

REVIEW

SOCIAL NETWORKS AND SOCIAL SUPPORT: LIVING WITH CHRONIC RENAL DISEASE

KATHLEEN A. ROUNDS and BARBARA A. ISRAEL

Department of Health Behavior and Health Education, School of Public Health, University of Michigan, 1420 Washington Heights, Ann Arbor, MI 48109-2029 (U.S.A.)

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ABSTRACT

Individuals with chronic renal disease who receive dialysis treatment are continually faced with major adjustments. These may include dealing with changes in work and economic status, social roles, activity levels, self-image, health status, and normal routines, as well as learning to live with uncertainty and loss. The individual's social network plays a key role as the individual experiences and moves through various stages of adjustment. Networks with certain characteristics (e.g. provision of affective support, reciprocal ties) may be more effective than others lacking these characteristics in meeting the individual's changing needs during the process of adjusting to chronic renal disease. This paper examines this relationship between the characteristics of an individual's social network and adjustment to chronic renal illness. The discussion focuses on the impact of chronic renal disease on the individual, the composition and characteristics of the social network, and on the relationships between network members. How the social network affects a person's adjustment to stages of adaptation to chronic renal disease is also addressed. Finally, suggestions are presented for how health care professionals can intervene at the individual, network, and organizational level to strengthen and enlarge social networks in order to enhance social support.

Key words: Social network — Social support — Chronic renal disease

INTRODUCTION

Persons with chronic illness such as chronic renal disease are continuously faced with adaptive tasks. As described by Moos [1], these include: dealing

with the physical symptoms of the illness, managing the required treatment, developing and maintaining relationships with health-care professionals, coping with a wide range of emotions, preserving one's self-image, maintaining a sense of independence and control while having to be dependent upon others, preserving relationships with family and friends, and living with uncertainty. While an individual may be able to confront some of these tasks alone, many of them require the involvement of members of the person's social network. The availability of social support from the personal network is one of a host of factors that affects an individual's adjustment to a chronic disease [2]. Other factors include the severity and timing of the disease, socio-economic factors, the individual's coping resources, and prior experience [1]. While the social network can serve as an important source of social support for an individual with a chronic illness, it is also possible that the functioning and structure of the network as a whole are affected by the chronic illness of one of its members [3].

Given the importance of a person's social network for living with a chronic disease, and the potential impact of such an illness on an individual's network, this paper will examine the relationship between the characteristics of an individual's social network and adjustment to chronic renal disease. The following topics will be discussed: social network and social support concepts focusing on characteristics of the personal network that may affect adaptation, the impact that chronic renal disease has on the individual and the members of the personal network, network characteristics that may contribute to the provision of social support during stages of adaptation, and strategies to strengthen and enlarge the social network. The interventions that are described are ones that can be initiated by health care professionals as well as by patients, and are ones that focus on the individual as well as network members and health care organizations. This paper is based on the convincing yet inconclusive evidence regarding a positive relationship between social network characteristics and health behavior and health status. The interpretations and suggestions made are offered on a somewhat tentative basis — reflecting present knowledge and awaiting future investigations.

SOCIAL NETWORKS AND SOCIAL SUPPORT: AN OVERVIEW

The literature on social networks and social support is replete with numerous definitions of both of these concepts. Mitchell [4; p. 2] defines a social network as 'a specific set of linkages among a defined set of persons with the additional property that the characteristics of these linkages as a whole be used to interpret the social behavior of the person involved'. The definition used by Walker, MacBride and Vachon [5; p. 35] is more specific including a functional component, and is useful to the discussion of social networks and chronic disease: an individual's social network is 'that set of personal contacts through which the individual maintains his social identity and receives emotional support, material aid and services, information and new social contacts'.

Social networks have been described by numerous authors within a conceptual framework that includes structural, interactional, and functional characteristics [5–11]. Structural characteristics (the links of the overall network) which seem to be most relevant to an examination of the relationship between social networks and how a person lives with a chronic disease are: (1) size or range, and (2) density — the ratio of existing ties to the number of ties that could exist in the network. Interactional characteristics refer to the nature of the relationships within the network. Drawing from theoretical and empirical findings regarding the psychosocial aspects of chronic renal disease [12–15], the interactional characteristics of social networks that seem to be the most important for dealing with a chronic disease are: (1) directedness — the reciprocity/mutuality in a relationship, (2) durability — the stability of network linkages and the degree to which the relationships are changing, (3) intensity — the emotional closeness between network members, and (4) dispersion — the ease with which a person can make contact with network members. Functional characteristics of networks relevant to this discussion include: (1) the provision of affective, instrumental, and cognitive support, (2) maintenance of social identity, and (3) access to social contacts and social roles (social outreach). Using this framework, the provision of social support is seen as one of the functions of the social network. Therefore, by understanding the structural and interactional characteristics of the social network, one can describe how the network functions and assess the quality of that functioning. More specifically, one can examine the type of social support and the degree to which it is being provided by network members and the nature of the relationships involved.

