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LIVING AND ACTING IN AN ALTERED BODY: A PHENOMENOLOGICAL DESCRIPTION OF AMPUTATION

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Abstract

Adults with recent amputations are often perceived as suffering from post-operative depression and phantom limbs. These states are frequently seen as failures in "adjustment" since there are often few physiological involvements which curtail daily functioning. This perspective is seen as compatible with major American values of pragmatism, individualism, and a mechanistic medical model. We suggest here that problems in daily living and the phantom limb are not "mental" aberrations but rather reflections of a radically altered lived experience. The performance of the actor is significantly changed and can be discussed as a function of changed experience and style. This perspective draws upon the work of phenomenology and dramaturgy and suggests a changed philosophical approach in physical rehabilitation. A brief application of the model is also presented.

Most of the literature written on the behavior of amputees is psychological in orientation. For example, early reactions to the amputation by a group of amputees were categorized by Simon and Albronda (1967) as including disbelief, stunned feelings, fear and panic, anger, grief, relief, guilt, and revulsion. Another study, determining amputees' readiness to accept the stresses of prosthetic restoration, categorized personality types such as the undisciplined, the emotional neurotics, the blamers, the fearful, and the isolated and depressed hypochondriacs (Weiss, 1960). Levin (1961) found that denial and phantom limb are associated manifestations of amputation rather than cause and effect.

This explanation of behavior occurring after an amputation supports three major American values and models for behavior: pragmatism, individualism and the medical model. These social constructions are examined here and alternate models (phenomenology and dramaturgy) for explaining the behavior of amputees are suggested.

Amputation: THe Existing Literature and View

Amputations occur with the severing of one or more body parts. In this study, amputations of the limbs are the focus of interest because they comprise the major part of the literature, and they exhibit patterns

and problems similar to those occurring with amputations of other body parts, such as the breast and nose.

Amputations are primarily found in the adult as a result of vascular disease, trauma, or malignancy. The distribution of amputations is often further stratified by age. Vascular disease is responsible for a large number of amputations in the geriatric population. (Aitken, 1961.) A disproportionate number of young people are involved in accidents causing amputations, and malignant tumors affect all ages.

One of the major post-operative problems associated with amputations is the phantom limb and its accompanying pain. The persistence of "feeling" in the amputated limb has been a frequently encountered difficulty, affecting recovery and prosthesis fitting. One study of over 7,000 amputees treated during a twelve year period found that all amputees at one time or another suffer some phantom pain, although not all have persistent stump pain (Canty and Bleck, 1958). Many theories of its origin, cause and elimination have been put forth: local stump irritation (Canty and Bleck, 1958), a psycho-physiological entity (Frederiks, 1963), and psychopathology (Frazier, 1966). Problems associated with adjusting to the amputation have also been discussed as a function of changes in body image (Saxvik, 1965; Fischer and Cleveland, 1968).

Improvements in surgery and the development of more "life-like" and flexible prostheses have characterized the treatment of amputations.[1] The potential for improved techniques in replacing human parts and functions is even greater. Murphy (1965) cites some of the challenges: increasing knowledge in biology, medicine, surgery, and engineering; "tissue-friendly" materials; infection resistent passage of inert material through the skin; reliability; minimum bulk; and developing the appropriate size and appearance.

Reading this medical literature, one finds the concept of a "mechanistic" medical model radically enacted. (See a discussion of the model in Freidson, 1975; Szasz, 1974; Scheff, 1966; Dreitzel, 1971). Body parts are discussed without reference to "being". Potential bodily responses such as pain or infection are "problems of management."

When the human is reintroduced he is discussed in terms of his "acceptance" or lack of acceptance of the amputation. As mentioned above, this state is determined by the individual's "psychological" response. He is measured and evaluated in terms of his ego strength, adaptability, and qualities of honor, courage and dignity. Succinctly, he must be a "strong individual."

