Hospitalization

PPWRKSHP. I. J.

WORKSHOP OUTLINE

PARENT-TO-PARENT OUTREACH

Saturday, March 9, 1991

~~8:30~~ - 9:00 Introductions;
1. My Background
2. Group Sharing - names, children, ages
3. Goals of Workshop - Parent-to-Parent Outreach
   a. Parents have things to give professionals lack (special kind of empathy, understanding; sharing a viewpoint)
   b. Need skills so they can do what they want to do

~~9:00~~ 9:30 Brief Overview of Outreach Concept
1. Doing and Being
   a. Support isn't something you do (like fix a car)
   b. More something you are, a way of being
   c. A process, dialogue, must be willing to enter relationship with the other
   d. not an appropriate formula for every occasion
2. Dual Agendas
   a. You bring your agenda (be helpful, get parent to express feelings, prove you are resolved about your child's condition etc)
   b. Parent brings theirs (expectations, feelings, fears, need for understanding)
   c. Agendas may fit together naturally, but at times may clash
   d. Successful outreach involves reconciliation of agendas
3. Not a social conversation
   a. Need to go much deeper
   b. Goal is to achieve mutual intimacy, authenticity
4. Enter into other's reality, help them tell their story
   a. Don't impose your story on theirs
   b. Don't impose an official, clean-up version
5. Motivations
   a. Importance of thinking through why we're here; what we want to accomplish
   b. Conscious and unconscious motivations (conscious: help another; unconscious: lonely)
   c. Mutuality of support
      1. Giving help and receiving help (much harder)
      2. Healing others; healing self
6. Group Sharing: Positive and Negative Prior Parent-to-Parent Experiences
7. Goals
   a. Acceptance, friendship, understanding

b. New approaches to solving problems
c. Practical ideas for action and for working with their children
d. Opportunity to share feelings
e. Reduced isolation - awareness of common needs and strengths
f. Greater self-understanding and insight

9:30 - 10:00 The Grief Cycle: Loss of a Dream HANDOUT

1. Group Sharing: Most Vivid Memory from Diagnosis
2. Grief Cycle (didactic); caution against stage theory
   a. Denial - loss; confusion; fear; mistrust; denial of reality; denial of affect; denial of consequences; wrong stage to make decisions
   b. Anger (Guilt and Blame) - inward and outward; socially unacceptable; underlying reasonableness - rage at injustice of world; distinguish between situational anger in response to diagnosis and characterological anger using diagnosis as excuse
   c. Bargaining (Hope) - doctor-program shopping; miracle cures; inordinate time "teaching" child
   d. Depression - Avoid trying to argue parent out of it; allow parent some space to give up for a while; focus on activity, exercise, other life priorities
   e. Acceptance - feeling comfortable, accepting; focus is on here-and-now
   f. Understanding - personal transformation; desire to help others; feeling life enriched

10:00 - 10:30 Values (discussion)

1. Nonjudgmental - suspend opinions about others' feelings, thoughts, behaviors
2. Encouraging feelings - special value to an environment which allows the free expression of emotion; active commitment to interaction at this level
3. Offering support - willing to share pain as well as joy with parent; stand beside them
4. Therapeutic Core Qualities: (didactic) HANDOUT
   a. Respect - ability to accept other as unique
      - nonjudgmental
      - attentive, focused on other
   b. Genuineness - ability to be oneself in relation
      - expressing appropriate feelings
   c. Empathy - ability to sense other's experience and feelings accurately and communicate them back to other
      - show other she is understood
      - help other clarify what he is feeling

10:30 - 11:00 Listening Skills (didactic plus group practice)
HANDOUT

1. Nonverbal - eye contact; body posture; body language
2. Touch - mythic power of laying on of hands; appropriate reassurance of hug or pat; cautions regarding opposite gender touch; relating to infant - way of expressing appreciation and caring
3. Paralinguistic (voice quality, speed, silence etc)
   a. tone - warm, breathy, tentative
   b. speed - fast vs. slow
   c. pauses - express hesitancy; warning of important statement coming
   d. silences - facilitative if maintain eye contact; encourage additional communication
4. Understandable language - use uncomplicated, accessible speech
5. Minimal encouragers/facilitators
   a. Nods, mmhmms
   b. Yes? and then?
   c. repeating last word or key phrase; what else? tell me more
6. Clarification and paraphrasing
   a. both content and process
   b. to ensure you have heard what other said
   c. way of showing respect and empathy
   d. It's sounds like; what I'm hearing is; Help me to understand...
7. Open-ended vs. closed-ended questions
   a. Open-ended invite other to tell more, elaborate
   b. Closed-ended cut off interpretations, depth
8. Questions behind the questions
   a. What the other is really saying
   b. respond to feeling rather than content
   c. personalize meaning ("Some people would feel like it was the end of the world")
   d. withold judgment ("I don't know if I'll ever be able to accept his limitations" - hidden: does that make me a bad person?)
9. WH questions
   a. don't be afraid of specificity - sometimes the pain is in the details
   b. WHERE (did it happen?)
   c. WHAT (happened next?)
   d. WHEN (did it happen?)
   e. HOW (did it feel?)
   f. WHY (did it happen?)
   g. WHO (was affected?)
10. Confrontation
    a. reconciliation of discrepant information, versions
    b. goal not to prove other wrong, but to deepen understanding, authenticity
11. Limit-setting
    a. be honest with yourself about your own