No unitary conceptualization of social support is used consistently throughout the literature on social support and health. (For a more comprehensive discussion of definitions of social support see Ref. 2, 16–20). While there appears to be some consensus about the general construct of social support, agreement does not exist regarding what specific aspects or dimensions of social support are the most strongly associated with well-being. The range of definitions include vague descriptions such as ‘support accessible to an individual through social ties to other individuals, groups, and the larger community [21; p. 109]’ to more explicit definitions such as Kahn and Antonucci’s [22; p. 267]: ‘interpersonal transactions that include one or more of the following key elements: *affect*, *affirmation*, and *aid*.’ Cobb [23; p. 300] defines social support as information that ‘leads the subject to believe that he is cared for and loved (emotional support), esteemed and valued (esteem support), and belongs to a network of communication and mutual obligation (network support)’. While Cobb’s definition is similar to the Kahn and Antonucci conceptualization of social support in that it includes affect and affirmation, it does not include the provision of material and/or instrumental support (provision of tangible aid).

House [16] includes these dimensions in his conceptualization of social support; he defines four broad types of supportive behaviors or acts: (1)

emotional support, (2) appraisal support (affirmation, feedback, social comparison), (3) informational support, and (4) instrumental support (aid, money). While he notes that emotional support is the most important of these in relationship to health status, House suggests that the other forms of support should be considered as they may be potentially important in specific instances. Drawing from several lists of components of social support, Wortman [17] identifies six distinct types of support; these involve: (1) expressing positive affect, (2) affirming a person's beliefs or feelings, (3) encouraging open expression of beliefs and feelings, (4) offering advice or information, (5) providing material aid, and (6) providing information that the person is part of a network of reciprocal aid. Wortman argues that while some of these components may overlap, it is important to assess particular types of social support because they may have different effects on specific health outcomes.

The link between social support and a variety of health outcomes has been reported in a number of review articles [2,7,8,18,19,23–26]. The reviews differ in how they hypothesize the relationship between social support and health and according to the health outcomes of interest. For instance, a number of articles review studies which conceptualize social support within the context of the 'buffering hypothesis', i.e. social support functions as a moderator variable or buffer that protects the individual from stressful life events [7,23,24,27]. These reviews conclude that social support interacts with life events to produce an impact upon physical or psychological well-being. However, Thoits [18] argues that these results must be taken with caution due to serious methodological problems with the studies. Broadhead et al. [25] examine studies of the social support-health relationship using Hill's [28] proposed criteria for inferring causality. They conclude that while there is support for a causal relationship between social support and health outcomes, weaknesses in the causal argument remain, especially with the necessary antecedent-consequent relationship. While most review articles include studies of both mental health and physical health status, the Wallston et al. [19] review focuses on studies with outcome measures of adult physical health. The authors conclude that findings differ depending upon the stage of health outcome and type of research, and that there is consistent evidence to suggest that naturally occurring support is beneficial to a person's recovery, rehabilitation, and adaptation to illness. This is consistent with the conclusion by DiMatteo and Hays [2] in their review of research on social support and serious illness.

Overall, one could conclude that the reviews of social support research document a positive relationship between social support and health outcomes. However, the strength of this relationship varies depending upon factors such as the population being studied, the research methodology, the conceptualization and measurement of social support and the specific health outcome being studied (e.g. morbidity, mortality, mental and/or physical health and/or illness, rehabilitation and recovery, modification of health behavior). It is particularly difficult to infer causality from most of the studies, although Broadhead et al. [25] note some exceptions.

In her discussion of the distinctions made between social networks and social support, Israel [6] reviews several advantages to using a network analytic approach in examining the relationship to health status. Of these advantages, three seem to be especially salient to the examination of the relationship between social networks and chronic disease: (1) the ability to investigate what types of support might be provided by different kinds of relationships, (2) the identification of certain network characteristics that are relevant to interventions aimed at helping persons living with a chronic disease and (3) the use of a neutral approach to analyze the role of social support (the extent and conditions under which network ties are supportive). By examining the role of social support using a network analysis, one can assess whether social relationships have a positive or negative impact [9]. Wortman [17] notes that it is important to look at both the negative and positive aspects of social interaction in studying the support available to cancer patients. This point can also be applied to the study of social support available to patients with other chronic diseases such as chronic renal disease.