This individualized interpretation is supported by the ubiquitous advice to learn to "cope" with one's handicap (Fink, 1967; Kerr-Cohn, 1961; Jones, 1972). This emphasis on individualism permeates our society (Parsons, 1951; Williams, 1960) and our myths (Cawalti, 1974).

Rehabilitation is oriented towards emphasizing the remaining skills and functioning (Rabinowitz and Mitsos, 1964; Safilious-Rothschild, 1970). It is this emphasis on functioning which so aptly combines many threads of American culture: pragmatism, individualism and the medical model.[2]

Pragmatism is one of the few unique American philosophies (Konvitz and Kennedy, 1960). It combines an optimistic view of man and science: science can be usefully applied to improve the situation of mankind. It is a philosophy that underlies physical rehabilitation.

Functioning in daily life is the major goal of rehabilitation. This is operationally defined as the ability to work and maintain self-care. These goals are operative for all of the occupations associated with rehabilitation; the physicians and specialists, the nurse and the therapists: occupational, physical, speech, vocational and recreational. When the patient is technically able to function and does not do so, or does so poorly, then the "client" is referred to a psychologically oriented "counselor" (e.g. psychologist, social worker or psychiatrist). This pattern of action is particularly important for the amputee. Many, if not most, amputees are capable of functioning in a manner similar to that prior to the amputation.

> An investigation into the effect of amputation upon employment in the record of 4,000 users that were scrutinized showed that, of those amputated above the knee, 65 percent returned to the same or similar work, 13.5 percent became financially better off, 16.5 percent obtained less renumeration, and 5 percent were unemployed or under training at time of check (Kelham, 1958:335).

A similar but slightly lower rate of employment is found with amputations of the upper limbs (Kelham, 1958). Usually physiological, sexual functions, mental awareness, speech and other "biological" capacities are "unaffected." Changes in behaviors associated with these life skills are considered, therefore, to be changes in one's"mental" attitude.

Phenomenology and Dramaturgy

The above model is obviously built upon a Cartesian dualism between mind and body (see Yankelovich and Barrett for an extensive discussion of the paradigm and its use in ego psychology, 1970). It is this arbitrary division which is attacked and resolved by phenomenology. The emphasis is on lived experience, and, most importantly for us, on the lived body (see Wild, 1964; Strauss, 1964, 1966; Zaner, 1964, 1965; Merleau-Ponty, 1963; De Waelhens, 1967). The experience of the world is enacted through and in one's body. The changes wrought by an amputation, therefore, are immediately interpreted as a function of a new lived experience. With phenomenology, daily, physiological functioning is not the major criterion for analyzing the effect of the amputation. The multiple changes initiated in one's experience can be further articulated using a dramaturgical approach to "map out: alterations in one's life--world (Schutz, 1962; Deegan and Stein, 1977).

Before proceeding further in this discussion, it is necessary to define what is meant by a dramaturgical approach. This is a perspective where man is an actor with parts to play on the stage of life. He has roles, scenes, settings and scripts to order the action. Most importantly for the amputee, he has a performance to enact; he has a style to fit his presentation (see Burke, 1969, 1969; Goffman, 1959, 1961, 1963; Strauss, 1959; Stone, 1963, 1959). For the amputee, he is an actor in a new body. The script goes on but he has entered the scene as a new performer. The most fundamental change has occurred. The most intimate part of the performance has changed: the body of the performer.

Here is no mere faux pas, no minor change in lines or scenes. The amputee is not taught to end one portion of the script or action, nor is he aided in entering a new setting. Instead, he is pushed into the same scene, given the same lines and parts and told to "adjust".

With this metaphor we can vividly see the consequences. The amputee must "carry on" the action while rewriting and redirecting. Simultaneously, a new style and performance must be learned. To appear awkward on stage "spoils" the performance (Goffman suggests it may "spoil" the identity, 1963: b), although it continues. Emphasis on the continuity and not on the quality blinds the actor and his partners. Although the script goes on, the performance has changed, and if the performance is bad, the actor is blamed. A new role is then assigned: the neurotic, the weak, the depressed. In time, the "label" (Becker, 1963) may become permanent and, in fact, the actor has a new, negative role.[3] He is moved off center-stage and relegated to a minor character.

