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Access to Health Information and Health Care Decision-Making of Women in a Rural Appalachian Community

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Access to Health Information and Health Care Decision-Making of Women in a Rural
Appalachian Community

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In partial fulfillment of the
Requirements for
the degree of
Doctor of Psychology
in Clinical Psychology

by

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ABSTRACT

Access to Health Information and Health Care Decision Making of Women in a Rural Appalachian Community

By Tracy L. LeGrow

Access to health care is a challenge in rural communities. Higher rates of chronic illness and poor use of preventive health practices combine to increase mortality rates among residents of rural areas. The health status of residents of West Virginia is among the poorest in the United States. The current study utilizes both quantitative and qualitative methodology, including the use of surveys, participant observation and ethnographic interviews, to explore the health status, beliefs and social support of women in a rural Appalachian community. Seven major themes were identified relevant to women's experiences with health care: Definitions of Health, Barriers and Aides to Obtaining Health Care, Attitude Towards Health Care, Faith's Role, Environmental Factors, Home Remedies and Sources of Information.

Health was defined as including both physical and mental health factors. Relationships and personal responsibility for one's own health were seen as important. Barriers identified included lack of night and weekend coverage, cultural differences between providers and patients, fear of hearing negative news and the implications of substance abuse in the community. The use of a health care consumer approach to health care was seen as helpful in terms of getting one's needs met and was often developed as the result of becoming a mother. The impact of faith on health care yielded mixed results. Concerns regarding the impact of coal mining on health were identified as an

area of concern. Home remedies were utilized often as a part of managing health and this was consistent with the importance of family as a source of support and of information regarding health. Implications for alternative methods of service delivery are offered.

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Introduction

Social support networks, defined as people in our lives who provide emotional comfort, information and tangible assistance, have been studied as an important positive factor in the management of a variety of health conditions including breast cancer (Spiegel et. al, 1996), HIV/AIDS (Walker, 2002), and serious mental illness (Stein et. al, 1995). Typically, individuals who have access to adequate support networks, both in number of connections and in subjective feelings regarding the adequacy of those networks, show lower utilization of more restrictive treatment placement, such as inpatient hospitalization in the case of serious mental illness, as well as increased use of other more community based treatment and support options (Albert , Becker, McCrone and Thornicroft, 1998)

While this information generally supports the use of psychosocial interventions in the diagnosis and treatment of illness, the large majority of these studies have taken place in urban areas where the number of options available to participants is significantly larger than those available to residents of rural communities. There is, in fact, some evidence that residents in rural communities may not use social support resources in the same way as people in more suburban or urban settings (Koopman, et. al., 2001). The potential for differences in the establishment and use of social support networks within rural areas makes the study of these communities a critical part of increasing our understanding of the role of social support.

The purpose of the current study is to explore the various ways in which women in rural Appalachia access health information and health care in their communities and how they make decisions related to their health as well as the health of their families.

Women's beliefs about the meaning of health as well as the efficacy of using established informal support networks to improve access will be examined using qualitative research methods. In addition, barriers to access will also be identified with an emphasis on the meaning of the barriers and the impact they have on seeking and gaining access to health care.

The current research will look first at the variety of operational definitions used under the heading of social support and how they are hypothesized to work. The definition and structure of social networks and issues of how to measure them will be examined. The lack of a clear, well defined construct and reliable and valid measures of the construct have been seen as problems within this area of study for some time (Barrera, 1986; Tardy, 1985).

Second, the relationship between social support and social network variables and factors such as gender, cultural values, and rural-urban differences will be explored. The data related to the positive effects of social support on physical and emotional health will be reviewed. Special emphasis will be given to relapse prevention and the differential utilization of services.

Third, the area of health beliefs will be reviewed. This area has been of great interest in recent years, and the use of qualitative methods as a way of exploring individuals' beliefs in an in-depth manner has gained popularity. The use of these beliefs as a means of predicting participation in both risk and prevention behaviors shows, promise in developing interventions that will both reach and be meaningful to their intended targets.

The culture of rural Appalachia will be given special attention, with a focus on the lack of relevant research tying the high incidence of chronic health conditions, such as diabetes, with the need for more effective prevention type interventions. Incidence and prevalence of chronic health conditions within this population as well as current access and barriers to services, will be addressed.

Finally, the use of informal, established social support networks to provide preventive information and how these networks serve as links between community members and outside agencies will be explored within the context of rural Appalachia.

Review of the Literature

Social Support Definitions and Measurement Issues

The concept of social support has been studied in various forms for over 40 years. Varieties of definitions have been and continue to be used to describe this construct. These include those related to number of people and interactions (Pilisuk & Parks, 1981), as well as those that have a greater focus on the quality of the interactions, the roles of various relationships, and the satisfaction with which one's network meets one's needs (Barrera et. al, 1981). House (1981) defined four types of social support: appraisal, emotional, informational, and instrumental. Appraisal support consists of those interactions which involve providing feedback, encouragement etc. about a given situation. Emotional support involves the expression of basic caring, love, and empathy. Informational support involves providing factual information, advice, or making a referral. Finally, instrumental support includes behaviors such as loaning someone a car, watching their children, and mowing their lawn.

These definitions can clarify the type of support one might be receiving. They are not as helpful in determining whether the support is effective for a particular individual. It may make a person feel a little better to have someone to vent to when they have had a bad day; that same type of emotional support may not be as helpful when what one really needs is transportation to a doctor's appointment.

Barrera (1986) reviewed the concept of social support and its measurement and found considerable disagreement within the field regarding the definition of social support. He identified three main components, social embeddedness, perceived social

support, and enacted support, which encompassed the majority of concepts and operational definitions.

Social embeddedness refers to the relationships within one's life, the social connections. Counting people and membership in community organizations, clubs, teams etc. is a way of measuring the level of embeddedness of a particular individual. Another way to look at this kind of information is through the use of more formal social network analyses which include measures of density and stability of networks. Stopping with an analysis of social embeddedness has been criticized because it provides little information regarding how networks work or even if they do work for a particular individual. Simply having people around does not necessarily mean that they will be helpful and/or available in a time of need.

Perceived social support involves the belief that one has appropriate social connections. The cognitive component of this type of social support emphasizes the availability of information and feedback from people within one's network. Measures of perceived social support tend to look at both what is perceived to be available to the person as well as the degree to which the support is seen as adequate. Concerns regarding measurement of this type of support are related to possible shared variance when measuring an individual's perception of their stress and/or psychological distress level (Gore, 1981). One positive aspect of this type of measurement is that it takes into account personal differences in terms of number of people in a network and the relative level of satisfaction one feels with the support network.

Enacted support is the final area identified by Barrera. Like House's (1981) instrumental support, enacted support involves actions or behaviors that are actually

undertaken to support a particular person. This goes beyond perceptions and looks specifically at what has actually been done. Concerns regarding the self-report nature of instruments used to collect these data have been raised. Behavioral observations have been offered as a way to verify the presence of enacted support.

Tardy (1985) took a different approach to the problem of defining the construct of social support. Tardy wrote “The solution, however, is not to get people to reach consensus on a single definition. Rather, the solution is to recognize and discuss issues involved in defining the concept at the theoretical and operational levels” (p. 188). Tardy laid out five issues to help researchers make clear informed choices about what they are measuring when looking at social support. These five areas include: (a) direction of support, (b) disposition of support, (c) description/evaluation of support, (d) content of support and, (e) networks.

Tardy pointed out that the direction of support can go both ways, support that is provided and support that is received. Often those who are receiving the help are the focus of the study, however, this is not always clearly defined within the research studies. Researchers need to decide, in advance the focus of their study, those who are receiving the support or those who are providing it. Dispositional issues are similar to those described by Barrera (1986) as perceived and enacted support.

Description and evaluation of support are just what they sound like. Tardy identified these factors as separate factors within the social support research. Descriptions of support offered would include those areas defined by House (1981), appraisal, emotional, informational and instrumental. Evaluation data can be collected

related to how well an individual felt that support offered was helpful within that situation.

The final area, network, involves the social connections available to the person and the characteristics of people within those networks. These can include family, friends, community members, professionals etc. Definitions of the type of relationship, numbers of interactions, years known etc. would be pertinent to this type of analysis.

Tardy's attempt to define the necessary variables when doing research on social support allows for the use of a variety of measures and the flexibility to look at how people offer and use support in real life circumstances. At the same time, the structure will help guide researchers to make the kinds of decisions that may lead to greater consensus and greater ability to make generalizations within the field, since data collected will be able to be classified along the five dimensions presented. Researchers must decide which of these areas are of interest and select their instruments in light of the data they want to obtain.

Social Support Networks

Social support networks are defined as "a set or range of regular interpersonal transactions that assist the individual in meeting physical, psychological and social needs" (Pearson-Scott & Roberto, 1985 pp. 624), and research indicates that involvement in a social support network is important in the functioning of individuals at all ages (Pilisuk & Parks, 1981). A number of models have been proposed to explain how these networks are employed.

The substitution model (Shanas, 1979), involves the availability of family members and friends in a serial order such that a person's spouse is generally the first to

be called upon, after that children, other family members and finally friends. Johnson (1983) proposed a shared kinship model in which several network members take charge in a shared way with no one person bearing the majority of the responsibility.

In addition, two other models whose focus was somewhat more inclusive than just family members were identified. The hierarchical compensatory model (Cantor, 1983, as cited in Pearson-Scott & Roberto 1985) involves friends taking over when family members are not available, in much the same way as the shared kinship model. The shared functioning model (Johnson, 1983) brings in more formal network resources when family members are living at a distance and unable to provide the level of support needed.

These models all involve the people included within social support networks as well as their relative availability to provide support to the individual in question. These are two of the major components that are principle measures within a network analysis. In their study of the social networks of older adults, Antonucci and Akiyama (1987), asked respondents to provide information about the people within their networks, their relationships (family, friend etc.) to the person, the length of time known, frequency of contact, and proximity to the person. Pagel, Erdly & Becker (1987) had respondents in their study identify people within the networks and then keep records for two weeks of daily contacts that included both phone calls and in-person visits.

This type of data collection allows for analysis of not only how many people are involved in networks but also individual variables which may have an impact, such as whether the network members are family or friends and how available they are to provide a variety of supports. These data also allow one to assess the frequency of contact and

the multiple roles that network members may take. The presence of both formal and informal supports are also critical variables to keep in mind.

Social support networks, as mentioned in the models presented, can include both formal and informal components. Formal components often refer to organized groups, agencies, and professional relationships that a person may be involved in, such as work environments or relationships with physicians and social service agencies. Informal components more typically mean friends and family who may provide support with greater frequency and with a less defined set of parameters.

For example, participation in religious activities has both a formal and an informal component, with scheduled services and roles within church organizations functioning in formal ways and friendships among parishioners functioning in informal ways. In a study of rural, elderly women, Zorn and Johnson (1997), looked at predictors of religious well-being including perceived social support, level of hope, and regular participation in religious activities. A moderate positive correlation between religious well-being and social support was found. Recommendations included using religious well-being and the related social support as ways to enhance provision of health care interventions.

Support groups around specific topics or concerns have also been areas of study within the social support literature and represent another type of interaction within the social network. Bond, Belenky, and Weinstock (2000), used a feminist community psychology approach to support low-SES women in a rural community. The premise of this project was that these women could become more empowered through their participation in this group. Participants were mothers between the ages of 16 and 34 who

had at least one preschool child and little family support, were living below the poverty level, and were seen as socially or geographically isolated. A wait list control group was also enrolled in the study.

Participants met weekly for an eight month period in community settings such as local churches etc. Reflective dialogue and problem-solving skills were used within the group settings. A number of interviews and more formal paper-pencil measures were used to collect data, along with transcripts of personal stories shared within group meetings. A significant effect of participation in the support group was seen, with participants showing an increase in available formal supports between the end of the intervention and the follow-up period. Control group women showed a decrease in available formal supports over the same time frame.

In an analysis of both the formal and informal social support networks of elderly, poor residents of rural Texas, Pearson-Scott and Roberto (1985), found that those residents who had the fewest economic resources tended to rely on both the informal support of children and more formal agency assistance. Formal supports were always used in conjunction with filial, informal supports. When formal supports were not used, there were three factors that accounted for it, higher SES, children living in close proximity, or the respondent living at a distance from her child and being widowed. A strong reliance on children was seen across the entire sample. The authors conclude that, “Strategies of service delivery must be developed that strengthen and preserve the primary role of family and friends in the helping networks of rural elders...” (p. 630).

The use of both formal and informal support networks as vehicles to promote change may be helpful in a variety of contexts. Many different types of stressors and

situations have been studied in relation to social support networks. These include studies done within laboratory situations as well as natural experiments and epidemiological studies done with existing populations. All of these methods have shown significant results when evaluating impact on behavioral health problems.

Impact of Social Support on Physical and Emotional Health

Social support and stress

Of particular interest in this study is the question of how social support operates to reduce stress. The lack of well-defined, and agreed upon constructs has contributed to the variability of results seen in the literature about social support and how it contributes to the reduction of stress. The two main theories involve social support as a buffer against stressful life events (Cohen, S. & Hoberman, H., 1983) and social support as having a positive main effect (Thoits, 1982). Some studies have also provided evidence that social support may also have negative impacts in certain situations (Rook, 1984).

Cohen (1988), reviewed models related to how social support functions, identifying both main effects and stress-buffering models. One major question when evaluating models of the way social support works is whether support will work only for those individuals who are under stress or whether there may be effects even for those who are not currently experiencing stress. Models that identify social support as a buffer against stress would hypothesize that social support has an impact for those experiencing stress and has little effect on those who are not. Cohen states that this buffering effect can occur at two points within the relationship between stress and illness. The first is when social support may prevent a stressful reaction as the person's perceived level of support leads them to appraise a situation as less stressful. The second point at which

support may buffer stress is when the person has adequate levels of support which may decrease the affective component of the stress reaction and therefore lower levels of physiological change i.e., lower levels of cortisol, a stress related hormone, would be seen in blood tests.

Barrera (1981) found a significant buffering effect in his study of the social support networks of pregnant adolescents. Barrera used negative life events and social support network variables including network size, conflict within the network, satisfaction with social support and need for social support, as well as the presence of received support from natural helpers within the networks, as predictors of symptoms of anxiety, depression, and somatization. Results indicated a strong inverse relationship between the presence of social support and symptomatology, with those showing the highest levels of support displaying the lowest levels of symptoms. A significant interaction between the presence of stressful events and the support variables provided evidence of the buffering effect.