CHRONIC RENAL DISEASE: THE IMPACT ON THE PATIENT AND SOCIAL NETWORK

The person with chronic renal disease experiences dialysis treatment as a new lease on life; however, with this new lease comes many stressful situations, for example, personal losses, restrictions, dependency, fear of imminent death, and changes in body image. The medical regimen for a person with chronic renal disease is difficult and time consuming. It requires adhering to strict dietary and fluid intake restrictions, taking medications daily (some of which have undesirable side effects), and receiving hemodialysis treatments 3 times/week of 3–5 h in duration (peritoneal dialysis, another form of dialysis, takes approx 12 h/session and is administered 3–5 times/week). Dialysis patients commonly experience lethargy and an overall lack of energy, gradual physical deterioration, and changes in sexuality and body image. Furthermore, it is not unusual for an individual during the course of treatment to have to deal with a number of life changes such as loss of or change in job and income, a change in family roles, reduction in social activities, and loss of security. (For an in-depth discussion of the changes in life-style imposed by dialysis see Refs. 12–15). The most common psychological problem experienced by dialysis patients, in part due to the losses that they confront, is depression [14,15,29]. Recognition and treatment of depression is important because there is evidence that supports the relationship between emotional factors such as depression and the course of existing disease and recovery from a medical crisis [1,30,31]. Additionally, the patient's emotional state influences his/her long term management of a disease [32–34]. Therefore, it is likely that depression can further exacerbate the patient's physical condition.

This depression is compounded further by the social isolation, sometimes self-imposed, that often accompanies chronic disease [35]. Loss of social contact occurs because individuals may not have enough energy or time to

spend with friends. Those individuals who have lost a job due to their physical condition, no longer have regular contact with co-workers. If the trajectory of the individual's condition is downward due to complications or other diseases (e.g. diabetes, multiple melanoma, lupis), some network members may withdraw because the relationship becomes too demanding, and/or they cannot cope with watching a friend or relative slowing dying. The end result for many persons, but certainly not all, can be a change in or shrinking of their social network at a time when support is most needed.

As the social network shrinks, the family, usually the most immediately available part of the network, takes on increased importance while also experiencing additional stresses related to dealing with the illness of a family member. Chronic renal disease has been defined as a family disease [36,37]. Especially in the case where the patient chooses to dialyze at home with a family member acting as the dialysis partner, the disease and treatment become intimately interwoven with the routines of family life.

A number of studies have shown that there is a correlation between social support provided by family members and a patient's adjustment to dialysis [14,15,38]. Specifically, there is some evidence that a family's attitudes might be a determining factor of the success or failure of home dialysis [14]. In a study conducted by Evans [39], it was found that the choice of treatment (home vs. in-center dialysis) was directly influenced by the 'perceived level of family support'. In another study which identified factors which influence the choice of dialysis treatment, the availability of a willing dialysis partner ranked fourth in importance amongst 73 variables [40]. In a study conducted by Dimond [41] which examined the relationship among support factors, medical status, and adaptation to chronic illness in hemodialysis patients, a significant positive association was found between the measures of social support and morale. Dimond used subscales of family cohesion (helpfulness and supportive behavior of family members), family expressiveness, and spouse support to measure family support.

The person usually most affected by dialysis, other than the patient, is the spouse or significant other. In a review of studies examining stress on spouses of dialysis patients, Czaczkes and De-Nour [14] noted that several studies found an increase in anxiety, depression, and insecurity amongst this group. This finding is understandable because spouses frequently experience many of the same losses that patients do, e.g. loss of income, shrinkage in social contacts, decreased sexual relations, and a general increase in uncertainty about the future. The stress on the spouse is substantially multiplied in situations where the patient becomes increasingly dependent because of physical deterioration or in those home dialysis programs where the spouse is expected to be the dialysis partner. The spouse or significant other is usually not treated as the person in stress, but as a partner in treatment [14]. As such, the spouse is expected by the medical staff to assist the patient in adhering to the regimen and cooperating with the staff. If the spouse's coping style is at odds with that of the patient, this partnership becomes a difficult one. Additional strains may arise in the partnership

if the spouse becomes over-protective of the patient. Furthermore, if the spouse's life becomes increasingly controlled by the needs of the person on dialysis, this may also cause a change or shrinkage of his/her social network making access to social support a problem. Therefore, at a time when the spouse is expected to be supportive to the patient, but needs support to deal with increased stress, he/she may be increasingly cut off from potential network sources of support.

STAGES OF ADAPTATION TO CHRONIC RENAL DISEASE

As Walker, McBride and Vachon [5] note in their discussion of the role of networks during crises, there exists a wide diversity between individuals regarding their needs for social support during a crisis situation. Factors which influence an individual's needs are: (1) the nature of the crisis, (2) the timing, and (3) the resources available both externally and within the individual (how that person copes with a crisis) [5]. Applied to this discussion, the role that the network plays in providing support for a person with chronic renal disease depends in part on the seriousness of the disease [2] (perceived and objective), its impact on the person's life style, the particular time in the person's life that the disease occurs, the transitional stage of adjustment that the person is experiencing, and the supportive resources that are available within the network as well as how the individual uses the network. One could hypothesize that during each stage of adaptation there might be networks with certain characteristics that are more helpful in providing the support that is required by the individual. A discussion of stages of adaptation to chronic renal disease will further illustrate this point.

