Counseling family members of recently disabled persons

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Counseling family members of recently disabled persons

Abstract
The terms "acquired disability" or "adventitiously disabled" are used to describe a person who has had a normal physical development and normal lifestyle until an accident or illness caused the physical and/or mental disability (Buscaglia, 1975). The trauma associated with whatever led to the disability will have affected the disabled person. They may have been in serious condition and near death during the incident, may have faced the death and dying process and resolved it, or be stuck at one of the death stages such as anger or depression. They may be feeling helpless or suicidal. They may be acutely aware of what has been lost or have no memory or adult level mental functioning after the trauma (Marinelli & Dell Orto, 1984).
COUNSELING FAMILY MEMBERS OF RECENTLY DISABLED PERSONS

A Research Paper
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The terms "acquired disability" or "adventitiously disabled" are used to describe a person who has had a normal physical development and normal lifestyle until an accident or illness caused the physical and/or mental disability (Buscaglia, 1975).

The trauma associated with whatever led to the disability will have affected the disabled person. They may have been in serious condition and near death during the incident, may have faced the death and dying process and resolved it, or be stuck at one of the death stages such as anger or depression. They may be feeling helpless or suicidal. They may be acutely aware of what has been lost or have no memory or adult level mental functioning after the trauma (Marinelli & Dell Orto, 1984).

Another facet of disability is the gradual process of aging. Many families find themselves in the role of caregivers for an elderly parent that can no longer live by themselves. The families often are not prepared to cope with the changes in their lifestyle that are necessary when the aged parent becomes dependent on them for daily care (Norris, 1988).

In this paper the impact the acquired disability of a family member has on the family unit and the counselor's role in helping the family members adjust to the changes in
their disabled member and in their own lifestyle will be discussed.

Impact on the Family

When such disability occurs, the family and significant others experience stress, a sense of loss, frustration, fear, and anxiety. They may be people whose self-esteem has been deeply hurt (Buscaglia, 1975).

Individual family members may have mixed feelings toward the disabled person, such as guilt, hostility, grief, and loss of a valued family member as they knew him. They may be resentful toward medical personnel involved with the disabled person; feeling that not enough was done to prevent the disability, or that the person would have been better off dead. They may be over-protective, treat the individual as a non-person, make decisions for him, and not attempt communication and interaction with him. Their behavior may sabotage a rehabilitation program for the disabled person who is in need of their positive support (Marinelli & Dell Orto, 1984).

Family members will be concerned with income change and increased expenses. There might also be changes in social life, including some modification to accommodate the disabled member. Family roles may also change. The role of primary caregiver to the others may have been that of the disabled
person, or the bread winner role may be assigned to another out of necessity (Eisenberg, Griggsens, & Duval, 1982).

Others have indicated that even concerned and stable families can be overwhelmed and alienated from the disabled person by the residual effects of physical injury and the long term, progressive, and disabling results of chronic disease. Troubled families can, with support and counseling, maintain contact with the patient and contribute to the maintenance of patient goals. Family participation can increase the likelihood of a successful rehabilitation outcome for the disabled person (Marinelli & Dell Orto, 1984; Dew, Phillips, & Reiss, 1989).

Counselor Role

Early involvement of the family as a group will have a positive affect upon the disabled person and the family adjustment. Not all the disabled and their families will require extensive therapy but some form of counseling may be indicated. Studies indicated that while family members offered genuine attempts to help the disabled member, potentially destructive reinforcing behaviors were sometimes developed and maintained unless family therapy was implemented (Herbert, 1989).

Family counseling for the family and disabled person addresses primarily the information and feelings regarding
disability and resultant occurring behaviors. It encourages each member to gain more insight into self and others in the family. The counselor may wish to explore the impact the disability has on each family member as well as any pre-existing non-disability issues which may impact the adjustment to the disability. The counseling experience should help the family arrive at new choices, support them in gaining strength to assume responsibility for their decisions, and to plan together (Herbert, 1989).

Counselors can not tell the family what to feel or do. They must allow them to find their own insights, and encourage and involve them in experiences to rebuild their self-esteem. This will allow these family members to establish or re-establish confidence in the future. They will need to know that the counselor cares, that they are working together cooperatively. They need to feel that they are working through the problems to satisfying conclusions. The experience involves the same basic understandings as those for all good counseling experiences (Buscaglia, 1975).