Thoits (1982) pointed out that research which supports the idea of social support as a buffer has suffered from methodological problems that should serve as a caution in how the findings are evaluated. She raised three major concerns: (a) poorly defined and operationalized constructs, (b) confounding of the direct effects of life events on social support and the interaction of events and support, and (c) the lack of focus on the main effects seen. She encouraged researchers to re-examine how these variables are related.

One example of a question yet to be answered adequately is what effects life events have on social support networks. The majority of studies look at the impact that social support plays when individuals are experiencing particular life events in a

unidirectional manner. Certain life events such as a moving away from existing support people, marriages, deaths etc. may alter the support network, and little information regarding this direction of the relationship has been explored and could be a focus of further study.

Main effect models focus on the effects of social support, regardless of the presence of a stressful situation. Both positive and negative main effects have been reported in the literature (House, Robbins, and Metzner, 1982; Rook, 1984). Cohen (1988a) observed that main effects are most often found when the measurement of social support involves the level of social integration. Social integration includes variables such as how a person is tied to network members who have multiple roles within the network (Thoits 1983). Social integration may influence well-being at a number of levels including increased access to information, provision of positive feedback regarding an individual's identity and self-worth, greater influence of social control by positive peers, and finally, increased access to aid, and tangible assistance from network members.

An example of a positive main effect is that which is seen when mortality rates of people with low and high levels of social integration are compared (House et al., 1982; Schoenbach, Kaplan, Fredman and Kleinbaum, 1986). These studies show that when variables related to health risk factors such as cholesterol level, smoking etc. are controlled for, among people who are currently disease free, those who have a higher level of social integration show lower mortality rates than those who are more socially isolated.

Negative main effects of social support are beginning to gain more notice. Ruehlman & Karoly (1991), in the development of the Test of Negative Social Exchange

(TENSE), found that negative social exchanges and social support were relatively independent of each other. For example, when offers of support, such as loaning money, are provided by network members but are not seen as needed by the intended recipient, support may be seen as meddling or intrusive.

Newsom (1999) reported similar results when looking at people who are receiving care, such as geriatric populations. Individuals who are receiving care can feel that the care they receive emphasizes their lack of competence or self-efficacy and can lead to higher levels of depression and anger. He suggested that a variety of variables, which may serve as main effects or moderators, be explored in order to more fully understand the relationship between psychological health and receipt of care-giving support. These included variables related to both the caregiver and the care-recipient as well as relationship and situational variables and the quality of the helping behaviors.

Clearly, the idea that social support is an easy, straightforward construct that always has positive impacts on individuals is a simplistic and potentially harmful one. Researchers are beginning to take an integrative approach to the concept of social support by looking at “how” social support may operate rather than simply what is being provided and to whom. The models that are being developed may lead to a better understanding of both when and how social support may be used to decrease both physical and psychological distress. Qualitative research methods provide the means to explore these types of questions.

The study of social networks and the interactions among members is one important component of this process. It is through this type of analysis that the presence of both positive and negative interactions and the idea of matching support needed with

that received may begin to clarify answers to questions about the process by which social support works.

Social support and behavioral health

The influence of social support has been studied at a variety of levels from individual physiology to community systems. Thorsteinsson and James (1999) looked at the effects of social support in instances where stress was induced in laboratory situations. Their meta-analysis included 22 studies where dependent measures included heart rate, diastolic and systolic blood pressure, cortisol levels and skin conductiveness. Social support conditions in these studies typically involved the presence of a supportive friend or a confederate versus being alone or having a non-supportive confederate. The questions put forward included: (a) evaluation of the relationship between experimentally manipulated social support and physiological reactivity, (b) determining what, if any variables act as modifiers of this relationship, and (c) what recommendations can be made for future research.

This laboratory research provided support for the protective effects of social support. Results showed medium to large effect sizes for those measures related to cardiac functioning (heart rate, systolic and diastolic blood pressure) when social support was manipulated. Little could be said about moderator variables, due to inconsistencies in research protocol, as well as small sample sizes. The authors suggest that further evaluation of potential moderator variables including perceived stress, cynicism, hostility, Type A personality, and task performance would be needed in order to make informed decisions about their impact on the effectiveness of social support.

Uchino, Cacioppo and Kiecolt-Glaser (1996), in their review article, assessed the impact of social support on a variety of physiological measures within natural environments. Evidence was particularly strong as it related to positive changes on measures such as heart rate, systolic, and diastolic blood pressure. Effect sizes ranging from $r = .12$ to $r = .28$ were reported. Evidence of benefits to immune and endocrine system functioning was also noted. Measures of immune functioning included counts of specific cells, such as T cells, and effect sizes were reported at $r = .21$. The use of social support interventions as they relate to chronic health issues was seen as relevant to improving treatment options.

The potential mechanisms for the effects of social support were also evaluated. The importance of family members as sources of support was noted; in addition, the presence of emotional support as a factor within the construct of social support was supported. Some evidence of social support as a buffer for stress was noted. The most interesting part of this analysis had to do with the fact that these positive benefits could not be accounted for by the simple presence of reported health behaviors; social support also played a role.

Evidence clearly identifies a number of positive, physiological changes that can be measured in the presence of available social support. The questions then can be stated in terms of how these small physiological changes impact an individual's mortality, their response to medical interventions such as cancer treatment, and their utilization of mental health services.

Social support and mortality

In a longitudinal study of mortality and the impact of smoking, consumption of alcohol, physical activity and the presence of close personal relationships, Rehm, Fichter and Elton (1993) looked at mortality rates 13 years after extensive interviews. Death records were searched and cause of death noted using International Classification of Diseases, Ninth Revision (ICD 9) categories. Data was obtained from 93% of the original participants (n=1536) in a rural area.

Results showed that death rates were increased for those who smoked and drank. The presence of close relationships and the performance of physical activity decreased mortality. The protective value of having a close relationship appeared to have a higher impact on males than females. No consistent, significant interactions were seen among the four major variables.

The authors looked at best case scenario (not smoking, low to moderate drinking, regular physical activity, and presence of a close relationship) versus worst case scenario (smoking, moderate to heavy drinking, no physical activity, and lack of a close relationship). When comparing the mortality rates of a 40 year old male, only about 1 in every 100 men in the best case scenario would die within the 13 year study period, compared to about 1 in 5 men in the worst case scenario. They go on to comment that these scenarios are not unrealistic because lifestyle variables often are highly related both in positive and negative directions.

Mortality studies like this and others (House et al., 1982 & Schoenbach et al., 1986) may provide people with strong motivation to seek out and maintain supportive relationships with others over their lifetimes as part of their preventive health practices.

Do supportive relations impact people going through a specific health crisis in the same way? Research in the area of social support and cancer can provide some answers.

Social support and cancer

Meyer and Mark (1995) used meta-analysis to evaluate the use of psychosocial interventions with adult cancer patients. They included those studies in which participants had been assigned to treatment conditions using randomized selection processes. Their specific questions related to (a) the overall effectiveness of psychosocial interventions, (b) the possibility that some interventions were better than others, (c) whether the severity of the disease would have an impact on effectiveness, (d) the impact of screening patients to include those with clear difficulties versus using no screening method, and (e) determining if effect size is impacted by having the treatment focus on coping with chemotherapy, radiation, or pain.

A total of 45 studies were included in the meta-analysis. Dependent variables included emotional adjustment, functional adjustment, treatment and disease related symptoms, medical measures and a global measure. Treatment categories included cognitive behavioral, information and education, nonbehavioral counseling, social support and unusual treatments. Moderator variables included risk for psychological distress as measured by how localized the disease was, the intensity of the treatment and the prognosis, focus of intervention (chemotherapy, radiation or pain), and the use of patient screening variables.

Results showed that the effect sizes for all but the emotional adjustment variable were within the same range, from .19 to .28. When one outlying study was excluded from the analysis, emotional adjustment effect sizes were also consistent with the other

variables. No significant differences were seen between treatment conditions. The authors point to small power as one reason why this result might have been obtained. They go on to say that while a clear benefit can be seen from the use of various psychosocial interventions, further studies need to look at those types of interventions with sufficient power to detect possible differences as well as to take a longitudinal look at the potential for long-term versus short-term impact.

Cain, Kohorn, Quinlan, Latimer and Schwartz (1986), evaluated the efficacy of using a thematically-based intervention with groups of women diagnosed with some type of gynecologic cancer (endometrial, cervical, ovarian, vaginal, vulvar). The intervention included 8 sessions with designated content at each time, including defining cancer and its causes, understanding the physical and psychological impacts of treatment, learning relaxation, diet and exercise techniques, exploring changes in relationships and developing skills to communicate with caregivers, and, finally, goal setting. Women were randomly assigned to one of three groups, standard counseling, thematic counseling-group, and thematic counseling-individual. Those who participated in the thematic group counseling showed significantly better adjustment at the 6-month post counseling check than women in the standard counseling group. This more positive adjustment was measured by absence of depression as well as by little or no anxiety. This result was also seen in women who had participated in the thematic individual counseling and was attributed to the emphasis on information-giving and problem-solving approaches used within the thematic conditions.

Similar results were seen in an ethnographic study of an ongoing breast cancer support group (Cope, 1995). Members of this group demonstrated many of the same

functions that were built in to the thematic approach (Cain et al., 1986). These functions included exchanging information, sharing the illness experience, and providing strength to fellow group members. The author emphasizes the need to further explore what individuals may be getting out of different types of interventions in order to better meet the needs of the individual.

Social support has been shown to have a positive effect on cardiac and endocrine functioning, to lower mortality rates of individuals who have strong social integration, and to improve quality of life and lower post treatment complications for people with cancer. These positive effects are also seen in the area of mental health. Individuals with strong social support networks utilize fewer services and need less intense services, such as the in-patient hospitalization, to deal with even severe mental health issues.

Social Support and Mental Health

Albert, Becker, McCrone and Thornicroft (1998) reviewed the literature related to utilization of mental health services by people with severe mental illnesses and the presence of social support networks. They included 25 studies whose participants were people with severe mental illnesses as exemplified by schizophrenia, bipolar disorder, and delusional disorders. Subjects in these studies had been diagnosed at least one year earlier and showed severe impairment in their ability to function in at least one area of daily living including work, family responsibilities and accommodation.

Questions posed for this review included (a) the relationship between psychiatric hospitalization and social network size, (b) service utilization and possible qualitative differences in social networks, (c) possible relationships between outcome measures in

mental health and social networks/social support, and (d) possible relationships between the use of community, outpatient services and social networks.

Results indicated that those patients with smaller network sizes did use inpatient services at a higher level. Mixed results were seen in terms of qualitative variables. Some evidence showed that a moderate network size tended to be more stable and lead to lower service utilization. It was hypothesized that larger networks were more difficult to maintain due to the higher level of responsibility on the patient to hold the network together. Smaller networks that had many overlapping relationships were related to increased service use due to the stress on network members who had to fill multiple roles. Having more members of one's parental family and fewer friends, as well as having more short-term relationships and relationships with those met in mental health settings, also showed some relation to higher levels of service utilization. Mixed evidence for the inclusion of mental health providers as part of one's support network was seen.

Evidence regarding social support network makeup and use of outpatient service showed that size of network was not as useful a predictor variable as the makeup of the network. Studies by Horwitz (1977, 1978), showed that referrals to psychiatric services by informed persons within an informal network and from friends, as opposed to family members, were more likely to result in the use of non-inpatient services. The authors conclude that "Thus, it is reasonable to conclude that ensuring adequate size and quality of social networks will reduce the likelihood of hospital admission, facilitate access to services and help to avoid adverse pathways to mental health care" (p. 263).

Bristow and Patten (2002) reviewed literature on individuals with depression and the factors related to treatment-seeking. They evaluated the literature to answer two

questions, the rate of treatment-seeking for depression and the factors that influence the likelihood that a person will seek treatment. The review included 17 papers which met exclusion rules. Articles reviewed showed a range of treatment-seeking across studies that ranged from 17.0% to 77.8%. Differences such as the definition of depression used, the use of self-report and/or retrospective reports and the time period used to measure treatment-seeking were seen as factors in the variability in rates. In addition, variables affecting treatment-seeking included the influence of public perceptions regarding treatment, improved ability to detect depression, and individuals seeking treatment who did not meet the full diagnostic criterion for a depressive disorder.

A number of mediating variables including ethnicity, age, available social supports, and psychiatric factors were also noted. Those least likely to seek treatment were young adults, the very old, minorities, and those with little social support. Social support is a possible target of intervention in that those who have a support network are more likely to seek treatment. This finding may be especially important in those groups where treatment-seeking rates are the lowest.

Social support level is also related to treatment outcome and relapse prevention in people with severe mental illness, although there are few studies of this area. The general trend is that those patients who show higher levels of social support tend to have more positive outcomes. Cole, Leavey, King, Johnson-Sabine and Hoar (1995) provided evidence that the absence of a family or friend when a patient was involved in their first diagnosed psychotic episode was predictive of hospitalization. The presence of a general practice (GP) physician provided some measure of support in keeping people out of the

hospital by providing treatment on an outpatient basis. It was noted, however, that living alone and not having family and friends around were related to not having a GP involved.

Social support appears to be an important factor in both severe and less severe forms of psychiatric illness. Utilization of services and the ability to treat patients within the community is related strongly to having, not only an available network, but also one that is manageable in terms of size and includes the right mix of people, family, friends, general practice physicians, and possibly mental health professionals. Another major question that is beginning to be answered is what, if any, demographic or contextual variables related to the individual may act as moderators of the relationship between social support and wellness, and if these moderators exist, how do they impact the relationship?

Demographic and Contextual Issues

One common moderator variable that is studied in psychology is gender. While data regarding gender are often collected, the presence of gender effects is not always analyzed and this is true in the case of social support and its impact on health.

Shumaker and Hill (1991) reviewed studies of social support and health with a particular emphasis on gender issues. The authors note that “investigations of the association between social support and physical health have been almost exclusively limited to White men. When people of color or women are included in study designs, the results are more complex...” (p.102). This critical review showed somewhat mixed results for women when mortality and social support were evaluated. Rather than the straightforward relationship seen in the data on men, i.e., higher support is related to lower mortality, women showed what was described as a threshold effect, where both

high levels of support and high levels of mortality were seen within specific age groups. The authors suggest that this may be related to being in networks and relationships that might provide, but also demand, high levels of support, which may lead to increased stress, as is seen in caregiver fatigue. These women were seen as being caught in the “sandwich” generation where they may be caring for both aging parents and children or grandchildren.