In the literature on adjustment to dialysis treatment, three stages are commonly referred to in the adaptation process [42]: (1) the honeymoon period — a time of marked physical and emotional improvement that begins 1–3 weeks after the patient begins dialysis; (2) a period of disenchantment and discouragement — this usually occurs when the person is faced with trying to resume an active life, and realizes how many adjustments that he/she has to make, consequently a depressive giving-up often follows; and (3) a period of long-term adjustment — this is a period of gradual acceptance often with alternating episodes of depression and contentment. A stage that is not included in this framework, but will be discussed here, is the period between the time of diagnosis and the initiation of dialysis (pre-treatment stage). This is a period where the individual may experience high stress, anxiety, and depression [29]. It is important to note that not everyone experiences these stages, nor in this particular order, while adapting to dialysis. However, this generally accepted framework is useful as a context for this discussion and for planning interventions.

If one examines each of these stages, one can hypothesize as to the type of social support that might be needed, network characteristics that might be the most relevant for accessing this support, and how the particular stage might impact the members of the social network as well as alter the characteristics of the network.

The pretreatment period. As noted earlier, the interval between the diagnosis of chronic renal failure and the initiation of dialysis or transplantation is one during which the patient is confronted with a major life crisis. Both emotional support and informational support are needed by the patient and family or close personal network in order to begin coping. Walker, MacBride and Vachon [5] note that networks with the characteristics of high density, homogeneity, and low dispersion are most conducive to providing emotional support. Intensity, the emotional closeness between network members, is also a key characteristic related to the provision of emotional support. In most cases, the patient and family will have to go outside the close personal network for informational support. Because the patient has not yet begun treatment at a dialysis center, he/she may not have access to many informational resources. At this point, the patient's contact with the health care system is fairly limited and consists mainly of visits with the nephrologist. Unless members of the health care system (dialysis center staff) make themselves available and encourage contact with 'veteran' patients prior to treatment initiation, it will be difficult for new patients to receive adequate informational support. Because the individual's ability to participate in his/her network is not significantly affected yet, the network will probably remain stable during this period. In fact, during this stage it would be expected that a network with high density would mobilize to support the focal person and prepare for the initiation of treatment.

The honeymoon period. During the initial phase of dialysis treatment, the patient may need assistance (instrumental support) with tangible tasks such as transportation, childcare, and household and job responsibilities, in order to maintain daily functioning while meeting the newly imposed demands of treatment. Instrumental support is more likely to be available within networks which are characterized by large size, high density and low dispersion (close proximity) [5]. As patients stabilize with ongoing treatment and begin to experience improvement in their physical condition, the availability of new information about self-care and psychosocial adjustment becomes important. This information is most helpful when it is provided by other patients who have successfully adjusted to dialysis. If patients are able to create new linkages with other dialysis patients outside of their existing personal network, they will find that much more informational support is available. Granovetter [43] describes such links as 'weak ties'; and hypothesizes that 'weak ties' perform a bridging function between networks and are an important resource in the diffusion of information. Information about how to cope with chronic renal disease will more likely be available through linkages with other patients than through the already existing network.

The period of disenchantment and discouragement. During this phase the reality of life on dialysis has sunk in, often accompanied by a depressive giving-up period. To combat this the patient requires a network that can provide emotional support. In addition, access to new social contacts and social roles becomes crucial in order to make the transition to a period of

long-term acceptance and adjustment. This requires a network with intensity (emotional closeness) and with 'weak ties'. One could hypothesize that this stage has the most impact on the social network. The interactional characteristics of durability and reciprocity are tested during this period. The patient may begin to cut himself/herself off from network members; or network members may begin to avoid the patient because he/she is depressed and they feel ill-equipped to deal with the situation. Also, if the patient's physical condition has further deteriorated, the issue of reciprocity can become painfully unresolvable as the patient becomes necessarily more dependent upon network members while less able to reciprocate. The sense of feeling like a burden may contribute to a cycle of depression, deteriorating physical condition and increased dependency. Furthermore, if the person is able to participate in fewer social settings due to increasing disability, the size and breadth of the personal network may diminish [44]. In their analysis of interpersonal relationships and cancer, Wortman and associates [45] note that persons who seem to be coping well are more likely to be regarded as attractive by others and less likely to be avoided than persons who seem to be having difficulty coping. Thus, at a period when the patient is having problems coping, he or she may receive less social support. If this period is lengthy, the size and composition of the network may change significantly.