This scenario can obviously be altered through the recognition that many amputees live a new performance after an amputation. Therefore, "rehabilitation" should provide a "script" which helps in re-writing the style of the actor and dealing with the changed experience. One of the most unusual experiences then becomes ready to be discussed (and not merely "treated"): the phantom limb.

The sensation of a missing part is a dramatic example of the unity of the actor. This unity cannot be mechanically treated. The body, the living experience, emphatically denies the "social construction of reality" supported by the medical model. The attempt to categorize and label a deep human experience as one of "neurones and neuroses" is a major factor in generating "the problem of adjustment."

The phantom limb experience points directly to questions of the self and its embodiment: "Is part of me gone?" "Am I less me?" "Who am I if not my body?" The living experience of one's being in an absent part can be seen, then, as a fundamental question of identity and self (see Stone, 1959, 1962 for a discussion of self and appearance). To apply these questions to a dramaturgical framework: who am I if not this actor? the person with this performance? With the significant continuation of functional capacities which were previously enacted in a different body, it is "normal" to expect continued experience in an amputated part. Major portions of the self have continued and this continued act supports the continued expectations.

To look at the phenomenon of the phantom limb in yet another perspective, placing the experience as a primary criterion for action and "rehabilitation" it becomes part of the total experience of an amputation rather than an "abnormal" adjunct to the medical removal of a limb. The medical model dictates the meaning of the experience. In phenomenology, the experience would dictate the meaning for the theoretical interpretive model.

Application of the Model

There is a direct need for theoretical elaborations and conceptualization of the rehabilitation process which avoid pitfalls of present models. A step towards new working models is exemplified in this article and several others (Deegan, 1977a, 1977b, Psathas, 1977). Since most of the helping professions associated with rehabilitation use psychological models of behavior, it is consistent that a sociological model is absent in their applied approaches. Therefore, once sociological theoretical frameworks are developed, the application of these frameworks can be undertaken in hospital and clinical settings, but most importantly,

in training rehabilitation personnel.

Application of these concepts in small groups is needed to enact concrete performances.[4] In addition, many programs or personnel may be drawing upon the model elaborated here and a search should be made to bring practioners and theoreticians together. One possible structured resource that has been actively engaged in social learning is rehabilitation therapy. For example, at the hospital where the author did her dissertation research they had a program for teaching amputees dancing skills at Arthur Murray's. Participant observation at such sessions and interviews with the participants and teachers would provide a significant basis for constructing a more elaborate foundation for developing and applying the model suggester here (see Deegan, 1975, Pp. 137-78 for a discussion of socialization and rehabilitation). A growing body of literature could be developed from these initial studies to help others in applying this model. As a brief introduction to some methods for doing this, a program of action is suggested here.

Group Settings

Many recent movements to change basic life orientations and belief systems have drawn upon a self help, peer-learning model. People with shared lived experiences can often explain the alterations in their worlds in a more realistic manner than "experts" trained to interpret that change. The use of group leaders is strongly suggested. Such organizers could lend structure to a group setting composed of recent amputees who have lived in different settings prior to their disability. After some initial discussions and mutual observations, training sessions could be organized around specific work and social setting problems: for example walking, sitting, dressing, shaking hands. Criticisms and suggestions for change could be more easily offered by people who actually share the experience, especially in such a sensitive area of evaluation. Making this a <u>learned</u>, <u>shared</u> experience rather than an isolating, often humiliating one, would be the goal. Films of awkward movements could be made and used for discussions of options leading to new methods of handling embarrassing situations, and new ways to learn good self presentation.