Cultural issues may also influence differences in social support. This author was unable to find any studies that looked at cultural differences in the provision of social support and its impacts on physical and psychological health. The available literature tended to pay little attention to the individual characteristics of the person receiving the support, but to focus more on the members of the support network and how the support was provided. There is clearly a need to include contextual issues as variables in the research. As cultural issues are addressed, differences attributed to other variables such as satisfaction with support may be more clearly explained. Understanding the characteristics of a population, especially when working within an ethnographic framework, will be essential when analyzing data and making potential comparisons with other groups.

Another significant limitation in the current research is the lack of rural samples. Although there are not many studies that look at social support networks in rural populations, those that have are beginning to discover that people who live in rural areas may use support resources in different ways than has been seen in urban samples.

In a descriptive study, Taylor (2001) looked at rural women who were receiving welfare. Areas of interest included work experience and aspirations, social support,

service utilization, and mental health barriers to employment. Results showed that tangible barriers such as a lack of transportation, informational barriers such as not knowing what programs they might be qualified for, and psychological barriers such as increased symptoms of depression or anxiety, were related to the actual presence of a barrier or the perception of a barrier to employment. What people perceived to be barriers was as relevant as what was an actual barrier.

Taylor comments that “For rural families, social support may be an especially important resource because other types of assistance may be less readily available. Not only does connection to family and friends serve a protective function in terms of decreasing depression and anxiety symptoms, this form of support may also mean increased exposure to material resources and information useful for individuals moving off of welfare” (p. 458).

Taylor points out the uniqueness of her sample and encourages further research. At the same time, the unique resources of each community might make generalization somewhat more difficult.

Another study, with a rural sample of women infected with HIV/AIDS, focused on the perceptions of women and HIV/AIDS service providers, barriers to services, and characteristics of resiliency (Walker, 2002). Prior research in this area had relied almost exclusively on urban samples.

In Walker’s study, extensive interviews were conducted with the infected women and their service providers. Seven categories were apparent in the data collected. These included caregiving, coping, stigma, social support, access to services, mental health counseling, and medications. Access to information and education was seen as an

important tool for women to manage their disease. This included understanding the importance of not neglecting health issues, understanding caregiving, and accessing support networks. The difficulty of accessing services due to transportation barriers was also seen. One difficulty mentioned in the Walker study was the failure to follow through on organized support groups.

Similar results were reported by Koopman et al. (2001). This study looked at reported distress, coping mechanisms, and social support among women recently diagnosed with primary breast cancer in rural areas. A group of 100 women completed a battery of questionnaires either within 3 months of their diagnosis or within 6 months of completing treatment. Measures included demographics, life events, mood profile, adjustment to cancer, and social support. Even when cancer support groups were available, the women tended to rely on them less than their own informal support networks, including family, friends, and people with whom they felt a spiritual connection. Koopman et al. (2001), also talk about the lack of access to educational materials and the distance from cancer specialists as barriers to care for rural women.

How then do these early results describing how and when rural residents use social support resources relate to needs in rural Appalachia? The needs identified in these other rural samples, lack of access to information, transportation barriers, lack of local medical providers and high levels of chronic illness (CDC, retrieved May, 2003), all make rural Appalachia a prime area in which to consider social network types of interventions.

Before these types of interventions can be developed and implemented, an understanding of what health means and how that meaning shapes women's behavior when it comes to making decisions about their own health becomes critical.

Health Beliefs and Attitudes

When looking at reasons for why people do or do not engage in health promoting behaviors, one of the most prominent theories involves understanding an individual's beliefs about threats to their own health and whether they identify a particular health behavior as a way to reduce that threat. The Health Belief Model (Hochbaum, 1958; Rosenstock, 1966) further defines each of the two major components of beliefs about personal threat or vulnerability and the efficacy of particular behaviors to modify or reduce one's vulnerability.

Within the area of whether individuals identify themselves as being at risk for a particular condition or disease, three factors are seen as important (a) general values about health, including how concerned and interested in personal health one is, (b) specific ideas about how vulnerable one is to a particular disease and, (c) beliefs about possible outcomes of having a disease. When looking at what an individual believes about opportunities to reduce what is perceived as a threat, two factors come into play, beliefs about what the individual regards as what behaviors are effective in reducing a health threat and how they weigh the costs and benefits of practicing those behaviors.

The Health Belief Model has been used in a variety of studies as a way of predicting participation in health prevention and health care practices. Researchers in the area of Health Beliefs have used a variety of methods to identify the particular beliefs of their participants. Although surveys can provide a great deal of information and in a

format that is easily compared across samples, some investigators have begun to understand the limits of survey research when trying to explain and predict health behaviors. Although survey data may reflect attitudes about health practices, they do little to capture the experience of making health decisions and navigating barriers to the health care system (Feather & Green, 1993; Polakoff & Gregory, 2002). The use of qualitative methods of inquiry that allow more in-depth understandings of how people are living and experiencing various phenomena in their daily lives is gaining favor when exploring health beliefs and practices.

Polakoff and Gregory (2002) used woman-centered interviewing to explore the experiences of impoverished women in terms of the meaning of health and the types of barriers they experienced in their journey to achieve it. The women (n = 6) were each interviewed four times. They ranged in age from 25 to 48 and all fell within the lowest income bracket designated by the government. The principles of content analysis (Fetterman, 1989) were used to identify two major themes that they called: *The Journey to Health-The Quest for Wholeness* and, *The Forces of Distress-It Takes Courage to be Whole*.

In the theme related to looking for wholeness, participants identified a connection between mind, body, and spirit as being an integral part of the experience of health. Feeling both a connection to faith, as well as to heritage and culture, was seen as important. Emotional safety was another identified component of health. The women described ways in which they would manage daily burdens by dealing with them one at a time and not trying to tackle all of their problems at once, which would be too overwhelming. The avoidance of alcohol was seen as a necessary strategy for all of the

participants, either due to the cost, or to understanding that the use of alcohol as a coping mechanism was not going to be effective. Finally, the support of friends and family was seen as one of the things that got the women through the daily hassles of life. They used these support people as confidantes, as sources of comfort, and as cheerleaders who helped them keep their focus on the most positive aspects of their lives.

When looking at the obstacles within their experience, the women identified the lack of privacy that comes with using public assistance. The women shared the experience of shame that they felt because they were unable to provide for their own basic needs. They felt humiliated and scrutinized, both by the workers they had to deal with, as well as by the public at large. Lack of encouragement from partners, husbands and neighbors was also seen as an obstacle for many of the women, taking away from their own efforts to stay positive and to maintain a sense of self-worth.

Polakoff and Gregory emphasize the importance of social relationships in the meaning of health for women. They state that “Women who live in poverty have fewer choices about where and to whom they might turn for support, advice, information, direction and assistance in their pursuit of wholeness” (pp. 843-844). They conclude that in order to meet the health needs of women, providers must see the woman within her context including her beliefs, her relationships, her resources, and her barriers. Interventions will need to assess not only traditional contextual barriers such as socioeconomic status and number of health care providers but also psychosocial barriers experienced within their most intimate and important relationships.

Chapman and Beagan (2003) examined women’s beliefs about health, specifically beliefs about diet and breast cancer. Participants, a convenience sample of women (n=

61) between the ages of 40 and 60, completed in-depth, semi-structured interviews about their current eating habits, beliefs about health, nutrition and cancer risk, as well as available sources of health information. The group was split about evenly between women who had been diagnosed with breast cancer sometime in the previous 6 months to 15 years and another group who had never been diagnosed with breast cancer.

Three perspectives on what was meant by “healthy eating” were identified using a thematic approach to analysis. The three themes were (a) *traditional eating* which was identified by an emphasis on home cooking and the avoidance of processed foods, (b) *mainstream eating* as defined by an emphasis on current nutritional guidelines including the consumption of minimal amounts of fat, inclusion of fruits and grains, variety in foods consumed and balance among the food groups and, (c) *alternative eating* which reflected a heavy emphasis on the consumption of vegetables and fruits, little or no red meat or processed foods and a focus on food’s impact on an individual’s immune system and risk for cancer. The authors note that these perspectives are not mutually exclusive; there is overlap between and among all three perspectives.

Women’s beliefs about the possible link between diet and breast cancer risk were related to the perspective they most closely identified with in terms of healthy eating. Women who identified with the alternative eating perspective were most likely to strongly acknowledge a link between diet and breast cancer. Those who identified with the mainstream perspective were somewhat less certain about a link, sometimes citing a lack of overwhelming evidence to prove the point. Those women who placed themselves in the traditional perspective were the least likely to acknowledge that diet had a role in breast cancer risk.

One interesting finding in this study was related to the women who had previously been diagnosed with breast cancer. These women believed that there was a strong link between diet and breast cancer. In spite of that, they were no more likely to identify with the alternative eating perspective than women who had never been diagnosed. In addition, they were no more likely to have changed perspectives following their diagnosis. The authors point out that this study confirms findings from previous studies indicating that people's ideas about nutrition and eating habits tend to be relatively fixed. They conclude that improving compliance with nutritional interventions may be improved by having a better understanding of the meaning of health and nutrition to the participants, and that this type of assessment will need to be a standard part of interventions if they are going to be applicable to the individuals who they are targeted for.

Beliefs about health and participation in mammography screening were examined by Russell, Swenson, Skelton and Shedd-Steele (2003). The low participation of African American women in breast cancer screening, leading to later diagnosis, has been identified as one of the factors contributing to the higher mortality rate from breast cancer among African American women (Eley et al., 1994).

Through the use of focus groups, African American women were asked to respond to two major questions: (a) "What is the meaning of health?" and (b) "How does the experience of having a mammogram screening fit within your definition of health?" (p. 29). Thirty women, over the age of 40, participated in one of three groups. The groups were divided according to occupation, with one group for women who had professional, executive or administrative positions, a second for women who had middle-

management and technical positions, and a third for women who were employed in clerical and service positions. Three themes were identified upon analysis of transcripts for the first question (a) the mind, body, and spirit connection; (b) living your life; and (c) looking good.

The mind, body and spirit connection involved an understanding of and value in the interconnectedness of these three entities in life. Having a “feeling of health” was seen as a better indicator of health than the number of medical diagnosis one had or the number of medications that one took. The women expressed strong spiritual beliefs that enabled them to take charge and make responsible decisions about their own health. They also saw having a chronic medical condition as different from being ill. Chronic conditions that were well managed were seen as less problematic than illnesses, and participants reported that actively managing chronic conditions was a way of preventing illness.

The theme of Living Your Life included beliefs about living long and productive lives. There was an emphasis on maintaining independence in activities of daily living. Again, a distinction was made between those illnesses that inhibit daily functioning and those that did not. The final theme, Looking Good, related to both physical appearance and youthfulness. Women reported that when they or others looked good and felt good, that they would identify themselves and others as healthy in all aspects.

When asked about the meaning of mammography and how it fit in with beliefs about health, four themes were identified: (a) good health-bad health; (b) prevention-detection confusion (c) being afraid of cancer and; (d) what gets in the way. The good health-bad health perspective highlighted the idea that having knowledge about one’s

body, either positive or negative, was one way to identify someone who was healthy. Women saw themselves as empowered in their decision making abilities by having the information both in terms of the physical dimension of caring for the body and the mind dimension of dealing with stress and worry. Women who had a family history of breast cancer identified this mind dimension most often. The women identified personal contact with women diagnosed as having breast cancer and the media as having an influence on getting a mammogram. There is a sense that the closer the women related to either the people they knew with cancer or the portrayals in the media, the more likely they were to seek and follow through with a mammogram.

One interesting finding among the women in this study was the confusion they had about the outcome of a mammogram, described in the prevention-detection theme. There were a number of women who falsely believed that having a mammogram would prevent them from getting breast cancer. It is notable that some of this confusion seemed to come from the promotion of mammography as a “preventive” tool. The majority of the women did see mammograms as important in terms of detection of cancer and with finding it at the earliest possible time in order to facilitate treatment.

Being afraid of possibly finding breast cancer was seen as a barrier to obtaining a mammogram. Women identified the belief that you shouldn't go looking for trouble as one that had a negative impact on women getting mammograms. Cultural beliefs were also noted within the African American community. The seeking of medical services can be seen as an acknowledgement of serious illness and so is something that should be delayed as long as possible. Denial that breast cancer is a concern among women in the

African American community was also noted; breast cancer happens to other people, not to us.

Additional barriers to obtaining mammograms were also identified by the women in the study. “What gets in the way” included financial problems, time constraints and a general lack of trust in those who provide medical care. Women described a lack of individuality within the health-care system as well as a lack of respect or value for the individual’s beliefs about her own health from the provider. Availability of health insurance as well as the multiple roles most women play in terms of caring for others in the family often lead to the woman’s health care needs taking a back seat to the more pressing daily demands of husbands, children, jobs, and managing the household.

The impact of widely held cultural beliefs on women’s understandings of the importance and impact of preventive health initiatives and their willingness to participate can not be underestimated or undervalued if participation is going to be improved. The authors identify a model of decision making that illustrates good health and bad health factors balancing on the fulcrum of mammography screening. Cultural beliefs and social support have the ability to tip the momentum in either direction. Listening to what the basic beliefs of a cultural group entail is a first crucial step in being able to plan and implement interventions that may actually meet the needs of those for which they are intended.

In an attempt to use the Health Belief Model to predict attendance at breast cancer screenings, Pakenham, Pruss and Clutton (2000) followed a group of women who had participated in a breast screening service ($n = 88$) as well as a group who had not participated in the screening but had used the health services data base ($n = 44$). The

women were asked to complete a questionnaire that asked for socio-demographic information such as age, marital status, highest level of education and occupation, as well as knowledge about breast cancer and measures of health beliefs that included their beliefs about their own chance of getting breast cancer as well as benefits and barriers to mammography.

Using multiple regression analysis, the authors attempted to identify those factors which would differentiate reattenders from nonreattenders. Marital status, age, and physician involvement reliably predicted reattendance. Women who were married, older and had good physician involvement were most likely to reattend screenings. The importance of social support, both from a spouse and from a caring physician, were critical in predicting reattendance.

When health beliefs variables were added, they provided a significant improvement in the model. Belief in the benefits of having a breast screening, as an individual variable, was significantly associated with reattendance. This finding highlights the importance of working with women to understand the benefits of mammography within their cultural and health beliefs framework.