The period of long-term adjustment. By this time the patient has resolved some of the interactional problems (durability, reciprocity) within the network, and the network has probably stabilized once again. However, the network composition may be quite different from the pretreatment period. During this period, a person's support needs would vary depending upon medical and social circumstances. Once the network has stabilized, there might be less need for new social contacts and new information.

INTERVENTIONS TO STRENGTHEN AND ENLARGE THE SOCIAL NETWORK AND ENHANCE SOCIAL SUPPORT

Although many questions about social networks and social support remain unanswered, it is still possible to design interventions that strengthen and expand networks and enhance social support. By evaluating such interventions, much can be learned about the process of the support interaction; situation-specific support needs, the association between support and health-related outcomes, and the impact that certain interventions have on characteristics of the network.

Mitchell and Trickett [11] suggest that interventions can be approached in a variety of ways depending upon one's ideological stance with regard to treatment vs. prevention-oriented and individual vs. system-focused. Froland [46] and his colleagues have developed a typology of agency strategies that includes personal networks, volunteer linking, and mutual aid networks. Such a typology is particularly helpful for this discussion of network interventions. The inclusion of members of the health care system in this typology increases its relevancy to chronic disease. It is advantageous that an inter-

vention be treatment- and prevention-oriented and that it focus on the patient as well as on potentially significant members of an individual patient's network (which may include health care providers as well as lay persons). While it is important that individuals learn how to develop and strengthen their social network ties and obtain needed social support, it is equally important that systems (family, organizational, and community) are responsive to and foster such behavior and the maintenance of networks. This section will discuss possible interventions within a treatment-prevention framework by examining interventions that impact on the individual, his/her personal network and the health care system, where the primary aim is to strengthen the naturally occurring personal network or to enlarge the personal network by creating new interpersonal linkages. The role of the professional as initiator and facilitator of interventions will also be examined with particular attention to the relationship between the health care professional and the personal network of the individual.

Strengthening the personal network

The personal network includes those individuals such as family members, friends, and neighbors that are already an existing part of the person's naturally occurring network. Interventions that focus on or involve the personal network of the patient recognize that individuals with a chronic disease rely heavily on family, friends, and others in their immediate network for ongoing support [2,31,36]. One aim of such interventions is to sustain and reinforce the individual's network at times when the demands of being a helper become stressful and burdensome. Health care professionals need to recognize the importance of the patient's network and the heavy demands that are being made on network members. The impact of long-term care giving on the members of the personal network have been assessed by a number of studies [47–50]. The research evidence suggests that if the responsibility of care is not distributed amongst the network members and if a sense of reciprocity between the patient and network members is not fostered, the results can be negative both for the patient and network member(s) who are providing the majority of the support [51,52]. Personal network members need support too when dealing with a chronic illness; the amount of support that they are able to provide the patient may depend in part on how much support they are receiving [2,17,53]. Health-care professionals can play a key role by recognizing the limits of the personal network, encouraging members in their efforts to foster reciprocity, and providing support directly to the members of the personal network.

Health-care professionals can intervene in a number of ways to strengthen the patient's personal network. The most common interventions employed with dialysis patients and their network are counseling, usually provided by the social worker on staff, and group interventions, usually facilitated by a member of the health-care team. The distinction between such group interventions and mutual-aid groups is that the former is initiated and directed by the health-care professional with a primary focus on strengthening

the already existing network while the latter is usually initiated and directed by patients with a primary focus on enlarging the network. Although there are many case studies in the literature of intervention groups which address the psychosocial aspects of chronic renal diseases [37,54–61], the effectiveness of this type of intervention is rarely evaluated. Of those patient/family group interventions that have been evaluated, the following has been demonstrated: Hastings [37] found that group interventions can be effective in alleviating some of the negative psychosocial effects of renal disease on both patients and family members; and Tucker [54] found that such interventions can be effective in building support (defined as improvement in the perceived quality of the relationship between patients and their family members) amongst those persons who participated in the support group.

Group interventions that attempt to strengthen already existing personal network linkages could be more effective if they were initiated early in the treatment process and if the issue of social support, specifically reciprocity, was dealt with directly. The time period between the initial diagnosis of chronic renal disease and the initiation of treatment can range from a few days to a year; however, most people are diagnosed and told that they will need treatment several months before they actually begin dialysis. As mentioned earlier, during this time period few professional resources may be available to assist the patient and network members in dealing with a life-threatening medical diagnosis. A pretreatment orientation group [62–64] involving the patient and significant members of the personal network could provide needed social support and information so that the patient and personal network members could begin to prepare psychologically for the demands of treatment. While the primary focus of an orientation group would be to strengthen the personal network, if the group consisted of several recently diagnosed patients and their networks, it would also function as a way to develop new network linkages. Gottlieb [65; p. 223] states that such a group could serve as a ‘temporary reference community activated during the early stage of life crises and where there is a need to supplement the support available in an individual’s social network’.