The counselor will need to be able to inform, mediate, support, explore, and be available to carry out counseling with the family. Counseling guidelines suggest that the family members need the counselor to: identify and appreciate their feelings, encourage ventilation of hidden feelings
without turning them off or judging, keep the focus on the real crisis, and help the family realize that their feelings are normal and acceptable. The counselor may need to explore the family's ideas for coping with problems, and to listen without offering false hope. They may also need to identify what is essential and what is not essential for the disabled person's welfare (Marinelli & Dell Orto, 1984).

As in any counseling intake process the counselor will need to gather information from the family to establish what has happened, to assess where the disabled person and the family are at now, and what changes are desired by the family. An important factor in determining what direction the counseling will take is whether the disabled person will be able to participate in the family counseling group.

In the intake process, the counselor can gather early and recent family history that may be relevant to the counseling experience. Another significant area to explore is family participation in the care of the disabled person and which members are viewed by the patient as being most supportive (Dew, Phillips, & Reiss, 1989). In assessing where the family is, the counselor will ask for information and observe interactions that will establish what the family was like before the incident that caused the disability of one
of its members. For example, was it a nurturing family or a troubled family?

One of the distinguishing features of nurturing families is that they realize changes are inevitable. They can more readily make adjustments when something interferes with their planning. The nurturing family may be changed to a troubled family as a result of a family member becoming disabled but they can be guided towards being a nurturing family again.

A troubled or dysfunctional family may be a family that has not resolved earlier conflicts. In rehabilitation counseling practice, dysfunctional families have been described as non-accepting of the client's abilities and disabilities. The counselor may observe such behavioral patterns as loud and chronic complaining, program sabotage, extreme overprotectiveness, somatic complaints, overt hostility, avoidance of the person with the disability, and psychosocial deprivation or symbiotic relationships that involve an unhealthy relationship between the person with the disability and one or more family members. These behavioral patterns may manifest themselves either directly or indirectly and often severely dysfunctional families will contend that all is well or, given time, everything will work itself out (Herbert, 1989).
It is important for the counselor to be nonjudgmental and empathic with the family and to be aware of the losses experienced by the family and the disabled person. The counselor needs to be aware that disabled persons often experience negative reactions from people, and that family members may also be experiencing similar feedback from others.

The sincere counselor will strive to learn about the problems inherent to the type of disability in the family that is being counseled. Counselors should become aware of their own attitudes and biases toward clients with impairments. The cause of such reactions and their impact on the counseling relationship should be explored (Crespi, 1988).

In the article "We Are All TAPS," Warnath (1989) commented that, in contact with counselors in social situations, many of them seemed unable to cope with the implications of his blindness. They find themselves vulnerable in their relationship with those who lack one of the major senses on which their communication relies.

The attitudes of professionals who work with the disabled persons and their families are probably more important in determining the outcome of treatment than any other factor. What affects the disabled person will carry over to the family adjustment as well. The counselor needs to be aware of this in order to seek out information and inservice programs to
improve the counseling experience for all involved (Chubon, 1982; Zipple, 1987).

The counselor needs to know how to put the client family in contact with support systems to help the family, the primary caregiver, and the disabled member. The former network of support that the family had prior to the disabling incident may no longer be available or adequate for their present situation.

Support groups are especially important when persons are experiencing transition and stress. Support can be defined as any physical, emotional, financial or spiritual elements that help sustain us through difficult times in our lives (Springer & Brubaker, 1985). One study concluded that wives who had larger social support networks and demonstrated more commitment to them were rated as having better overall adjustment following their husband's strokes than those who had less support (Van, 1984).

The counselor may be the one to facilitate contact with other professionals according to the needs of the family and the disabled person. What resources are available is another area the counselor should be prepared to explore with the family. The counselor should be aware of the sources to acquire information about the disability and what other educational sources are available to the family.
The availability of respite care for the disabled person is another item of information the counselor can provide. If the disabled person is living in the family home, the use of respite care will no doubt be of vital importance to the primary caregiver. In many large communities there are adult day care centers sponsored and funded by human service agencies. Some support groups offer a network of caregivers who will provide respite care. The Agency on Aging often coordinates a Senior Companion Program whereby volunteer senior citizens will spend two to three hours a day with a disabled senior citizen providing companionship and light duty help such as reading or writing letters for the homebound. Many churches have a support system that involves respite care. An extended family group may also be the source of the respite care (Springer & Brubaker, 1985; Norris, 1988).