Working within a cultural framework can be a slippery slope when the researcher is not aware of what factors define that culture. One can not assume that ethnicity is the primary factor in determining membership in a particular culture. Bryant (2003) examines this idea when looking at birthplace as a determinate of culture and health status within the Black or African American culture in the United States. While the Black population in the United States may be seen as representing one culture by those

on the outside, variations in region of origin (Africa, Caribbean etc.), as well as time in the United States, can have an impact on how women define their health status.

Three questions were posed as part of this study: (1) What is the relationship between place of birth and health status?; (2) Does the relationship between health status and socioeconomic status vary by place of birth?; and (3) Does the relationship between health status and social support vary by place of birth? Data from the 1991 National Health Interview Survey (NHIS) were utilized to answer these questions. These data include things like what types of illness are in the population, and in which sub-groups are they found, as well as disability impact, and types and utilization of health care resources.

A sample of women of African descent was used. Women born in the United States (n = 8,574) were compared with women born in Africa (n = 393). Findings indicated that women who were foreign born were more likely to report their health status as excellent than women born in the U.S. overall. There were some age group trends however, with younger U.S. born women rating their health status as excellent more often than foreign born women. As age increases, this trend reversed and foreign women rated their health status more positively.

This type of divergent result was seen in other areas as well. While education and occupational status were generally seen as positive contributors to health status, this was only the case for the U.S. born women. Foreign born women with less education and lower occupational status reported higher health status. The author highlights the importance of understanding cultural beliefs about health status when trying to understand an individual's judgments about her own health status.

Different cultural groups do appear to hold a wide variety of beliefs about health which can lead to differences in their evaluation of their own health status, as well as the likelihood that they may participate in a variety of health care services. Is there a way to cut across these differences and look at a classification that is based on general attitudes about health?

Hagoel, Ore, Neter, Silman and Rennert (2002) categorized women into lifestyle groups based on behavior patterns. Three clusters were identified from a sample of 1,075 women between the ages of 50 and 74. The clusters identified were the “health-promoting” cluster which involved those women who were actively involved in living a healthy lifestyle, conforming to medical and health recommendations, and not participating in health risk behaviors; the “inactive” cluster which included those women who did not participate in either health promoting or health risk behaviors and; the “ambivalent” group who engaged, to some extent, in both health promoting and health risk behaviors.

These groups were then used to predict participation in mammography screening and were found to do so. Women who were identified as members of the health promoting cluster were more likely to self-initiate mammography screening than women in either the inactive or the ambivalent clusters. This was true even after controlling for demographic variables such as age, SES, education, ethnicity, and work status. The authors point out that the inclusion of cognitive components such as beliefs about health status provide another tool to use when attempting to influence the health behaviors of individuals. They highlight the importance of seeing lifestyle as the sum of not just behavior, but also of attitudes, perceptions, and life circumstances.

Age may also play a role in determining health concerns and health beliefs. Banister and Schreiber (2001) examined the health concerns of adolescent women in order to gain a better understanding of their needs at this critical time in development. The women interviewed ranged in age from 16 to 24 (n = 42). Using ethnographic interviews and participant observation, eight focus groups were conducted and two major themes were identified, “feeling invisible” and “struggling with independence.”

The participants related experiences that focused on feeling invisible in terms of their concerns while at the same time becoming the focus of attention in terms of problematic behaviors. Within this invisibility, disrespect by male partners and authority figures was mentioned. For many of the girls and women, school experiences tended to be negative; the women did not feel that their teachers took interest in them, and they said that there tended to be a double standard in which the women were required to attend and focus on everything that the teachers said but there was no reciprocity within these relationships, and little concern was shown for the daily stresses of the women.

The women also experienced this type of invisibility within their relationships with their physicians. They felt that their concerns were not taken seriously within the relationship and that often the physicians were unapproachable when they had concerns. Feelings of intimidation were also common. The women avoided potentially negative interactions with their physicians by not asking questions about their sexuality and birth control. This set up a cycle of frustration and distrust with the physicians that only increased the feelings of invisibility among the women.

Rather than being a good source of social support, relationships with boyfriends were often viewed as disrespectful. Pressure to engage in sexual activity, being called

derogatory names, and being threatened with the loss of the relationship if demands were not met were common experiences for the women in this study.

The young women in this study reported incidents of emotional, physical and sexual violence that often went unrecognized/ unacknowledged by those people and agencies most equipped to help them, including their schools. This lack of recognition was seen as one factor that facilitated the young women's lack of recognition of the seriousness of these incidents. The women reported a sense of shame that reinforced their choice to not discuss these violent incidents with anyone.

Age stereotyping was another factor that emerged. Due to their young age, many of the women felt that they were being judged harshly by the public at large. This was especially true of those women in the study who were already mothers.

Beliefs about health and its meaning can have a significant impact on how one chooses to use available resources. In rural areas, one's beliefs may not have the same impact, especially when these resources are limited. How do beliefs and availability of resources interact within rural areas?

Health Beliefs and Health Resources in Rural Areas

The reality of women's lives in rural areas is that no matter how positive their beliefs about their own health and the efficacy of participating in health-promoting behaviors, the lack of availability of resources to do this has a substantial impact. In an attempt to integrate the influence of both health beliefs and the availability of health resources as a way of predicting the participation in health promoting behaviors in rural communities, Pullen, Noble-Walker and Fiandt (2001) examined the lifestyles of rural elderly women.

Using a telephone survey, data were collected using the Health Promoting Lifestyle Profile II (Walker, Sechrist and Pender, 1987). The Health-Promoting Lifestyle Profile II (HPLPII) measures several types of behaviors which are seen as promoting healthy lifestyles. These behaviors included physical and nutritional health activities as well as interpersonal and spiritual health, responsibility for one's health, and stress management. In addition, women were asked their definition of health, including both wellness and clinical, using the Laffrey Health Conception Scale (LCHS) and to rate their perceived health status (physical and mental health), on the Medical Outcomes Study Short-Form General Health Survey (MOS). Demographic data including age, marital status, health insurance status, educational level, and income were collected. These measures were all grouped under the category of Personal Influence variables.

Contextual Influence variables measured included sources of health information, provider counseling, and attempts to change behaviors. Sources of health information was measured by operationally defining sources as the number of professional, personal, and media resources available to the individual. The offer of provider counseling regarding health behaviors was measured by adding the number of points (0-3) for responses to the question of whether or not a health care provider had talked with the individual about changing physical activity, nutrition, and stress management behaviors. The number of attempts to change behavior was defined as a simple count of the number of attempts made by the individual to change health behaviors, whether or not they were successful.

Hierarchical regression analyses were used to examine the relations of personal and contextual influences on the presence of behaviors which were considered to be

health-promoting. Personal influences were entered first, in three groups, and contextual influences were entered last, in two groups.

Results indicated that 47% of the variance in health-promoting life-style was explained by the model. The greatest amount of the variance (31%) was explained by the personal influence variables. The inclusion of the definition of health and perceived health status, beyond the demographic variables of age and living arrangement, increased the amount of variance explained significantly, pointing to the importance of health beliefs as determinants in participation in health promoting behaviors. In addition, the definition of wellness and mental health status made significant independent contributions to the model.

Contextual variables explained an additional 16% of the variance within the model. Both sources of health information and offers of provider counseling significantly increased the variance explained, as well as being significant independent contributors within the regression equation. Results showed that the women surveyed used a variety of resources to get information about health. These included health care providers (58%), family and friends (45%), and media sources such as magazines (94%).

Overall, the largest contributors to the equation were the wellness definition of health and the sources of health information. It is unclear if those two variables are correlated, in that those with a stronger wellness definition of health are also those who would be most interested and aware of sources of information or vice-versa.

The importance of understanding the meaning of wellness, the inclusion of mental health status as part of general health, and sources of reliable health information clearly can have a major impact on how and if women in rural areas utilize health care resources

and whether they see these resources as having benefit. One can not assume, however, that being able to identify sources of information means that one can actually access these sources in a meaningful way.

In a study of the impact of literacy on participation in health care, Gannon and Hildebrandt (2002), evaluated the literacy of a sample of women (n = 50) who utilized a rural health care clinic and compared that to measures of readability of educational materials commonly used in the clinic. The authors report that health information is often written at about an 8th grade reading level. Results showed that more than one out of every six participants could not read the educational materials used when providing patients with health information. Consent forms were estimated to fall at the 11th grade or higher in terms of reading level.

Patients who are unable to read educational materials are at a distinct disadvantage in terms of their ability to access all aspects of health care provision. The fundamental issue of literacy and an understanding of how it may impact patient compliance with treatment and the development of better care of chronic conditions can not be underestimated and needs to become part of the assessment of what is working or not working in a given intervention. This is particularly true of populations who may be at higher risk due to decreased access to education. One can not assume that poor compliance with treatment is a function of a negative attitude or other more tangible barriers.

While personal and contextual variables can all have an impact on women's use of services and perceptions about their own health, the question of whether there are

particular barriers that have a greater impact on access to health care in rural areas remains to be answered.

Barriers to Care

Barriers to health care have been a popular topic in both research and in the popular media over the past two decades (Institute of Medicine, 1988; Aved, Irwin, Cummings & Findeisen, 1993). Often the discussion has revolved around the impact of the availability and the high cost of insurance. Hsia et al., (2000) as part of the Women's Health Initiative (WHI) Observational Study looked at health insurance status, the type of insurance, and perceived health variables in a sample of post menopausal women (n = 55,278) to determine what impact health insurance status had on access to health care. Within the sample, 5% of the women under age 65 had no insurance and .2% of women age 65 and over had no insurance.

Results of the study indicated that those factors related to having not seen a health care provider in the past year for women, aged 50-64 included fewer years of education, lower household incomes, being Hispanic, and current smoking. The women least likely to have seen a provider in the past year were, indeed, those who lacked insurance. Women over 65 who had not seen their provider in the past year were more likely to be Hispanic or African American, to be current smokers, to have lower incomes and to have only Medicare coverage for insurance. Those women who had prepaid, private insurance, chronic health conditions, and more negative perceptions of their own health status were the most likely to have seen their doctors.

Results, using logistic regression, indicated that those women with prepaid insurance did appear to have greater access to health care as determined by having visited

a health care provider in the previous year. This was in comparison to those women who had Medicare alone or who had fee for service types of arrangements. The continuing health care crisis in terms of insurance status does appear to have a significant impact on the use of services by women in the United States.

Another question is whether the use of health care is related not only to insurance status, but also to gender. Xu and Borders (2003), using data from the Medical Expenditure Panel Survey (MEPS), evaluated gender differences in the number of visits to physicians while controlling for variables such as perceived health status. The MEPS is a national survey, representative of the current population of the United States.

In this study, the dependent variable used was participation in a physician office visit during 1996. Independent variables included current health conditions, financial barriers to the use of services (income, receiving food stamps or AFDC and insurance status), non-financial barriers (number of hours at work, having a usual source of care, transportation to care, availability of off-hour care, waiting time, having children) and demographic data including age, gender, race, marital status, education, employment status, geographic location.

Predictors of having had an office visit differed by gender. Women were more affected by financial barriers, and when looking specifically at low income, were the least likely to have visited the doctor. Men were more impacted by non-financial barriers; waiting time, in particular, had a negative relationship with having visited a doctor.

It is interesting to note that many of the variables listed as non-financial have a financial component, such as having the money to buy a car, pay for gas, insurance etc. as well as waiting time, which might have greater impact on those who hold hourly wage

jobs or who are limited in terms of time that can be taken off of work. The authors suggest that further studies should examine other areas where gender differences might have an impact on service utilization, including perceptions of accessibility and satisfaction with care.

Anderson et. al. (2001), used focus groups to examine women's satisfaction with their primary care. Eighteen focus groups (n = 137) were run at six National Centers of Excellence in Women's Health (CoEs) in six different regions of the United States. Topics for discussion included the primary healthcare needs of women, their preferences for care, and what constituted quality of care.

The focus groups consisted of women of various ages and races as well as those who received their healthcare at the CoE and those who did not. Thematic coding of the group transcripts was used for the analysis. Themes were uncovered and each theme was given an operational definition. These definitions were then used to group text units, in this case paragraphs, within each theme. Three major content clusters were identified in the analysis: (a) general views on women's healthcare, (b) dimensions of primary healthcare and, (c) disease prevention and treatment.

General views on women's healthcare included content related to having cohesive, comprehensive service availability that allowed for the use of both traditional and alternative therapies. The women voiced a desire to have health care options that did not involve numerous health care providers who often asked the same questions but did not focus on the individual as a whole person. Health care was also seen as more than traditional medical interventions. Educational support groups as well as an understanding

of social issues such as domestic violence, balancing multiple roles, etc. were also seen as important.

Within the dimensions of care cluster, access issues including both non-financial concerns, such as hours of availability, and financial issues, such as insurance coverage, were identified. Of note is the emphasis placed on trusting the health care provider and being able to maintain provider continuity, even when insurance changes. Women putting their own health care needs aside in order to get others' needs met was also identified as a theme. This was due in part to limits on financial resources, but might also be related to limited time and energy to see two different providers who may not be located in the same place.

Women also identified the importance of positive relationships with their providers as related to their satisfaction. Qualities that were seen as important included someone who respected them, who listened, who took the time to see them in light of their multiple roles and needs, as well as providers who did not see their patient's health care needs as tied so directly to their age. Women wanted to be seen as partners in this relationship and expressed the opinion that having detailed information regarding test results, procedures etc. was not overwhelming to them, but rather was empowering in their efforts to take control of their health care needs. Climate issues including privacy and office environment were also seen as meaningful

Disease-targeted issues included activities that were related to education and prevention. Women identified these components of care as important, especially those women who were older and had a diagnosis of a chronic condition. Ongoing assistance in prevention efforts and monitoring of those efforts were seen as a critical.

While a great deal of research is available that looks at urban populations, little has been done to define and evaluate the impact of barriers on rural populations. In particular, low-income residents of rural areas have been underrepresented in the current literature.

In one of the few studies addressing this group, Omar, Schiffman and Bauer (1998) evaluated both recipient and provider beliefs about barriers to prenatal care for low-income rural women. Research regarding barriers to care is often focused on improving access to care by reducing barriers. This study is unique in that both the recipients of prenatal care and the providers of that care were asked about what they perceived to be barriers to care.