limitations and resources
b. don't wait too long to set limits, thus allowing your anger to build up
c. communicate directly

11:00 - 12:00 Common Mistakes (discussion)

HANDOUT

1. Changing the subject (blocks communication)
2. Giving meaningless reassurance (reduces your credibility)
3. Giving stereotyped replies or using cliches (makes person feel their communication is trivial)
4. Giving advice quickly or peremptorily (solutions that obvious are rarely any good)
5. Excessive self-disclosure
   a. too much talking about yourself focuses discussion away from other
   b. appropriate sharing will increase other's willingness to self-disclose
6. Showing disapproval or judgment (other will withdraw)
7. Asking questions which begin with the word "why?" (interpreted as a demand for self justification)
8. Talking in generalizations and stereotypes ("Kids like these..." vs. "Your baby...")
9. Too much talking - (you are there to listen) tendency to fill space with words; words used as a way of relieving anxiety
10. Too positive/ too negative
    a. Occasionally, try to dampen denial with pessimism (It'll be harder than you think)
    b. More likely to be a cheerleader (excessive optimism invalidates their feelings, makes them wrong)
    c. Strive for authenticity
11. Telling others how to feel (only that individual can know her own feelings)
    feelings are not right or wrong

12:00 -

12:30 - 1:30 LUNCH; ~~Video showing "Life Goes On"~~ Discussion

12:30 - 3:30 Problem-Solving Tough Situations (role-play and discussion)

HANDOUT TIPS

Anger - acknowledging (I see you are angry)
normalizing (it's natural; many people)
self-disclosing (I had similar feelings)
encouraging verbalization (tell me about it)
avoiding cut-offs
discourage dysfunctional expressions
problem-solve solutions (behavioral rehearsal of direct confrontation;

practice letter-writing)

Denial - listen and encourage disclosure; the more they talk, the closer they'll come to real feelings

avoid telling other what to do or feel
if asked, share own experience
give them time; encourage them not to make decisions; keep door open for further discussion

Tears - self-disclosure: "I still cry"
normalization: "sadness part of being parents"
allowing of tears
avoid too-quick comfort
reassurance of your own comfort: "I'm glad you're able to cry with me"
validation of feeling: "This is really hard"
supportive silence

Adoption - avoid judgment
encourage communication ("Tell me about it")
show understanding ("I can understand why you would feel this way")
avoid advice-giving, even when asked by other
encourage communication between spouses
help create an atmosphere for careful decision-making

Extended Family - avoid taking sides
encourage parent to communicate directly with family member
provide support for parent
elicit parent's needs, priorities

Referral to Professional - assessment of suicidal risk
threats of violence to infant or other
lack of resolution at any stage of grief cycle
existence of underlying pathologies/conflicts
bizarre speech, affect, behavior

Dependency - willingness to acknowledge own limits
clarity from the start about what you are able to give
ability to set firm boundaries
clear communication when limits are violated
fear of not being seen as a "nice person"

Feeling Overwhelmed - willingness to acknowledge your own limits
awareness of point at which your own feelings pass comfort zone

taking time for yourself - not dedicating yourself exclusively to other
admitting you can no longer handle a particular situation and asking for help

Reactions of Spouse - partner doesn't leave because of DS but because of poor relationship and lack of communication
encourage communication between spouses
legitimize private time as couple
avoid colluding with parent in interpretation that problem is with the partner

3:30 - 4:00 Health Belief Systems: The Meaning of Disability

1. Metaphors of Disability:
   a. Challenge - something to be overcome; mastery model
   b. Punishment - from God or universe; sense of guilt, wrongdoing; sense of deserving; fatalism, self-blame, paralysis
   c. the Enemy - adversarial model; mobilization of resources; danger is a win-lose analysis
   d. Weakness - inadequacy, powerlessness, impotence; danger of masking; fear of exposure
   e. Loss - grief; vulnerability; depression, victimization
2. Dominant metaphor represents key stumbling block to be transformed
   a. Opportunity for learning, personal transformation
   b. Way of giving to others