The patient’s and network members’ need for social support in this situation can be approached within a group setting by teaching individuals techniques to build and maintain social relationships and appropriate ways to obtain support [11,44]. This initial training in skills necessary to maintain supportive relationships could be followed-up with additional sessions facilitated by the social worker at the dialysis center once the patient has begun treatment. The purpose of these sessions would be to reinforce new learning and address specific relationship issues that arise as the patient begins to adjust to dialysis, such as the need for reciprocity and how to prevent family members from feeling overburdened by the demands of a chronic illness.

Several authors have emphasized the network characteristic of reciprocity in their discussions of interventions. Gottlieb [44; p. 28] argues that ‘the mutuality of helping is the cement stone of social support’. Mitchell and

Trickett [11; p. 39] note that one of the most consistent findings in the social support literature is that 'persons lacking reciprocal relationships are less likely to experience satisfaction and to function effectively'. DiMatteo [2; p. 140] points out that counseling and rehabilitation programs for the seriously ill or injured 'should focus on issues of equity and reciprocity to help family members restore equilibrium in their relationships'.

Most helping relationships are built on reciprocity; however, when one member of the relationship becomes ill, this balance is upset [2,31,66]. This is an especially difficult problem for people on dialysis because the nature of their medical treatment requires that they receive assistance from others, while at the same time the nature of their health condition may limit their ability to actively participate in previously held roles and carry out former responsibilities. Persons on dialysis need to redefine their roles and responsibilities within the personal network in such a way that they feel useful. For example, within the family system this may mean that household tasks are reassigned so that the person on dialysis is still actively involved in the maintenance of the household but responsible for tasks which require less physical stamina. If the patient and spouse are involved in home dialysis, a system can be worked out whereby the patient participates in self-care as much as he/she is physically able to (e.g. doing machine set-up and maintenance), while the spouse is responsible for the monitoring during treatment.

Enlarging the personal network by creating new interpersonal linkages

Because most naturally occurring personal networks, no matter how functional, are not able to meet the difficult and chronic support needs of a person with renal disease, interventions that enlarge the network by creating new interpersonal linkages increase the availability of various types of support to the focal person and alleviate some of the demands on the resources of the naturally occurring personal network. Two such interventions will be discussed here: mutual aid/self-help groups, and volunteer linking. Katz and Bender [67; p. 9] define self-help groups as:

Voluntary small group structures for mutual aid in the accomplishment of a specific purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or a life-disrupting problem, and bringing about desired social and/or personal change. The initiators and members of such groups perceive that their needs are not or cannot be met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions, and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently 'cause'-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity.

Silverman [68] notes that while mutual aid and self-help are frequently used interchangeably, the term mutual aid or mutual help group is more appropriate than self-help because the nature of the helping is based on mutual exchange and reciprocity.

Several authors [68-71] have suggested that the growth of mutual help

groups is the result of consumers' dissatisfaction with their relationship to medical and social service professionals and/or the result of technological advances in medicine which have far outpaced this society's ability to assist persons dealing with the psychosocial difficulties of a chronic health problem. The growth of mutual aid groups amongst individuals on chronic maintenance dialysis is probably due to both of these factors. The development of renal dialysis in the 1960s was a major medical and technological advancement. However, while saving lives, it also requires individuals to make significant changes in their self-identity and in the way that they interact with their world. Most individuals, unless they have a history of chronic illness, have had no prior preparation for this adjustment. One of the ways that a person can learn how to make this adjustment and deal with the long-term stress of chronic renal disease is through the support of others who have successfully made the transition. Silverman [68; p. 11] refers to mutual help groups as 'enabling organizations' in that they assist persons moving through major life transitions. Because they are made up of people experiencing similar problems, mutual help groups can provide an opportunity for members to express feelings openly, discuss problems, and receive support from others who are dealing or have successfully dealt with similar problems. Because the group is founded on the mutuality of the helping relationship, reciprocity is emphasized. The opportunity to give support as well as receive support from equals can be empowering to members who may feel overly dependent in other areas of their lives.

The types of support provided by the mutual help group depends upon the focus of the group. In their analysis of self-help groups of families of children with cancer, Chesler and Yoak [72] discuss five types of support that members give and receive of one another. These include: (1) educational or informational support; (2) instrumental support which can take several forms such as helping others with tasks like child care or transportation or on a larger-scale organizing to make the medical care system more responsive to specific needs of patients; (3) non-specific support that consists of interpersonal network linkages which are 'just there'; (4) emotional support and reassurance; and (5) support to deal with the existential challenge of having a life threatening disease.