Using multiple methods, a descriptive survey of recipients of care and a focus group with the providers of care in a rural community were used as data sources in this comparative study. The community used in the study was identified as both rural and within a designated medically underserved area. The women within the county were unable to receive prenatal care after 28 weeks in their community because the hospital located there did not provide delivery services.

The women in the study (n = 61) were a convenience sample recruited from a number of agencies that provided services to pregnant women and all were in their third trimester of pregnancy. Barriers to care were identified using a checklist of barriers to prenatal care that fell into three categories, economic, organizational and attitudinal. If items were checked off, more in-depth questioning was done to obtain descriptive data.

Health care providers (n = 15) included physicians, certified nurse midwives, registered nurses, a social services coordinator, and a provider of support for pregnant

women. Both primary focus group and follow-up questions were developed that related to the same barriers that the recipients of care were asked about. Transcripts of the focus group were analyzed and responses categorized and grouped into the same three categories from the recipient group: economic, organizational, and attitudinal. Frequency of responses between the two groups were compared, as were differences between the more quantitative data collected from the recipients and the qualitative data collected from the providers.

In an unexpected finding, about half ($n = 29$) of the women reported no barriers to prenatal care. The others ($n = 32$) reported at least one barrier, with 15 of the women reporting two or more barriers to care. All of the providers reported that they believed the women had at least two barriers to care.

Economic barriers were the most often reported by both the providers and the recipients. Payment for care and the difficult process of obtaining Medicaid were frequently reported as barriers. Of note was the confusion among some of the providers about who took Medicaid and who did not. Some of the providers who were often referral agents were unaware that others took Medicaid and were unaware of some available services.

Transportation was considered a prominent barrier by the providers. This was not the case with the recipients. Fewer than 20% of the recipients saw transportation as a problem; all of the women reported that they either had a car or could borrow a car to get to appointments.

Organizational barriers were not seen as major problems for either group. It is interesting to note that providers did not see their office hours, typically weekdays from 9-5, as being a potential barrier to care.

In terms of attitudinal barriers, providers identified negative attitudes regarding prenatal care as a significant barrier. In contrast, the women, all identified prenatal care as important and most reported liking doctors. What might account for this mismatch in perceptions and possibly in the allocation of resources to address barriers?

The authors of the study identify several possibilities. It may be that pregnancy is not seen as a health “problem” but rather as a natural event that the women were equipped to handle if there were no signs of difficulty. Along with this attitude, the women in this study may not have seen the need for the typical schedule of prenatal visits that are viewed by the providers as the standard of care. The authors suggest that the use of either home visits by a nurse or periodic telephone contact to check on the progress might be a way to bridge the gap between the perceptions of the two groups.

The results of this study point to two important considerations when conducting research on the health practices of rural women. The first is that results that may have been replicated on urban populations over and over again, may not have any validity in terms of the experiences of rural women. In addition, assuming that one group, such as health care providers, will provide information that is meaningful about another group, rural women accessing prenatal care, is a leap that may prove too great in terms of developing a better understanding of the experiences of those women and in helping to identify possible points of intervention. How then do these lessons learned apply to the women in Appalachia?

Rural Appalachia

West Virginia is ranked as the second most rural state within the United States, having 64% of its residents living in towns with populations of less than 2500 people. Forty-five of 55 counties in West Virginia are designated as rural by the U.S. Census. Access, availability of, and proximity to services is limited in these areas, including access to local health departments, information available, and facilities to obtain electronic transmissions via e-mail. There is also a shortage of physicians and other medical providers (West Virginia Healthy People 2010, retrieved May, 2003).

Physician shortages are part of the daily existence of rural West Virginians. Health Professional Shortage Areas (HPSA) are designated by the federal government as those areas with below adequate numbers of primary care physicians to meet the needs of the population. In West Virginia, 50 HPSA have been identified and include all or part of 40 out of the 55 counties in West Virginia (West Virginia Healthy People 2010, retrieved May, 2003). In addition to primary care services, areas lacking in both dental and mental health services are being identified.

These resource deficits have been identified as areas of need by West Virginia in the West Virginia Healthy People 2010 goals and objectives. These objectives, designed in conjunction with the federal project of the same name, are focused on the improvement of health care delivery and the reduction of risks associated with chronic illness and injury. Specific objectives related to health concerns such as cancer and heart disease have also been developed in line with the incidence and prevalence rates of the population of West Virginia.

According to statistics compiled by the Center for Disease Control, Behavioral Risk Factor Surveillance System, and based on data collected between 1995 and 1997, West Virginia has the highest mortality rate in the United States. The West Virginia rate exceeded the national rate by between 56 and 110.9 deaths/100,000 people (CDC, retrieved May, 2003). Health factors such as lack of exercise and obesity place 81.9% and 59.8% of West Virginians, respectively, at risk for health problems. Preventive care statistics for women show that 36.2% of West Virginia women have never had a mammogram (CDC, retrieved May, 2003). All of these risk factors are occurring despite the fact that 80.7% of West Virginians have health care coverage (CDC, retrieved May, 2003). What then are the barriers to care that are seen in rural communities? Factors that appear to contribute to these access issues include geographic, social, and possibly cultural barriers.

West Virginia's identity as the "Mountain State" provides a clue to some of the difficulties inherent in getting from one place to another. Winding mountain roads make travel more time consuming than looking at a map might predict. Availability of professional resources including specialty physicians or mental health care may literally involve a day's travel.

The current social climate that includes high malpractice costs for physicians may also contribute to physician shortages. Many physicians are leaving the state due to the high cost, and recruitment of physicians to come into the state is also hampered. Physicians who may be inclined to stay may need to look at working in the more suburban and urban areas of the state in order to meet costs. Social issues such as the

battle over malpractice litigation and costs can have an impact on residents in their daily lives.

The culture of rural Appalachia may also play a role in when and how residents access health care services. The mountainous terrain of West Virginia has contributed to the development of a culture that has been isolated both from other groups of people and from broader resources. This isolation and independence from others may make it less likely that residents will explore resources outside of their kinship and community groups (West Virginia Healthy People 2010, retrieved May, 2003). Evidence collected as part of the West Virginia Healthy People 2010 project indicated that interventions which are sensitive to these kinds of cultural issues show the greatest success in making positive changes in the health status of West Virginia residents.

Given the fact that there are many unmet needs within the population and that it is unlikely that physician and broader health care shortages will be resolved in the near future, changes that focus on using existing social support networks may provide the best chance for change. What resources are available and what barriers are present with the social support networks of people in rural Appalachia?

Social Support Networks in Rural Appalachia

West Virginians have been described as “clannish” in their affiliations. Support networks may be especially heavy with family members, due in part, to the geographic isolation of many rural communities. This high level of involvement with family members as social support was identified in a rural Appalachian sample by Fish (1998). In a study of infant temperament, maternal social support, as measured by both the amount of contact with people within one’s social support network and satisfaction with

the level of contact, was seen as a significant predictor of positive changes in child functioning. This included both decreased negative emotionality and increased positive/ social behavior by the child over time. Of the sample of 94 families, more than 90% of the mothers reported that they had at least weekly contact with their parents, their significant other's parents or other relatives. They also reported high levels of satisfaction with their support networks.

Johnson's shared kinship model (1983), which emphasizes the provision of support by a small group of people, none taking the majority of the responsibility, may apply here. The shared functioning model (Johnson, 1983) might also predict that formal resources would be used to a lesser degree, and only when family resources were not available. These results would be consistent with research within other rural communities (Koopman, 2001; Pearson-Scott & Robert, 1985).

The need to examine social network variables, i.e. size, distribution of family versus friends, presence of formal supports, and how and when these resources are used will be a first step in identifying possible points of intervention that may be both culturally relevant and in touch with the needs of the community. The purpose of the current study is to examine the social networks of a rural Appalachian community in West Virginia in relation to Johnson's (1983) shared kinship model. Following the collection of data related to social networks, the extent to and the ways in which these networks may prove effective access points to increase awareness of behavioral health issues, information, and resources will be evaluated. Understanding how residents in these rural areas are currently gaining access to information and services may begin to

illuminate some of the reasons why more traditional service delivery models are not as successful in reaching those in need of care.

Specific questions that guided this research were: (1) What is the daily experience of women in rural West Virginia as it pertains to obtaining health information and health care?, (2) What resources are identified by the participants as available to them in their efforts to stay healthy ?, (3) To what extent do health beliefs and health status play a role in the procurement of health care?, (4) What role does social support play for these women?, and (5) What barriers are identified by participants, both personal and contextual, which inhibit the procurement of health information and health care?

To address these questions, a mixed methods design, using both quantitative and qualitative data was employed. This approach is currently among those most used in the literature when addressing access to health care.

Method

Design

A mixed methods design was utilized to conduct this study. Qualitative methods included participant observation and ethnographic interviewing. Qualitative methods included the use of the use of surveys to measure social support, health beliefs and health status.

Measures/Areas of Investigation

Demographic data

Demographic data including age, marital status, years of education, employment status, years of community residence, and family constellation were collected using a semi-structured interview format.

Social support

The Social Support from Community, Family and Friends questionnaire (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983) was used to look at who was included in social support networks as well as frequency of contacts and satisfaction with support. This questionnaire yields three factors: intimate relationships (spouse/partner), friendships and, neighborhood/community support. Internal consistencies for these three factors have yielded Cronbach's α values of .69, .65, and .50 respectively. In addition, individual participant interviews were used to gather more in-depth data regarding people, places, and organizations listed on the measure of social support in order to gain an understanding of the roles they play in the participant's health care experiences.

Health beliefs

Participants were asked, as part of the ethnographic interviews, to define what health meant to them. This included their ideas of how they determined their level of health, at what point they seek outside care, and their expectations regarding their health in the future.

The Laffrey Health Conception Scale (LHCS) (Laffrey, 1986) was also administered. The LHCS is a 28-item measure of the definitions of health. Items related both to illness and wellness are presented in a Likert-response format. Alpha values of .93 for the wellness scale and .84 for the clinical scales were obtained with a rural sample by Pullen, Noble-Walker and Fiandt, K. (2001).

Health status:

As part of the interview process, participants were asked to describe their current health status. This included the areas of physical, mental, and spiritual health.

Participation in health services, both preventive and acute, was discussed. In addition, participants were interviewed regarding their use of vitamins, supplements, and home remedies in order to more fully understand all ways in which they care for themselves. Attempts to change habits as well as current efforts to enhance healthy lifestyles were also explored within the interview sessions.

A quantitative measure of perceived health status was conducted. The Medical Outcomes Study Short-Form General Health Survey (MOS), (Stewart, Hays, and Ware, 1988) was administered. Pullen, Noble-Walker and Fiandt, (2001) obtained alphas of .79 for physical functioning and .81 for mental health with a rural sample.

Educational information available:

This was assessed during the initial participant observation portion of the study and included visiting community locations to identify sources of health information including the library, the local supermarket and pharmacy, as well as what was available within the community action agency itself. Participants were asked, within the previously mentioned interviews, about their knowledge and perceptions of the information that is available within their community.

Participants

Participants were recruited from a convenience sample served by a community action agency in a rural, southern West Virginia county. Women working within the agency as well as those being served by the agency, were contacted to identify those interested in participating in the study. They were also asked to refer others who might be interested in participating. Women, aged 18 and older, living within the identified community were asked to participate in the study. Purposeful sampling (Bogdan & Biklen, 2003) was employed in order to access a maximum variation sample of viewpoints within the community. A total of 10 women were selected to participate. The sample was drawn with intent to include women who varied in age, marital status, and employment status.

Procedure

A period of initial participant observation was conducted in order to gain information about the specific resources within the community. Locations included the medical van providing primary care services, the community library and pharmacy. Key informant interviews were used to supplement these observations. These included, but

were not limited to, community service workers, a physician providing services within the area, and the director of the community action agency.

The participants were recruited from among those who were providing and accessing services through the community action agency, were then asked to complete a series of in-depth , semi-structured interviews as well as the formal measures listed above. Following the completion of informed consent, as approved by the Institutional Research Board, interviews took place at the community action agency. All questionnaires were read to participants and all interviews were audio-taped. Interviews were initially scheduled to last approximately 1 hour per session, with a minimum of two sessions and a maximum of four sessions. Time and availability of participants made this schedule unrealistic for some, and interview sessions were tailored to meet the needs of the participants. Of the 10 participants, 3 utilized 3 sessions, 4 utilized 2 sessions and 3 utilized a single session. A total of 20 individual interviews were conducted. Regardless of the number of sessions utilized, total interview time ran between 90 minutes and 150 minutes for each participant. Data collection continued until data began to repeat across participants, suggesting that a saturation point had been reached and further data collection would not yield additional novel information.

Questions related to how and where the participants accessed the information which they use to make health care decisions were asked and probes made in the areas of social support, health beliefs, health status, and sources of health information known to the participant. In addition, potential barriers to care were identified as they related to the daily experiences of those interviewed.

The interviews followed the following general session outline:

Session #1: Completion of informed consent, completion of formal measures of social support, current health status and health beliefs, and initial discussion of the meaning of health.

Session #2: Current involvement with health care providers, access to information about health concerns, use of formal versus informal sources of information and services.

Session #3: Barriers to care, impact of social support system, follow-up probes regarding previously gathered information.

A list of potential interview questions used is included in the appendix.

Following the collection of the data, written transcripts were developed from the audio-taped interviews. Identifying information such as participant names and the names of any specific individuals discussed in the interviews were removed prior to the analysis of the text; initials and/or numbers replaced identifying information. Pseudonyms were used when communicating results. The primary investigator maintained a confidential list of names and corresponding initials and numbers in a locked file to ensure the privacy of the participants. Audiotapes were stored in a locked file following transcription.

Data were analyzed, with the paragraph being the smallest unit of text for analysis. An inductive content analysis was conducted using the interview and observational data collected. Data coding included the types of information sought and gathered, the sources of the information, the sequence in which the information was sought and gathered, as well as scenarios or types of health conditions which might differentiate among the other factors in obtaining and using the information. In addition,

the identification of major themes within the interviews was evaluated in terms of its relevance in telling the story of the women's experiences with health care.

Quantitative data obtained from the social support measure were analyzed to identify possible patterns as well as to describe the participants. Particular attention was paid to determining whether there were distinct patterns found in rural West Virginia. Network variables assessed included the size of network, contact patterns, proportion of family and friends, formal and informal supports, as well as the types of supports provided.