Obviously, using the dramaturgy model, role scenarios could be devised and acted out. Self-help groups would provide relatively "safe" areas in which to experiment with actions resulting from inexperience in coping with an altered body. Discussions of such exercises would be keyed to role and acting concepts as well as the individual experiences of the "actors." Discomfort, elation, dismay and humor

are all possible responses. Comparisons of these staged actions and everyday actions could then be made.

After a period of work with amputees only it would be desirable to have families and friends participate. The same model emphasizing group experiences, social expectations, and learning behavior could then be stressed. It would be vital that such groups not degenerate into group therapy sessions; i.e., locating problems primarily as a function of personality. Since the psychological model dominates outside the rehabilitation setting as well as within it, this would be a constant strain at first.

Individual Learning

The group process could operate in conjunction with individual consultations and aids. Some people might find groups intimidating and need to search out new behavioral cuses and roles on a one-to-one basis. The direct use of dramatic metaphors in this interaction is suggested for the model developed in this paper. Since sociologists are most interested in group dynamics and structure, primary emphasis will be placed on the group environment presented above rather than on individualized application of a shared, social process. A significant part of the "clinical" sociology exchange would be devoted to the integration of the individual into everyday life. Emphasis would be given to people immediately interacting with the amputee in face-to-face situations.

The Sociologist as an Applied Practioner

Sociologists are becoming increasingly aware of possibilities for sociologists as providers for human services. (See for example, Gouldner and Miller, 1965; Street and Weinstein, 1975; Glass, 1977). Of course, the most established model for a combination of theory and practice (praxis) emerges from the Marxist tradition. The description of alternative theoretical models is very recent and the combination of these new frameworks with sociological practice is in its infancy. With the present model, all of the physical rehabilitation training done with the sociologist would proceed under the a priori assumption that the "phantom limb" experience exists and that there is a need for a new vocabulary to express the reality of and response to this experience. Phenomenological/dramatists would then search for theoretical constructs as well as practical methods for interpreting and acting on this assumption. More concrete paradigms for theory and practice than that offered here would necessarily emerge from the exchange between everyday action

and scientific research.

Conclusion

This paper has addressed itself to adults' responses to amputations. It has shown that our view of amputations is grounded in three major American values: individualism, pragmatism, and a mechanistic, medical model.

We have suggested here that these social constructions of reality (Berger and Luckmann, 1966) ignore the experience and performance of the amputee. Instead of determining "functioning" in a mechanistic manner measured by physiological capabilities, the concept of "functioning" should include one's total reality experienced in a lived body. Radical changes in one's lived body would be expected also to cause radical changes in one's everyday life. This different reality is naturally new, and frightening, particularly since it may hold a "stigmatized" role for the actor. Comprehension of this reality points to new directions for the generation of more positive "cues" and "acting lessons" as part of physical rehabilitation.

A brief presentation of possible applications of the model was presented in order to show the changed physical rehabilitation program which would result. These suggestions are exploratory and a more elaborate model and its application depend upon the lived experience of both amputees and sociologists with a phenomenological/dramaturgical praxis.

FOOTNOTES

[1]Extensive bibliographies on amputations and amputees are available. This provides an excellent, cross-disciplinary introduction to the literature (See Amputees, Amputations, and Artificial Limbs, 1969,1971).

[2]For an analysis of the contradictions inherent in the rehabilitation goals, see Deegan 1977b, 945-49.

[3]Discussions of the negative consequences of a physical disability are frequent. For an in-depth analysis of "stigma" see Goffman (1963).

[4]Although role playing and sociodrama appear to be similar models to that suggested here differences between these methods for group teaching and a dramaturgical theory needs to be established. Such a comparison is beyond the scope of this paper, but a few examples can be given. Dramaturgy is more than role playing. When one's personal, sexual and financial statuses are threatened, role enactment is of vital concern. Lived experience, not just an enactment of someone's possible experience, is a fundamental assumption of our model. Social expectations are constraints, they are part of objective reality, but different dramas can exist within those boundaries. The dramaturgical model suggested here is also a factor in explaining the phantom limb which challenges the dominant social construction of reality of this experience. (See pp.

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