Nursing home placement is another option that may need to be explored. In placing a loved one in a nursing home or institution, a caregiver and family may experience feelings of sadness, fear, frustration, anger, guilt, failure, and relief. Counselors can help in sorting out the mixed feelings and in investigating the choices available. When nursing home or other institutional placement is being considered, the family needs to be encouraged to communicate with the
disabled person and have that person be as involved as is physically or mentally possible in the decision (Springer & Brubaker, 1985). The counselor can be helpful in encouraging the family to maintain family relationships with the disabled person even if the disabled person has to be cared for in a nursing home. Counseling can work toward relieving the sense of guilt, failure, frustration, and other mixed emotions that the family may harbor after the relocation is complete and they are adjusting to living without the disabled person. They can be encouraged to take the disabled person home for weekends and holidays for short visits (Marinelli & Dell Orto, 1984).

Disability is outrageously expensive, yet society determines that individuals must pay for their own care and that of family members. The family may have been fortunate enough to be part of an employer subsidized health insurance plan at the time of the incident that caused the disability. However, in most cases there would be a dollar limit on the amount paid by the insurance company and then the family would be forced to seek other financial assistance. Medication costs, continuing surgical procedures needed, special diets, and adaptive equipment needs, may severely strain the family budget. Money management, or how to obtain money to manage, becomes another source of concern and frustration for the
family of the disabled (Eisenberg, Griggens, & Duval, 1982). Again the counselor can ease some of the frustration by knowing how to locate sources of financial assistance for the family. They may also need to work toward easing the feeling of guilt or shame that family members may have in regard to accepting financial assistance from public assistance organizations.

After working through the seemingly unsurmountable concerns that go with being a family of a disabled person the counselor can be a facilitator in getting the family to want to look ahead and to plan for the future. Is there potential for rehabilitation, for future employment and/or independent living for the disabled person? Does the nature of the disability indicate the death of a disabled person in the near future?

Counselors need to recognize their own feelings on death and the grief process so that they do not let their own fear of death and loss cause them to fail to recognize the grief component of the client family's problem. It is crucial to the family to not gloss over the grief issues involved (Fitzgerald, 1979).

When rehabilitation is a likelihood, the family support to the disabled person will be important to the emotional outlook of the person and also of assistance in physical tasks needed to work toward rehabilitation. Other
professionals in rehabilitation will be working with the disabled person on an individual basis more than with the family. The family will still be needing the counselor support in mapping their future plans.

Another facet of future planning for the family is when the disabled person is awaiting an organ transplant and the hope is that the person will be able to resume a normal or semi-normal way of life once a transplant is received. The patient and the family may wait for months or years before an organ of the correct tissue match is available. Then on a moment's notice the organ is available and their lives change again. In waiting for a donor organ, as in the case of a kidney dialysis patient, the family will be hopeful that the transplant will be a success and that the patient will be able to resume a near normal life again. Through counseling, the possible outcomes can be explored. The counselor can help the client family be prepared to accept the outcome and/or plan for alternative ways to cope with whatever changes occur (Eisenberg, Griggens, & Duval, 1982).

Summary and Conclusions

In preparation for counseling families of a disabled person, counselors need to become familiar with problems associated with specific disabilities. Counselors need to recognize their own feelings about the disabled. Are they
comfortable talking with a blind person, who does not have
eye contact? Do they unconsciously view an amputee as an
incomplete person because arms or legs are missing?

An in-depth self-analysis by counselors will help them
to develop more empathy toward the disabled person and family.
The family may have similar feelings about the disabled person
and need help in working it through. Literature indicated
that counselors generally need more insight and information
in working with adults with disabilities (Chubon, 1982; Crespi,

Terminology about disabled people needs to be carefully
selected. Counselors are advised to avoid using descriptions
that portray people with disabilities in imprecise,
stereotypical or devaluating ways (Hadley & Brodwin, 1988).
Families will feel more positive about counseling if they
are influenced to describe the disabled person in specific
terms as they are, not as a stereotype with a label.

Counseling for families of a disabled person will be a
growing area of concern as more people survive accidents and
illnesses that in years past would have killed them. Medical
advances have enabled physicians to save lives, but not always
are they able to prevent permanent damage from the trauma.

Changes in concepts about disability, expansion of legal
rights and services to the disabled, and advancements in
rehabilitation have all improved awareness of the problems of disabled persons. As they become more visible to society, such changes are making life less difficult for people with disabilities.

No one is ever prepared for the sudden accident or illness that causes a healthy able-bodied person to acquire a permanent disability. Counselors need to be better prepared to help families adjust to this event when it happens.
References