Triangulation of multiple informants and multiple sources of data, both quantitative and qualitative, was used to increase the reliability and validity of the results. Also, internal validity was enhanced by the use of member checks done on an ongoing basis by sharing early coding strategies and emerging themes with the participants. The multiple interview format as well as the individual time spent with participants allowed for this collaboration in the process. In addition, making this research process as transparent as possible, as suggested by Altheide and Johnson (1998), is another way in which the reader of the piece is given all the information available to determine the external validity of the analysis and to enhance the replicability of research.

Results

Demographics

Ten women agreed to be participate in this study. They ranged in age from 23 to 69. The mean age was 39.1. Four participants were in their twenties, one in her thirties, three in their forties, one in her fifties and one in her sixties. Six participants were married, one was separated, and three were single. In terms of educational status there was one participant who did not complete high school, four who had completed either a high school diploma or a GED, four who had taken college classes and one who had earned a master's degrees. Six participants were working full-time, two part-time, one was retired and one was not employed. The mean income of the group was \$12,440. The average number of years spent in the community was 17.27, with the overwhelming majority of the women, seven of the ten, being born and raised within the county. The number of individuals in the household ranged from 1 to 11 with a mean of 4 people in each household.

In terms of health insurance, 8 of the 10 participants had health insurance. Half of those had private insurance such as Blue Cross/Blue Shield. Two participants had a state medical card and one had Medicare. Six participants had an identified primary care provider. Demographic information is summarized in Table 1.

Table 1

Summary of Demographics (n = 10)

	<i>Mean</i>	<i>Range</i>	<i>Standard Deviation</i>
Age	39.1	23-69	15.13
Education	13.2	11-20	2.53
Income	\$12, 440	\$ 0-40,000	\$11,000
Years in Community	17.27	.67-58	17.05
Years in County	26.97	.67-58	17.92
# in Household	4	1-11	2.94

Social Support from Community, Family and Friends

Participants completed the Social Support from Community, Family and Friends questionnaire. The majority of participants rated their support as sufficient and satisfying ($M = 88.3$, $SD = 14.58$). Support often involved daily contact with family and friends. Eight of the ten participants reported having close family members living in the community, often in the same geographical area so that daily contact was the norm. Contact typically took place face to face or over the phone. There was limited use of the internet for family contact except for those participants who did not have family in the area.

The women were able to identify at least one person with whom they could share their most private thoughts, reveal when they had problems or were upset, or share a happiness. They stated that they could do this most of the time without difficulty. The majority identified church as another source of support for them (n = 7).

Health Conception

The Laffrey Health Conception Scale was used as a measure of the women's perception of health and what it means to be healthy. The Laffrey measures several types of health conception. A Clinical health conception is one that identifies health as the absence of disease or symptoms of illness. A Functional health conception sees health as the ability to fulfill one's roles in life, to complete one's normal tasks. An Adaptive health conception focuses on the ability to adjust to change and stress in life. Finally, a Eudaimonistic conception of health is one where health is identified as a full and exuberant life experience, one that would be more closely related to the idea of wellness, a more holistic sense of well-being.

Participants' scores on the Laffrey identified health concepts most closely related to Clinical and Functional Health. The average score for Clinical Health was 32.7 and Functional Health was 31.2 out of a possible total of 42. Adaptive and Eudaimonistic concepts showed somewhat lower mean scores with 29.9 and 28.9 respectively.

Health Status

Participant responses on the Medical Outcomes Study Short-Form General Health Survey (MOS) indicated that the majority (n = 7) rated their health as at least "good." Three of the women reported that they experienced moderate levels of pain. Back injuries were the primary cause of pain. In general, participants were not limited in any

daily tasks, social functions, or moderately vigorous activities such as carrying groceries, moving a table etc. Mental health concerns were limited among participants, with identified concerns related primarily to stress and anxiety.

Educational Information Available

Community resources identified included the town library, the community grocery store/pharmacy and the nearest large chain store with a pharmacy which was approximately 20-30 minutes away. The town library is located in a small building near the local firehouse and police station and is housed primarily in two rooms whose dimensions are approximately 20 feet by 40 feet. Materials located in the library include encyclopedias and basic reference books as well as some national news magazines. There were almost no books that provided up to date or in-depth information regarding health topics. Internet access was available with two computers for use by patrons. Internet access was also available at the community action agency where there were 6-10 computers available most of the time.

The local pharmacy as well as the most accessible large chain store both had informational pamphlets produced primarily by or in conjunction with drug companies. The large chain store had a series of brochures on a variety of preventive health topics and acute health conditions available.

Interview Analysis

Four categories, Definitions of Health, Barriers and Aids to Obtaining Health Care, Attitudes Towards Health Care and Sources of Information were identified a priori. Through the use of inductive content analysis three additional themes emerged from the

data: Faith's Role, Environmental Factors, and Home Remedies as well as the subthemes of relationships and personal responsibility within Definitions of Health.

Definitions of Health

The participants' definitions of health most often included ideas related to physical health, consistent with their responses on the Laffrey Health Conception Scale. Dawn, a 23 year old, single woman defined health as "...strong, and not dependent on pills, not sick." Helen, a 58 year old wife, mother, and grandmother expanded that definition, "Like there's nothing wrong with you; you can get out and do what you want to. Enjoy life, not worry about being hurt or sick or anything."

Physical health was also emphasized by Trixie, a 30 year old single mother who stated

Well, yeah, the physical part would be more important if um I was needing to take my daughter to King's Island, would I be able to take her, to do those things with her? Because sometimes even though buying your child, buying things for your child is important, you need to also make memories for your child; this is something that she will remember down the road and if you aren't physically able to get out and take her, to whether it is a dance recital or whether it is a PTA meeting or t-ball practice, maybe at that moment, the physical may be more important.

Other participants defined health in a somewhat broader way. Mary, a 69 year old woman, a member of a religious order, defined health as "physical well-being, emotional well-being, mental well-being, spiritual well-being. A well rounded person, that seems to me to be, I think you can be real physically healthy and still be emotionally unhealthy."

Amy, a 28 year old single mother also identified health as including things like mental health and the ability to cope with stress.

Health is such a big, broad area, of course, different aspects of health. There's mental health, physical health, uh illnesses you know that are daily, some that are crippling. I mean health, it's just, to say health is just a big, huge, to put everything into one category.

These same ideas were echoed by Bea, a 47 year old married mother and grandmother:

I think being healthy means um, of course taking care of yourself with proper diet and exercise, um getting checkups and then if there's anything wrong, doing your follow-up on it and making sure you are doing anything that your doctor tells you to do. Um, not being stressed out and I guess health is just not physical, it's mental too, so dealing with stress issues and just taking care of yourself both physically and mentally.

Relationships was a subtheme that emerged within discussions of health. Dawn stated:

I think that when you are out with people and you are talking and you are having fun and there is something going on in your life, I think that kind of takes your mind off other things. So I think, I do think part of a healthy life style is being surrounded by people that you enjoy, people you can get along with, stuff like that.

Likewise, Rose, a 29 year old married mother of two children, related how her relationship with another participant, Helen was part of what kept them both healthy:

Like me and Helen, she's an older woman and her mom passed away. She took care of her mom literally for years till she died. I lost my grandma and then we got together, starting coming here, keeping from staying so depressed at home. And we're all the time cracking up and laughing. We take, we go out and eat all the time, me and her, we have a blast. She's like, "I don't know what I'd do if it wasn't for you." I think I've helped her a lot.

A second emergent theme within the discussion of definitions of health was personal responsibility. Amy and others reported that even though they knew that there were things they could be doing to improve their health, they were not always doing them.

I think most people think just because they feel good, they're ok. And that a lot of times, we take just, we think, well like me, I still think or like when we're younger we think we've got plenty of time to change, and we take time for granted and a lot of times, we're just, cause we're like and I'm guilty of not exercising and eating poorly and that kind of stuff myself and I know that's what I feel like. I have plenty of time in the world to change so why do it now but that's not necessarily the case so we take it for granted a lot of times.

At times, the idea that an individual had control or responsibility over her own health was tempered by the belief that some people are born with "bad blood." Michelle put it this way:

Well when I was growing up, if you weren't healthy, it was your own fault. I mean, there was, your genetics determined it, how your health was going to be and if you had bad genetics, it was kind of like a bad reflection on you. It goes all the way back to your forefathers you know. "Oh Lord, don't hook up with her! She's got bad blood."

She went on to say: "when I was growing up you didn't see so many bad nerves, well they (people were said to have) had bad blood, now they just do drugs. And they're more tolerant of people who do drugs than people with bad blood."

Dawn was one participant who put her beliefs into action following the death of her grandfather from cancer. She took pride in her ability to make significant changes and began to see herself in a different light.

Well now, I did not used to take, well I went through a really hard time and I stayed at home for two years; I didn't do anything. All I did was work and I gained about 70 pounds. Right and I gained about 70 pounds. When I graduated high school in May I had worn like size 9's and 10's in clothes, and then before I got on this diet, I got so big. I'm only about 5' 2'', you know and I was really depressed and I didn't take care of myself. And then like, I smoked and everything and now, it's like I don't smoke anymore, I've lost 50 some pounds, um I walk everyday. I do aerobics every evening with my girlfriend who lives down the street, um just, I am changing everything, just everything.

However they defined health, the women had both positive and negative things to say about their experiences within the health care system.

Barriers and Aids to Obtaining Health Care

Participants identified a number of barriers to care including lack of time, communication problems, differential treatment based on insurance and personal apprehension about what they would be told if they went to a medical provider. At the same time, many of the areas identified as barriers were also identified as aids depending on the health care provider or office that was being utilized.

As the old saying goes, “Time is Money,” and this certainly appeared to be the case when it came to accessing health care providers. The most commonly mentioned barrier to obtaining health care for the participants was time. This included problems with getting into the provider’s office during the available hours to time spent waiting to see the provider to taking time off from work to see a provider and the pay that was lost as a result as well as the time it takes to meet the demands of a family.

Bea stated :

Well I think it’s [time] a big barrier. Because I think people just don’t. They sit there and nod their heads and go on you know. Because you usually go into your appointment, you have like a 10:00 appointment [but] you may be lucky to get worked in before lunch. So you probably sat there 2 or 3 or 4 hours; that’s a possibility before you even go in to see the doctor. And I think by that time they’re just wanting to get out of there. Somebody just give me some medicine and let me get out of here you know.

Rose talked about the difficulty getting an appointment. “You can’t never get in there. It’s like months, 2 months down the road; if you call in for like next week, you

can't get in." This was echoed by others who discussed the problems with getting in, especially with their children. Amy talked about trying to get her daughter, who suffers from asthma, in to see the doctor:

I wish it could go more rapidly but I understand, you know there are times when you can't. You know the thing that gets me is like I wish there were doctor's offices open on the weekends. It seems like Melissa always got sick on Friday night and were always in the emergency room by Saturday because it would, it would hit her all of a sudden. And the thing is, her doctor, our family doctor, I mean their office is usually closed on Monday too so it's a really long time when you think about it. And it seems, and they're always opened during work hours so you have to miss work in order to go to the doctor, and I just think there should be some kind of after hours, weekend sort of thing if possible.

Finding time among the demands of a busy family life often meant putting off one's own needs to take care of children or other family members. Bea put it best: "And getting the time to do it. I mean there are so many things I need to do. I'm lucky to get the kids to the dentist and the eye doctor, let alone take myself." Trixie, a single mother, also emphasized multiple demands: "Well, sometimes you have to work. If you don't work, you don't get paid. If you don't get paid, there's no food and you can't pay your bills." When asked how she managed these tasks and getting in to see a doctor she stated "Sometimes you just have to tough it out until you can."

Patient-provider relationships was one area in which participants had either very positive or very negative experiences. On the positive side, participants felt comfortable

when working with providers who were kind, caring, and spoke to them about their health in a way that they could understand. Dawn described her providers in this way: “They are really calm and laid back, down to earth and they talk to you on a level that you can understand. I mean I just really feel comfortable with them two.” She also stated that her provider would “call and see if you are feeling better, if you want to come back in, is your medicine working for you, did you get everything filled? If you don’t have like a prescription plan, he will try to give you some that he has in the office so you don’t have to pay for it. He’ll just give it to you; he does stuff like that.”

Michelle, a married mother of three, talked about her experiences working with her son’s doctors to diagnose and treat a serious chronic illness. “...every week we’d go to see him and every week he’d have something new to say and I always felt he was a good doctor. And I always felt like he tried really hard, and I always felt like if something wasn’t working he’d change it. But you always have to wonder, but I think, the thing that really made me trust him the most was because he took Brad’s consideration [wants and needs into account]. Even when he didn’t have to. Brad was first.”

Other participants described extremely negative experiences they had when trying to communicate with either their own or a loved one’s provider. Amy described this situation that occurred with her father:

He died during just a routine balloon surgery and they told us there was a 99% chance that nothing was going to happen and that he was going to be, I meant [the operation was] nothing anymore. They were just getting him ready for open heart surgery and he died during the balloon surgery and they come and tell you and it’s

just like “He’s gone.” He’s what? I means it was just so like, just so heartless, cold you know, just like business as usual or something.”

Communication and cultural differences often came hand in hand and impacted the kinds of relationships that developed between providers and patients. There is a high percentage of foreign born doctors practicing in rural areas because they are able to obtain work visas when working in identified health shortage areas. This was the case for the participants of this study and at times, resulted in problems both with communication and cultural competence. Mary, a member of a religious order, reported a time when she had just such a difficulty.

And I broke my leg when I was down here in '77 and I went up to, over to [the hospital], uh and uh while I was there in the emergency room on the gurney the leg began to spasm and I don't know if you've ever had a broken leg but it's like it doesn't even belong to you but anyway, it's jumping around on my body and in terrible pain and I said “Can you please give me something for the pain?” And I don't know where he was from but he said “Pain, you need something for pain?” And I said “Yes.” [He said] “You ever had any kids?” And I said “No.” “Then you do not know what pain is.” And I thought “Did you have any kids?” Now I don't know what that had to do with anything. I didn't get anything for pain.

