient-related inquiries:</i>	
1. Lack of "buy in" into the potential value of compensations for their loved one and unwilling to participate in the training process	1. Receptive to the idea of compensations for their loved one and interested/coachable in the training process
2. "Yeah buts" and rejection of available objective feedback from collateral sources (e.g., school grades and work-performance evaluations)	2. Receptive to the meaningful contribution of existing postinjury objective external data to their loved one's symptom picture
3. Expect a full recovery in the patient "no matter what"	3. Open to the idea that a full recovery may not be feasible
4. Want instant results for their loved one	4. Realize that "things take time" and that the recovery process is slow and arduous
<i>Caregiver/support network topics:</i>	
1. Present with a defensive, demanding, or argumentative stance about how they are coping with their circumstances	1. Are cooperative and amenable to inquiry about how they are coping
2. Are distrustful of the motives of the psychotherapist regarding providing the family with assistance and relief	2. Are trusting that the psychotherapist will have the family's best interest at heart

Table 2.3 (continued)

3. Are unwilling to commit to and engage in the therapy process for themselves, thinking it is superfluous	3. Are eager to immerse themselves in the therapy process
<i>Limited realism</i>	<i>Good realism</i>
<i>Patient-related inquiries:</i>	
1. Overly idealistic, with the “shoot for the stars” and “prove the doctors wrong” mindset about their loved one	1. Practical and “down to earth” approach, yet hopeful about their loved one
2. Overshooting school/work goals, based on their loved one’s neurological limitations	2. Reasonable fit between their loved one’s neurological limitations and their work/school aspirations
3. Overreliance on community supports at school and work to ensure their loved one’s success	3. Appropriate level of community supports at work and school to ensure their loved one’s bona fide accomplishments
<i>Caregiver/support network topics:</i>	
1. Insufficient planning for the realities of the changes in their own circumstances, resulting in “being spread too thin”	1. Initial steps taken to accommodate their complex circumstances, so as to aptly juggle multiple responsibilities
2. Resentful of others who suggest the need for reconfiguration of schedules and priorities, at least temporarily	2. Appreciative of others who suggest or actively volunteer to provide assistance so as to reduce strains

his or her loved one’s injury consequences. In this regard, there are gradations of awareness, as oftentimes, the physical compromises are at first more obvious to the family, while the cognitive, emotional, and interpersonal factors seem more elusive (Smith and Godfrey 1995). Therefore, when the psychotherapist asks general questions (i.e., what changes have you observed in your loved one?), the family with “limited” baseline awareness may spontaneously identify only one or two obvious physical difficulties (e.g., balance or vision changes), yet be unable to identify other cognitive, mood, or psychosocial challenges. Even with direct questions (e.g., what thinking changes have you noticed? or, how has your loved one’s memory/personality changed?), relatives with “limited” awareness will show a dearth of insight, with a tendency either to negate any other difficulties or acknowledge only one or two rudimentary changes (e.g., forgetfulness). Conversely, when the psychotherapist asks open-ended questions about the family’s perception of injury-related changes, those with “good” beginning awareness are able to spontaneously identify a broader range of physical, emotional, cognitive, and psychosocial difficulties. With further inquiry, they recognize the saliency of cognitive, mood, and psychosocial problems as impediments to their loved one’s level of adjustment.

Emotional and behavioral symptoms are crucial to evaluate (Jackson et al. 2009). Therefore, another mechanism to abstract the family’s early perceptions is to ask direct questions about specific injury effects based on multiple domains. Table 2.4 is a family checklist which contains severity ratings of a number of common neurologically based physical, cognitive, language, emotional, behavioral, and psychosocial deficits which may be negatively impacting the family. Ratings can be based on numerical values (e.g., 0 = no problem; 1 = small problem; 10 = large problem) or

descriptive terminology of none, small, medium, or large problems. This represents a more extensive overview of possible patient characteristics which could be most troubling to and cumbersome for the family. Depending on the preference of the psychotherapist, he or she can either obtain verbal ratings from the family or, alternatively, have the family members provide written ratings. Families with more “limited” baseline awareness will provide ratings which are at the lower, less impaired end of the spectrum, relative to what other medical and neuropsychological records indicate. For example, if a family member rates memory and attentional problems in his or her loved one as a small problem, while neuropsychological test data suggest large (or severe) deficits, the psychotherapist can hypothesize that the family is underestimating the severity of the deficits, suggesting that they may not be fully aware of the seriousness of the injury. A hallmark of limited awareness in family members are less severe ratings of injury deficits compared to those of their loved one, especially when collateral data are also contradictory to the family’s ratings. However, the scores on the Deficit Rating Scale by families with “good” preliminary awareness are “in the ballpark,” based on good concordance with collateral objective data (e.g., medical and neuropsychological test data). Generally, the family’s perception of the severity of problem areas are higher than the perception of their loved one, secondary to his or her organic unawareness.

As depicted in Table 2.3, another mechanism for assessing the family members’ initial awareness of their loved one’s injury sequelae is their ability to generalize possible deficits to the “real world.” This includes whether or not the relatives recognize that certain deficits would hinder community activities. For instance, if the family endorses big problems with memory, speed of thinking, and attentional skills, but then suggests that their loved one is capable of returning to graduate-level coursework in a university or highly cognitively based occupations (e.g., law, medicine, engineering, etc.), the psychotherapist may begin to surmise that the family members do not fully understand or are not able to acknowledge how their loved one’s challenges are translating to functional difficulties.

As indicated in Table 2.3, the other index of family members’ baseline level of awareness is their insight into their own predicament. For the more aware family, this includes their realization that the neurological event in their loved one has had a substantial and enduring effect on their own existence. The relatives also perceive that they need assistance from outside professionals (phase 3 of the FEM), as there is a limit to their own knowledge and experience with the effects of brain injury in a loved one. In contrast, the family with “limited” early awareness communicates a reluctance or unwillingness to acknowledge the deleterious and/or stressful aspects of their new lifestyle. Due to their poor grasp of the complexities of their situation, they also discount the need for outside professional interventions.

2.2.1.2 Acceptance

Examples of markers of the family’s baseline acceptance are also presented in Table 2.3. As with the conceptualization of awareness, the acceptance considerations

Table 2.4 Family member's deficit rating scale. (Have the family member provide ratings of patient deficit domains. Use the following scale: No problem; Small problem; Medium problem; Large problem)

<u>Domain:</u>	No problem	Small	Medium	Large
<u>Physical:</u>				
Vision				
Headaches				
Dizziness				
Weakness/hemiparesis				
Overall coordination				
Tremors				
Balance				
Fatigue				
<u>Cognitive/Language:</u>				
Confusion				
Memory				
Attention and concentration				
Speed of thinking				
Reasoning and problem solving				
Decision making				
Organization				
Multitasking				
Impulsivity				
Initiation (getting tasks started)				
Perseveration (fixated)				
Understanding language				
Expressing himself/herself				
Reading				
Writing				
Spelling				
Arithmetic				
<u>Emotional/Behavioral:</u>				
Frustration				
Depression				
Anxiety				
Mood swings				
Feeling overwhelmed				
Irritability/anger				
Aggression/rage reactions				
Distrust				
Apathy				
Poor insight				
Childlike				
Restless				
Irresponsible				

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