4:00 - 4:30 Final comments, questions, wrap-up

SUPPLEMENTARY MATERIALS

Tips for Parents
Grief Cycle
Therapeutic Core Qualities/ Listening Skills
Common Mistakes
Diplomas

LISTENING SKILLS

1. Have a compassionate, caring concern for the speaker

2. Cultivate a respectful, nonjudgmental attitude toward the speaker

3. Take your time - periods of silence can be useful and healing.

4. Use attentive nonverbal behaviors, such as eye contact and posture, to keep exclusive focus on the speaker

5. Use touch in an appropriate, reassuring manner (especially with infant)

6. Pay attention to your voice tone; the speed of your words; as well as these aspects of the speaker's communication.

7. Allow the speaker to initiate the conversation

8. Encourage description and elaboration through WH questions

9. Help the speaker to clarify and express feelings through the use of minimal encouragers and open-ended questions

10. Note discrepancies between verbal and nonverbal communication

11. Attend to, and be willing to make observations about, nonverbal behaviors of the speaker

12. Express your own desire to understand the other, as well as, when appropriate, your own feelings of sadness, confusion

13. Clarify - through paraphrasing and restatement - to make sure you are hearing what the person is saying.

14. Be aware of, and willing to comment on, the emotional as well as the content message of the speaker

15. Listen for the questions behind the questions

16. Validate by acknowledging that the feelings, thoughts, confusions of the speaker are genuine; it is OK to express emotion

17. Provide information and explore alternatives

18. Encourage person to set goals and plan activities toward those goals

19. Be willing to set limits with the speaker based on your on abilities, skills, and resources

20. Summarize and review significant points of the communication

COMMON MISTAKES

1. Change the subject (blocks communication)

2. Give meaningless reassurance (reduces credibility)

3. Give stereotyped replies or use cliches (it makes the person feel that their feelings or communication are trivial)

4. Giving advice (usually, if solutions were that easy, the person could have figured it out on their own)

5. Excessive self-disclosure (you are not there to talk about yourself)

6. Show disapproval, judgment (person will withdraw)

7. Ask closed-ended questions (tend to limit other person's response; encourage you to do most of talking)

8. Speak and act inconsistently (smiling and laughing when you are nervous)

9. Ask questions that begin with the word "why?" (indicates you want the person to justify their statement)

10. Talk in broad generalities (your intention is to focus on the unique individual in front of you)

11. Talk too much (you are there to LISTEN)

12. Be excessively positive or negative (a cheerleader or a wet blanket)

13. Tell someone else how to feel (only the person knows her own feelings)

14. Use complicated or technical language (confuses other, tends to create distance between you and them)

THERAPEUTIC CORE QUALITIES

I. RESPECT

* Ability to accept other as unique person
* Nonjudgmental
* Being attentive, focused on other

II. GENUINENESS

* Ability to be oneself in relationship
* Expressing appropriate feelings

III. EMPATHY

* Ability to sense other's experience and feelings accurately and communicate them back to other
* Show other she is understood
* Help other clarify what he is feeling

TIPS FOR PARENTS

1. Don't assume anything
2. Offer handshake at introduction
3. Make experience personal (home visit; bring flowers, small baby gift)
4. Be aware of openings to call back; call back in a short time
5. Don't give advice
6. Avoid being critical or judgmental
7. Humor has its place; don't be afraid to laugh with your family
8. It's okay to stop the relationship if you feel there's a personality clash
9. Remember to keep time for yourself: don't get overwhelmed
10. There are negative aspects to having a child with Down Syndrome:
    don't overglamorize
11. Warn against reading dated material
12. Try to have both parents present
13. Try to have baby in the room; make sure you interact with baby in a positive way
14. Make a special effort to involve dads in outreach
15. Take pictures of your own children, but don't push them on parents
16. Encourage parents to take pictures of their child
17. Be ready, if necessary, to help referred parents with new medical terms and vocabulary
18. Remember you are there to listen
19. Be prepared to "wean" your parents; allow them to function on their own when they are ready
20. Ask for help from other outreach parents or staff when you need it

ROLE-PLAY SCENARIOS

PARENT-TO-PARENT WORKSHOP

ANGER: SCRIPT: You have just learned of your newborn's Down Syndrome diagnosis. You are angry with the world. Why did this happen to you? You are only 28 years old (not one of these old mothers who probably shouldn't be having children anyway). You took perfect care of yourself during pregnancy (not like some women who smoke, use drugs, drink). You've been planning for this baby, waiting till it was the perfect time -- financially, in your marriage. You are angry at your doctors - they told you without your husband present; they acted as though they didn't care that they had just destroyed your life. Even your husband doesn't seem to be there for you. And come to think about it, what can this parent from PROUD do for you anyway? You are mad, mad, mad, but remember that underneath the anger is tremendous pain and fear.