Insurance status was mentioned primarily by the women who currently didn't have insurance or who were receiving services through Medicaid or those who didn't have insurance at all. Some of the women felt that they were not treated as well if they were obtaining services with a medical card. Bea stated:

I think for a woman to go back [to the doctor] is how they get treated. Well, if they [providers] are “Well it’s another Medicaid case...and they got a medical card, she’s probably got 10 kids at home.” Um, I think sometimes it depends on how you get treated. I’ve never had any bad experiences with doctors or nurses; I’ve always been treated well, when I worked at the bank and my husband worked on the railroad and we had good insurance and everything you know or even when I brought, had the other ones and was on a medical card. Where I never did see getting treated any different. But I have heard women say that they’ve thought they’ve been talked down to or they didn’t really tell them nothing. And of course sometimes it does seem like they’re in a hurry.

Rose talked about her cousin’s experience when she was pregnant. “She didn’t have a medical card so they wouldn’t even circumcise her baby. They wouldn’t do nothing for her. They treated her bad, were hateful to her, wouldn’t give her no pain shots. Wouldn’t give her nothing.” Rose herself had lost her medical card for an unknown reason and talked about the difficulties of trying to find out why her insurance had been stopped. Rose went to the regional office to meet with the person who was in charge of her case and described her experience:

You have to sit up there for 4 hours back in the office. And that woman would sit there and the computer and punch in, punch in, and I just sit there and wait and wait and wait and wait and I sit there for 4 hours. I said “I’m going home.” [She said] Well, well, we ain’t done. I said “I’ve been here for 4 hours, I’m going home, do what you gotta do. She cut me off of everything so I called the state capitol on her. They (State supervisors) had her, they took her out of that office.

At least one participant wished that she had a medical card because the insurance that was provided by her husband's company was not accepted by the majority of local providers, even though the company he worked for was locally owned and operated.

Michelle stated:

Well now you are still limited when you're on that medical card. You can't go to any doctor you want but you can certainly find a competent doctor in your circle and if you can't there's places you can go where you can file complaints and I learned that very quickly and I think you probably still have, even with the medical card, probably about 80% control [of your healthcare.]

A related issue was the impact of the substance abuse problem in the community on how individuals were treated by providers. There is a significant problem with the abuse of prescription pain medications and this means that for some, there are extra hoops that must be jumped through in order to obtain needed medications. Michelle shared her experience with the insurance that she gets through her husband's company:

One of the people he works with, his wife had knee surgery recently so she's had a lot of pain medication so they made him, they made the person who worked there [the company] go to the doctor and get a list of why they say she needed to have, how much she had to have and how often she had to take it and told them they had to get that approved before they would continue to cover it.

Rose also discussed this problem:

Well half the people aren't sick. They [the doctors] don't check anymore. "My back hurts" and they're hollering take this, got get this. Then they take it out and sell it, or

snort it or whatever. They [the doctors] don't even check to see if it's in their system. They think...I know a guy that hollers he's got, takes seizures and stuff, just so he can draw a check so he doesn't have to work. He don't take his first pill at all. They don't even draw his blood check to see if he's still sick or anything. He's been on a check since he was a teenager, he's a 37 year old man now. That's bad. That's bad. People that get out here and work for stuff and then get hurt, can't get nothing.

Personal fears about what they might learn at a doctor's visit was a factor that several participants cited as a reason why they would put off their own health care, especially preventive health visits. Bea, 47, was a prime example of this. She had only been to the doctor during her pregnancies during the majority of her adult life.

I really know that I need to find me a good regular doctor, go to him, have these tests done, and then just keep doing my follow-ups with them. And I think the reason being, I don't is because if there is something wrong, I don't want to know. I mean I hate to, I really don't because as soon as you found out, I could go to the doctor tomorrow, find out something is wrong with me and in two months I could be dead. If I hadn't went, he wouldn't have told me.

Trixie stated:

I think a lot of people are just apprehensive about the whole going to the doctor situation. I mean, because I hate it, I don't like to go to the doctor, and people put it off as long as they can." When asked where the apprehension comes from she stated "I don't know. I mean cause it just seems like...most of it's bad news. I

don't know why, that's what I characterize it with. Like I'm going to the doctor; there's going to be bad news.

This view of the medical provider as the bearer of bad news meant for many participants that a doctor's office was a place to go only when there was some acute need and often as a last resort. Very few of the women were utilizing their providers, if they had one identified, for preventive care visits. This was regardless of how they rated their own health status. As stated previously, seven of the ten women rated their health as at least good on the MOS and had no reason to believe that they were going to receive bad news. The factor that seemed to make some difference between those who utilized preventive care and those who didn't was their view of themselves as either a consumer or a recipient of healthcare.

Attitude Towards Healthcare

While the participants of this study identified a variety of definitions of health, barriers and aids to healthcare and their attitudes often varied in relation to particular providers or experiences, one clear division that seemed to stand regardless of other factors was whether they saw themselves as either "Recipients" of health care or "Consumers" of healthcare.

Recipients were identified by their more passive approach. These women tended to see the doctors and other medical providers as the experts and as having the bigger say in what happened during interactions. Recipients of healthcare were best represented by Helen, 58. She stated: "I just go to the doctor's and do what he says." Dawn shared her feelings that being a good patient sometimes means that you don't question your provider: "I think when you ask too many questions, sometimes people think that you are

not, that you don't trust them and you don't believe in what they are saying, like you are questioning what they are doing." She also pointed out that some people may feel that they are not equipped to understand what is being said:

Well, I think a lot of people, a lot of people in this area don't feel like they have enough intelligence to question a doctor. I know a lot of people that would never go to a doctor's appointment by themselves because they want "so and so" there with them so they can understand what the doctor is saying and so they can relay the messages back to the family or whatever. I just feel that they think they don't have enough intelligence to talk to doctors and they don't ask questions. A lot of people don't know what to ask.

Consumers were those who saw healthcare as a service and providers as their employees. They were more active in their approach to visits, often preparing questions and demanding the time they needed to both express their concerns and ask their questions. Michelle was the clearest example of a consumer: "And I learned that I pay the doctor and if he don't listen to me, I'm going to a doctor that will." Mary described herself as her own advocate: "I feel like I have to be an advocate for myself and I have to know you know what. I like to know why I'm being given certain things or being told to do certain things. And I will ask "Why is this?"

Pam, a 27 year old wife and mother stated:

I make sure when I go in there, I'm like" this and this and this is going on. I want help with each area. I'm sorry I took up so much of your time or whatever but please answer all my questions." I just be blunt. Soon as I get there I'm like this, this, and this is going on you know and I...and like I did that emergency

room doctor, he kept walking out but I didn't care. I kept shouting my questions at him. I just make sure that you know I get them out.

While it might seem that consumers are born, they seem in fact to be created. Most of the women who could be classified as consumers could identify an event that facilitated their transition from passive recipient to assertive consumer. This most often involved the transition to parenthood. Ruby stated: "I figured that I was young when I had my kids... Mostly by taking them to the doctor and I always wanted to know like "Why do you need to give them this medicine?" "Why are they picking at their ear like that?" or you know." Amy said: "I think that it's changed. I think that when I was younger, I didn't ask any questions. I was just like you tell me what I needed to hear and they did. But I think now I've gotten more comfortable or when you get older, especially with kids, I think that changes you."

Michelle, the ultimate consumer, whole-heartedly believes that you can teach someone to be a consumer of health care and sees this clearly as an important role for parents to play in the lives of their children. "If you don't teach your children, how do they know? You need to teach them how to advocate for themselves but you need to teach them how the right way to do that is. And they need to have tolerance and understanding."

For the participants of this study internal factors such as assertiveness are constantly in play with both the cultural and environmental landscape that is so much a part of the daily life of the residents of Appalachia. It was therefore, no surprise that both Faith and the Environment were issues raised during the interviews.

Faith's Role in Health

Participants had a variety of perspectives about faith's role in health. For some, it was a primary factor and the place that they turned for a first response to illness. Ruby describes her husband's conversion following a massive stroke. She states that once he left the hospital and was back on his feet he returned to church and on one night "God told him that he really didn't need that medicine. He's really a believer, so when that happened he said, "I just quit taking it. You know, which if God tells me again to go to the doctor again, I would do it."

Others saw faith or spirituality as one aspect of what kept them healthy. Mary described how her faith and health are united in terms of her ability to carry out her duties: "We've always been encouraged to take care of ourselves, and that's sort of a spiritual thing. It's part of theology too you know, your body is important too. It's your hands are his hands so you know you've got to take care of them. You've got to take care of yourself in order to continue to work, to minister." While Mary did not see faith in the same way as Ruby, she did acknowledge the power of faith and the role that it plays in aiding some people's cure or recovery: "And then there are people who think that faith has been the thing that's cured them. And I do believe that there is truth in that, in some of that. I do believe that prayer and faith can sustain you through serious illnesses."

There were other participants who had more negative experiences with faith and health. Michelle described her early family life as marked by strong fundamentalist beliefs. They did not see doctors despite the fact that her father had excellent insurance through the railroad. She describes the typical response to illness in her household:

Oh the preacher prayed over you and he'd stand there and he'd sweat and he'd moan and groan. I'm not much for that anymore, that kind of thing. I think we could have died. I seriously think we could have died. Looking back on it I can remember being really sick. I'd have tonsillitis and be puking up parts of my tonsils, terrible fevers. I can remember having many terrible fevers. Not only did we not have any transportation or any car, or any boat or anyway to get anywhere, cause dad worked away, but it ain't like they cared anyway cause they [the family] was just going to call the preacher!

Mary expressed one concern regarding faith and health, even given her strong personal beliefs:

Sure the snake handlers around here believe that if you have strong enough faith the toxin in that snake will not hurt them and I was volunteering at this hospital and in fact, we had several of them when I was here and we had people come in with snake bites all the time and the reason they got snake bitten and the reason they got poisoned was because they didn't have enough faith and that was it pure and simple.

She later stated: "...the problem becomes when it [cure] doesn't and then you're guilty cause you haven't had the faith, enough faith or whatever people give."

As strong as the influence of faith in this area of Appalachia is the influence of the mining industry. It is the major provider of employment in this area and has been for many generations. The relationship between the mines and the people of the region is a complicated one since it allows families to exist while at the same time slowly destroys the landscape that is so much a part of the heritage.

Environmental Factors

While this study did not specifically seek information regarding environmental health issues, several participants commented on widely held beliefs regarding one of the mines in the area and the cancer rates which were perceived to be abnormally high by many residents. Dawn was the first to mention the mine and an incident of flooding that had occurred many years back:

Everybody says that when the mines flooded at [mine name] and all that water flooded the creek, that that is when everyone started getting cancer. But in all honesty, the water never made it down no farther than a couple of miles from the mines because the hill slid off and closed the creek off and it was stopped; it was like a mine break they said, and all the water was tested in the creek and it was fine, no toxic levels of anything, no more than you would find in a dirty creek. A lot of people here have got that in their head. They really believe that when the mine broke and the water contaminated the creeks, and all this stuff, they really believe that there was something in the air that was making people get cancer.

Bea also reported having concerns about the impact of the mines:

You know, I don't know if this really has anything to do with that but I've never seen, when you talk about health, answering those question you talk about the environment never have I worried about water before. And you know, we have well water now, used to be we had city water, but I look on the creek from the head of the holler to the mouth of the holler you can actually count the number of people who have died of some type of cancer. I mean from house to house to house to house to house. And a lot of them's like "What are you buying bottled

water for? That water's good. That's the best water in the creek." People's been dropping like flies left and right. Oh they had the water tested, it's ok and I just don't feel safe about my drinking water. I don't know if that, I started thinking about the role of my environment and everything you can do and now I think about it, the water.

Trixie said it most succinctly: I'm telling you, it's really quite scary around here. I've had, I means it seems like maybe it might be something like in the soil and the water system. Especially up at [mine name].

The possible dangers of life near the mines is common knowledge in this area. The old ways in which illnesses were treated, including home remedies, are also common knowledge to the people in this part of rural Appalachia and continue to be used on a regular basis.

Home Remedies

Almost all of the women were able to identify home remedies that they had been given, most often by their mothers or grandmothers. These ranged from honey and lemon for a sore throat to the use of whiskey or moonshine for cough syrup. Dawn explained further: "Honey and lemon plus a little bit of moonshine. Just, I mean, I don't think it's helping; I am just staying drunk. You know, I don't think the pain's went away, I'm just drunk. We was laughing the other day, you wonder why everyone here has an alcohol problem."

Helen talked about the poultices that her mother made out of onions that she would wrap around the child's chest to "break us out" and help to sweat the cold out.

Rose identified the use of catnip tea as something that would be given to babies who “would have their eyes half way open while they’re sleeping.”

Both Trixie and Amy supported the use of wrapping a vinegar soaked paper bag around sore muscles to take the soreness out. Trixie stated: “a friend of mine, he was a basketball coach, an older fellow, when his basketball players would turn their ankle, he’d always tell them to soak it in vinegar, a brown paper bag, soaked in vinegar and wrap it and it pulls the soreness out of it. Kinda like Epsom salts. Same thing and it works.”

According to these participants, passing down of home remedies from generation to generation was done, almost exclusively among female family members. These women also heavily relied on family members, often older women, to serve as sources of health information.

Sources of Information

Among the sources of information about health that participants identified in this study, the most commonly mentioned was family members. The close proximity and daily interactions with family members that seven of the participants indicated on the social support measure made it almost a sure thing that family would be involved or at least aware of health concerns for better or worse and this was born out by their responses in the interviews.

Many of the women identified family members who were nurses that they often called for information. These included mothers, sisters, and sister-in-laws. One woman had a niece who worked at the local pharmacy. These were often the first people called and were used for triage, providing information about what the next appropriate step

would be for treatment such as using an over the counter or home remedy, calling the doctor, or making a trip to the emergency room. Amy talked about her use of family members:

I have several nurses; there are several nurses in the family. If there's a problem, I usually call them. I say "This is going on, do I need to go to the doctor; will it be ok?." And they kind of direct me, do I need to go or not or if like Melissa has a cut, one time she had a pretty bad burn and I took her to their house, "Do I need to taker her to the emergency room or is she ok?." They'll direct me where, what I need to do.

At the same time, information from family members was seen as questionable and could serve to create more problems. Amy identified her mother as someone she wouldn't talk to:

There are several incidences and mom just goes off the deep end you know. She had my sister convinced that she had shingles one time. I mean, my aunt was convinced she had shingles. I mean it wasn't even shingles. I don't know what it was; she thinks she knows what she's talking about and she really doesn't.

Family members were used not only as sources of information regarding current health issues but also as contributors to the development of participants' ideas about health. Bea identified her mother, a nurse, as a major source for her current ideas/beliefs about health:

Um, my mother was a nurse and she always, she always had us involved in some kind of physical activity. Um, we didn't get a lot of junk at home growing up.