The relationship between professionals and mutual help groups has been addressed by a number of authors [44,67-69,73,74]. This relationship is frequently one that can be fraught with tension. One reason for this conflict is that while both systems may have the same goals, to improve the ability of the individual to cope with his/her medical problem or disability and to enhance overall functioning, their approaches may be very different. Wollert and Barron [69; p. 116] argue that professionals view these problems from an 'evaluative and theoretical perspective' while members of mutual aid groups view them from more of an 'affirmative and experiential perspective'. This difference in approach is further magnified when professionals act from a position of expertise and attempt to control the efforts of the mutual help group. The tendency of health care professionals to play the expert role

increases with the complexity of the medical treatment. Conflict is heightened in situations where the mutual-aid group is challenging institutional policy. Although professionals may not agree with institutional policy, they may have to support certain policies in order to preserve their position in the agency.

Whether or not this conflict arises depends on a number of factors, one of which is the attitude of the members of the mutual-help group and the professionals toward each other. In situations where these two groups recognize their interdependence, an atmosphere of collaboration can be fostered [73]. Professionals have access to resources that can be helpful to mutual aid groups (e.g. referrals of new members to the group, information about and access to services and funding sources) [74]. Conversely, mutual aid groups can fill the gaps in services that professionals cannot provide and can challenge organizational policy in ways that professionals within the organization cannot.

For those individuals who choose not to become involved in a mutual help group and/or for those individuals who have limited or non-supportive networks, other strategies to develop and enlarge the network are available. Interventions described up to this point have been ones which work well with persons who have social networks that are intact and who with some assistance, can learn ways to enhance and maintain their networks. However, there are individuals who have a very limited social network or their existing network is such that it is stress producing rather than supportive. Such individuals may need substantial assistance from professionals if they are going to survive a chronic illness such as kidney disease which requires consistent adherence to a difficult regimen. It is the role of the health care professional, to screen for such high risk individuals early in the course of treatment. A network analysis can be carried out for this purpose. (See Gottlieb [44] p. 107–115) for a discussion on clinical assessments of an individual's network). It has been noted that professionals become the support givers and that too often high risk people 'become isolated within networks of care giving professionals'. [11; p. 40]. While this is difficult to avoid in the initial crisis stages of dealing with chronic renal disease, it is incumbent upon the professional when working with individuals who have limited personal networks to emphasize increased contact and collaboration with non-professional community resources and to develop intervention strategies that facilitate the development and maintenance of increased social network linkages.

One strategy for enlarging a limited network is what Froland and his associates [46] refer to as 'volunteer linking'. The purpose of volunteer linking is to develop one-to-one relationships between people undergoing a crisis or major life transition and individuals who have successfully coped with such a transition. Experienced patients can be trained to provide 'informal care giving' along the lines of Walker, MacBride and Vachon's [5] intervention strategy with widows. Widows were given a brief course in counseling to assist them in giving support to other widows which ranged from listening

and empathizing over the phone to providing more tangible support. Tucker [54] in her research on outpatient dialysis treatment used 'peer facilitation training' with experienced patients to facilitate adjustment of new patients and those patients experiencing difficulty with dialysis. Roy and Atcherson [75] describe a project, the Patient Visitor Program, that trains more experienced patients to assist others who are new to dialysis.

Another important part of the patient's network that is often neglected in discussions of network interventions is staff of the health care system [76,77]. This includes those people that patients interact with on a regular basis in the process of receiving health care; for dialysis patients this usually consists of their nephrologist, nurses, dialysis technicians, dieticians and social workers. These health care providers are especially significant for those persons who dialyze in a medical center rather than at home. Because most patients receive dialysis at least three times a week, if they come into a center for treatments, they spend a great deal of time interacting with health-care professionals. While the objective of this system is to provide quality medical care, information and psychosocial support that will assist the patient and family, and to promote long-term rehabilitation, this goal is not always accomplished because of some of the inherent strains between the health care providers and the patient and his/her personal network. One reason for this conflict is that even though the patient and the health care system may share the same goals, their approaches may be entirely different. Another cause of tension within these interactions is that reciprocity is usually lacking. Lenrow and Burch [73; p. 238] describe this professional-client relationship as one where 'one participant has greater power and uses it in the service of what he or she perceives as the other participant's interests under circumstances that provide no prospect of reciprocation by the person helped'.