APPROACHES: Recognize the anger (you're angry right now). Normalize the anger (you have a lot to be angry about). Talk about your own anger. Help focus on the anger (tell me more about the anger). Set limits on inappropriate anger (I don't think you're really anger at me). Try to get beneath the anger to the hurt (What do you need from other people right now? From me?)

DENIAL: SCRIPT: You have just learned your baby has Down Syndrome. But hey, it's no big deal. Other people have to deal with much worse problems. You knew a kid with Down Syndrome on your block when you were growing up and she was very nice. In fact, you're feeling special - sort of chosen to take care of this baby. It's wonderful in a way. There are so many medical miracles these days that maybe in a few years someone will discover a cure. Also, maybe your baby just has a little bit of Down Syndrome - that's what your mother told you. Basically, you are denying that there's a problem; or you're denying that, if there is a problem, it's really a problem. Happy and accepting are the only emotions you are allowing yourself to feel.

APPROACHES: Acknowledge positive attitude. Be supportive without being directly challenging. Agree this isn't a tragedy. Talk about the whole gamut of emotions - normalize fact that, faced with this kind of experience, often a range of feelings emerges. Reflect on your own reactions - not judgmentally, but just from the perspective of how different people can be (Everyone was telling me how wrong everything was, I just wanted things to be right; the rest of my family was so depressed, I felt I had to be positive for them). Leave door open for expression of other kinds of emotions.

TEARS: SCRIPT: You are completely overwhelmed by your baby's diagnosis. You have not cried before, but now you can't stop crying. If your parent tries to stop you from crying, just keep breaking down. On the other hand, if your parent gives you permission to cry, is comforting without being emptily reassuring, compose yourself after a minute or two.

APPROACHES: Acknowledge pain. Give permission to cry. Allow space to cry. Reassure you're there for her. Share your own need to cry.

ADOPTION: SCRIPT: You are a young single mother. You and the baby's father are both students. He is supportive, but is feeling pretty overwhelmed. You are not sure you love him, or want to marry him. Your family is angry, both that you became pregnant, and that the baby "has problems." You had thought about adoption during the pregnancy, but had decided you would try to keep the baby. Now that you know the baby has Down Syndrome, this is the last straw. You feel it would be best both for you and the baby to put the baby up for adoption. You've heard there are lots of people who want to adopt a Down Syndrome baby.

APPROACHES: Avoid judgment. Make sure mom has made a careful decision - has she explored her feelings carefully? Who has she talked to? Are there important aspects she has overlooked?

ADOPTION II: SCRIPT: You are the baby's father. This baby does not fit in with your life plans. You are a high achiever, and you expect your son to be a high achiever. This is not the baby intended for you and your wife - the best thing to do would be to get rid of it as quickly as possible, before anyone has a chance to become attached. Your wife isn't so sure, but she's very upset now, and someone has to make a decision. A baby like this might do fine in someone else's family, but not your family. There are plenty of people who want to adopt a retarded kid, so why not let them? It's too bad this happened, but the best thing to do is to clear it up, and get on with your life.

APPROACHES: Avoid judgment. What makes it so important that decision be made immediately? Encourage more discussion with wife, perhaps others. Challenge gently: Is he so sure there's "no attachment" yet to this baby? Is he afraid this is a situation he simply couldn't deal with? Share own feelings of wanting to give baby away, "disappear" the whole situation. Support his need for freedom, for potency (I remember feeling so helpless, I just wanted to do something to show I was still powerful). Use metaphor (story of man rebuilding his car). Offer self as sounding board - maybe things will come up that he hasn't considered yet. Be low-key and nonthreatening, reinforce his crumbling image as competent, successful.

REACTIONS OF SPOUSE: SCRIPT: You have just learned your baby has Down Syndrome. You don't want to talk about your own feelings, you want to focus on your spouse. You are fine, but your spouse is falling apart. Only he won't even admit it. He won't really talk to you, but you see he's different with the baby than with your other children. He won't touch the baby or look at her. He's spending more and more time at work. He's not eating or sleeping well. You're really worried about him.

APPROACHES: Try to help her focus on her own feelings. Does she feel she has to take care of her husband as well as her baby? To address husband's problems, she needs to let him know she can give him space to deal with his feelings; she doesn't need anything from him right now. She can also model being loving with baby. Maybe she shares some of his feelings - it would help her husband feel like less of a monster if she could speak honestly about her own reactions to the baby.

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