One way to develop a sense of reciprocity is to encourage all involved parties to recognize the interdependence between the health care professionals and the patient and his/her personal network. While this interdependence is often obscured in a hierarchical setting such as a medical care organization, Lenrow and Burch [73] note that all forms of helping require interdependence between the parties involved. In order for health care professionals to be effective, they depend upon the active participation of the patient and family. This interdependence is particularly important in long-term management of a chronic condition such as renal disease. While the patient is dependent upon the health care team for medical services and guidance; the health care team is dependent upon the patient and personal network for information to make an accurate diagnosis and prescribe care, to acquire adequate knowledge and skills for self-care, and to follow prescribed regimens. This collaborative partnership is based on the recognition that while the medical staff has the technical expertise, the 'experts in the meaning of illness are the sufferers and their families [77; p. 111]. These are the people who have the experiential knowledge of how to cope with a chronic illness and enhance health and functioning.

Like the patient's personal network, the members of the health care system also need to receive support in order to provide support. The level of support that health care providers can give to the patient is partially a function of the amount of support that health care professionals perceive that they received from their co-workers and the overall organization [2,17,78]. The feeling of being 'burnt out' is a common experience amongst health care professionals [79,80]; especially those who work in settings where there is limited job mobility, repetitive tasks, responsibility for individuals in life and death situations, and whose job tasks include giving patients treatments (dialysis) that often are uncomfortable. The literature on dialysis is replete with articles on staff burnout [81-83]. Because staff burnout affects the quality and quantity of social support that patients receive from the staff, it is a critical problem that needs to be dealt with by the organization and by staff members. While it is not possible to address dialysis staff burnout in any depth in this article, the following should be noted. As suggested by Pines [80] there are a number of ways to prevent and deal with staff burnout, one of which is the development of supportive networks amongst staff members. However, probably equally effective, if not more so, are interventions aimed at the organizational level of analysis and change. McKeivitt [53] suggests several such strategies to provide support to staff and prevent burnout: manageable patient-staff ratios, effective channels for team communication/collaboration and problem solving, and staff input into policy and program decision making are a few of these.

Similarly, because an individual's personal network is often so crucial in his/her adaptation to a chronic illness, efforts should be made at the organizational level to maintain and enhance this network. When the patient's personal network breaks down or is functioning poorly, the job of providing quality medical and psychosocial care to the dialysis patient becomes infinitely more difficult. Several examples of interventions of an organizational nature that could contribute to strengthening networks are briefly discussed below.

(1) The development of organizational policies that clearly promote patient choice in the mode of dialysis treatment (hemo, peritoneal, continuous ambulatory peritoneal dialysis) and location of treatment (in-center or home).

(2) The adoption of programs that allow people who live a distance from the dialysis center to stay in their own communities and dialyze at home. An example of such a program is a strong home-dialysis program that trains either a member of a patient's immediate network or someone from the patient's community and provides ongoing back-up and support once that patient is dialyzing at home [84].

(3) The creation of a scheduling system for patients who dialyze at a center which allows patients to dialyze at a regular time and place so that they are surrounded by a consistent group of staff and other patients. Primary care nursing also helps to maximize a stable group of health care providers for the patient.

(4) The development of responsive scheduling for in-center patients that

minimizes the interruption to the patient's and family's personal and social life.

(5) The design of dialysis units that maximize small group interaction amongst patients while they dialyze as well as amongst family members while they wait during treatment.

(6) The development of a dialysis partner relief program so that patients can continue to dialyze at home when their dialysis helper needs respite from the stress of being a dialysis helper [85].

CONCLUSION

This paper has attempted to present an overview of some of the key issues that are involved in examining the relationship between characteristics of an individual's social network and how he/she lives with chronic renal disease. The following has been discussed: the impact that chronic renal disease has on the individual and the social network, characteristics of the network that contribute to the provision of social support during specific stages of adaptation to chronic renal disease, and interventions to strengthen and enlarge the social network.

As with any overview, many questions remain unanswered. The focus of this paper has mainly been on the positive functions of the social network; further discussion should examine those characteristics of the social network that would have a negative effect on adjustment to chronic renal disease. For instance, what characteristics of the personal network and what types of social support contribute to over dependence and discourage rehabilitation efforts?

The individual's 'network orientation' [7] and the role that the individual plays in influencing the social network have been touched upon in this paper. Because persons with a chronic disease experience fluctuation in their condition, it is important to determine whether an individual's network orientation changes over time. For instance, how individuals' interest in, need for, and ability to obtain social support from network members change as their physical condition varies; furthermore, how does this change affect the make-up of the social network? Additionally, how might health care professionals assist social networks to anticipate changing demands in order that possible negative consequences be reduced? Longitudinal studies of social networks could address this question.

There exists a paucity of evaluation research on social network interventions in health care settings. Studies which evaluate interventions that aim to preserve and enhance rather than disrupt the naturally occurring network are needed. These types of interventions are especially relevant to health care professionals because health care delivery itself is often times disruptive to the patient's social network. Such intervention research could contribute both to our understanding of the processes through which social networks affect well-being, and to improving the quality of care provided to and quality of life of chronic renal patients.

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