Mom might have kept ice cream but you didn't get 10 bowls; you got a little bowl of ice cream before you went to bed or something like that. Um, she always made sure we had bikes so we could get out and ride.

She was also able to identify false information that she had been given by her great grandmother that to this day still resonates with her: "I can remember my great grandmother saying if someone got cancer, if they operate on them, they are going to be dead as soon as that air hits that cancer, it spreads and they are gone. That's in the back of my head playing over and over. Of course you always heard that."

The internet was mentioned by almost every participant as a source of information. The internet was often used to look up a set of symptoms or to research a particular diagnosis that had been given. Michelle relayed her most recent experience with the internet which involved finding information regarding high blood pressure after a recent diagnosis: "I just typed in risk for high blood pressure. And I type in like diet for high blood pressure and then I type in um possible causes of high blood pressure then I just kept going from there."

This was typical of the search strategy used by the participants. When asked about how they evaluated the information they found, Dawn reported:

I usually won't go to one particular site, I will go to a couple of different ones and compare or whatever, you know what I'm saying. But I kind of have a general idea about the lymphoma from listening to the doctors and stuff like that and I just got on the internet and took time to read up on it and see how they treat it, if it was treatable and whatever.

The use of multiple sites to evaluate and make judgments about the veracity of information was the most often employed search strategy though some participants identified particular search engines such as “Ask Jeeves” or sites such as www.medical.com that they turned to on a regular basis.

Traditional forms of written information such as books, magazines, and pamphlets were mentioned in passing but were often not seen as a primary source. The accessibility of this information, however, does identify a location where if information is made available, it might be utilized. Several participants identified their doctor’s or hospital waiting rooms as places where they had read either medical pamphlets or women’s magazines that had articles pertaining to healthcare. Pam reported: “Like Parenting or Good Housekeeping, things you read on the internet, you know, just...I don’t really have any set magazines that I read. Just mostly when I’m sitting in the hundreds of doctor’s offices that I visit. Well, I used to get Parenting and things like that, so that’s been the biggest source.” Ruby stated: “As much as my sister’s been sick up in Pittsburgh, they got so many of them handouts; you’re just sitting there and read, and read, and read so you learn a lot. Believe it or not, you really do.”

Discussion

While no specific hypotheses were generated in the current study, support for a number of previous findings was evident. Of greatest salience was the support for a shared kinship model of social support as put forth by Johnson (1983). As would have been predicted with this model, the women in this study showed a preference for reaching out to family and friends prior to accessing professionals. It was often only after consultation within their circle of support that they would take a next step and reach out to a medical provider.

Polakoff and Gregory (2002) identified the importance of women being seen within the context of their lives as a key to receiving appropriate health care. For the women in this study who had positive experiences with their health care providers, this seemed to be the case. They identified care, concern and understanding as what helped them to develop a sense of trust. The women who had experienced more negative interactions, lack of understanding or respect for the demands of their lives outside of the provider's office were often overlooked or downplayed.

Barriers identified were generally consistent with previous findings including limited choice of providers, financial and time issues. As in Russell, Swenson, Skelton and Shedd-Steele (2003), the difficulties of managing multiple roles makes it difficult for women to prioritize their own health when they are the primary caretakers of children as well as maintaining jobs and marriages or intimate relationships. This is only compounded by the belief that one should not go "looking for trouble" and that a visit to a physician's office will only bring bad news and makes it even less likely that women, as those participants in this study, will engage in ongoing preventive care.

The supportive nature of religious affiliation (Zorn & Johnson, 1997), received mixed support. For one participant and her family, their health practices were directly related to their religious practices and that is where they turned for guidance. For another, her early negative experiences with the use of prayer as a primary intervention for illness made her more likely to go directly to a medical provider when she had a concern. The remainder of the participants used a more integrative approach, having some type of faith based component in their beliefs about and practice of health.

One finding that was not supported was that those participants with health insurance were not any more likely to have participated in preventive care than those who did not have insurance. This is somewhat contrary to what was found by Hsia et al. (2000). It is unclear to what extent this was a function of difficulty navigating the insurance system, poor coverage or the impact of beliefs and the previous experiences of the participants.

The experience of health care for these women in rural West Virginia can not be easily summarized as a simple problem of lack of resources, knowledge, or motivation. Whether it is “bad blood,” concerns about environmental toxins, or managing the demands of multiple roles, these women often delay or deny themselves access to the health care that they need. The question becomes what can be done to forge and strengthen a connection between women such as those who participated in this study and the health care system? A number of implications may be derived from the current study and can be grouped in terms of education, alternative service delivery, and the development of new beliefs about health and health care.

The identification of a set of behaviors that defined “consumers” of healthcare and the fact that many women were able to identify particular events that lead to a change in behavior make this a prime target for educational intervention. What many people knew as Home Economics class has now been changed to be Family and Consumer Science with an emphasis on the development of critical thinking skills. This same kind of change might also be possible in the public school system so that Health class is less focused on the symptoms of disease or the “what” of health and more focused on the management and behavioral changes necessary to manage conditions, the “how” of health. Learning how the system works, gaining assertive communication skills and learning how to work with providers as health care partners may provide the kind of interactions that will facilitate a more proactive and preventive approach to health care.

This type of approach could be classified as a primary prevention approach in that it would provide information/skills to a large group of individuals who did not necessarily have any kind of identified risk. If this was indeed the case, the potential for making fundamental changes in how individuals interact with the health care system could be increased and the likelihood that new behaviors would be modeled for the next generation would also be increased.

The importance of children and their impact on their mother’s behavior can not be downplayed in this arena. Becoming a mother was the single most identified factor when it came to changes in behavior from a more passive to a more active approach to healthcare. The women felt that it was their responsibility to find out everything they could about their children’s health and at times, this translated into the sense that they needed to take better care of themselves because if they didn’t, there might not be anyone

else to care for their children or they might not live to see their child graduate, marry or produce grandchildren. The possibility that educational programming for mothers-to-be or new mothers in the same vein as natural child birth classes might also be a point of contact that could be utilized. The motivation is potentially high at this time in a woman's life and is typically occurring at a young age before the onset of most chronic health conditions. The possibility to prevent the development of or to diminish negative health behaviors before they have significant impact might also be possible at this time.

Partnerships with major corporations who have the time, money and ability to distribute information should also be encouraged. The "Speaking of Women's Health" program that provides educational materials, conferences and television programming is sponsored by multiple major corporations, including Walmart, Lifetime Television, Dove and Kelloggs, is one example of a program that is making health care information accessible to women at all socio-economic levels. While women may not intend to pick up health information at the same place that they get their groceries, the reality is that this is a place where they almost certainly spend time on a regular basis and where those who are not connected to a regular primary care provider might begin to access important information.

Partnerships with corporate America can provide access to information for millions of women. At the same time, however, grass roots types of programs that work with a woman's existing support network to develop health care awareness and to promote the utilization of preventive services provide a more personal and generally more culturally sensitive approach to the issue. The use of this type of approach builds on the already present sense of trust and respect, using these values as a vehicle to

encourage new learning and promote new behaviors. The success of the community action agency that was the base of the current study is one example of how programming at this level can build social capital. Of the six women interviewed who were employees of the agency, two had received direct services from the agency prior to becoming involved and advancing to positions where they were paid employees, and in one case a program coordinator.

The use of alternative approaches or locations to distribute information naturally dovetails with the possibility that alternative delivery systems might facilitate better health care experiences for women in rural areas. The related issues of time and money were frequently raised by participants. The majority of the women who worked were hourly employees. Therefore they had to make the decision each time they accessed health care services about what was more important, the pay they were losing or the current health care issue. This meant, for most, that only acute health issues were addressed and then only those that would likely prohibit them from working. The emergency room became the facility most often accessed due to its 24 hour accessibility; this was not the preference of the women interviewed. There were almost no medical offices open in the evenings or on the weekends and as mentioned previously, one office was also closed on Mondays, which meant that if one did not get care on Friday there was a three day wait before care could be accessed again.

One alternative approach to this deficit in care would be the building of local coalitions of providers who would provide coverage on nights and weekends on a rotating basis. While it may seem that this would impede competition and choice among providers, it may in fact, enhance all practices involved because consumers would feel

that their needs were being met while not taxing the limited time and resources of providers in these rural areas. Incentives from insurance companies and state government might aid in this process since ultimately it could save money that is being paid in both emergency room and hospital fees and in more complicated and extensive care when people are not managing chronic conditions but rather waiting until they become medical crises.

Alternative service programs might also do things like provide nurse help lines to assist patients in managing their care. There already exists an informal triage network as evidenced by the use of family members and friends who are nurses in the community. It might be possible to tap into both these existing networks and use these identified individuals by formalizing the process and paying the providers for their time. Again, the potential for cutting down on unnecessary emergency room visits and providing better continuity of care could be an incentive for the development and funding of this type of program.

One growing approach to healthcare is the development of school-based health clinics. These clinics generally include both medical and dental health care, but are also entry points for social and school programming including preschool, WIC services and other assistance programs. The beauty of this kind of system is that these clinics have the potential to become community resource centers where community members know that they can get assistance with answering their questions as well as be provided with basic medical care. Again, this approach builds on the reality that in rural areas, schools are often the centers of the community and places where most people feel comfortable.

This approach again builds on the experience of many women that becoming a parent changes their approach to their own health. A school-based clinic offers an ideal environment for offering educational programming for both parents and children. Much like the Head Start model where parents and children are provided with opportunities to learn and grow together, school-based health clinics could serve a similar need with an emphasis on the importance of preventive care and positive health behaviors. The use of available classroom space to provide classes on nutrition and fitness as well as easy access to a variety of health care providers would again be a way to facilitate the development of not only healthy individuals but ultimately healthier communities. These clinics could work with existing programs that provide health fairs and community outreach projects so that they would not be replacing existing, successful programs but rather coordinating and enhancing existing resources and again developing a more comprehensive continuum of care.

A community-based health planning committee might be naturally located in a school-based clinic and could include everyone from medical providers to community recreation leaders to citizen members whose mission would be to care for the health care needs of the community through the coordination of activities, the development and facilitation of programming and the procurement of resources and funding to implement this type of program.

The greatest challenge implicit in the experiences of the women interviewed seems to be overcoming the negative beliefs they have about themselves and their own health. These negative beliefs are often the things that get in the way of their accessing existing available services and would likely interfere even if the barriers related to time,

money and insurance were eliminated. Of significant concern is the belief that it is better not to know what is wrong with you than to know and have to deal with it, which seems to be keeping women from going for preventive visits and yearly tests such as pap smears and breast exams.

It is unclear from this study how much this belief is related to old ideas about things like cure rates for cancer and how much it is a general approach to life. This approach might be described as the Scarlett O'Hara approach to life, "I'll think about that tomorrow." Although this type of approach may provide short term relief, it clearly can have significant consequences when it is applied to situations like the early detection of cancer or early treatment of chronic health conditions such as diabetes and high blood pressure. It is unfortunate that this approach is, in fact, mirrored in health care coverage plans where preventive care visits are not covered and acute care visits and hospitalization are. This can put people into the position that they are in a hold pattern until things get so bad or become a health care crisis that they can go to the hospital and get treatment, often at great expense to the system and with significant disruption to activities of daily living and family functioning. One has to wonder if this belief set does not in fact reinforce the kind of health behaviors that do become costly, both in terms of an individual's quality of life but also in terms of money and health resources.

Another belief that was prevalent was that of the women not seeing themselves as important enough to take care of themselves until they were spouses or parents. One of the participants stated that if it weren't for her husband and children, she probably wouldn't have taken care of herself at all. While it may be common for women to put their needs behind those of their children and spouse, in some cases it appeared that these

women had not put their own health on the priority list at all. Again it is unclear to what extent traditional gender roles impact these beliefs and if so, how amenable would they be to change? Change at this level would almost necessitate that “permission” be granted for women to see themselves as worthy of the time and effort needed to maintain good health. It is unlikely that this is purely related to rural life or to this region of the country, but rather is the result of sociocultural processes that have been in existence over the centuries.

The over use of the word empowerment has made it almost meaningless. However, the idea of women developing the knowledge, the skills and the motivation to become advocates for their own health continues to have meaning today. The need to develop the kind of social capital and action oriented approach to seeking out and obtaining good quality health care is a must, and given the complicated systems that women are forced to deal with, the days of being passive and trusting the first thing that you are told are no longer valid and successful approaches. This is true not only for women who are navigating these systems now, but also their children who are learning from the behaviors they are seeing modeled for them.

Given the limited sample size and the possibility that these women and the community they live in have characteristics that are unique to them, it is unclear to what extent the experiences of these participants can be generalized. This study is probably best thought of as a pilot study from which further explorations of alternative service delivery and health education models might be explored both in other parts of rural Appalachia and in rural areas in other parts of the country. It is likely, however, that experiences such as having to choose between earning pay and taking time off to attend

appointments and lack of access to primary care sites in the evenings and on the weekends will translate to other areas. The use of qualitative methods such as individual interviews and focus groups would be appropriate ways to gather information from women in other communities and other regions to begin to identify possible patterns of service utilization and common beliefs that could be targets of intervention.

Interventions that focus on education, skill building, and coordination and enhancement of existing social networks and resources with an emphasis on patients as partners in the system may be one of the few ways that limited health care resources can be utilized in a way that provides both adequate access as well as quality care. This is especially true in rural areas where time, distance, and traditional roles contribute to health care disparities. In a twist on an old saying, if you give a woman a doctor's appointment she will get her immediate needs taken care of, if you give her the skills and knowledge to make her own decisions, she may change the world.

Appendix

Interview Outline/Potential Interview Questions

Session #1

- I. Informed Consent
- II. Demographic Information
- III. Completion of Quantitative Measures
- IV. Meaning of Health
 - a. When you think of the word “health,” what do you think about?
 - b. Tell me where you got your ideas about health.
 - c. How do you know when you are healthy/unhealthy?
 - i. What things do you take into consideration when thinking about your own health?
 - ii. How has this changed over the years?
 - d. How much say do you feel you have in your own health?
 - e. How have your ideas about health changed?

Session #2

- I. Current Involvement With Health Care Providers
 - a. When you have a health problem where do you go? Who do you see?
 - b. How long have you been involved with the same health care providers?
 - c. What have your experiences been like?
 - i. Tell me about your last experience with a health care provider?
 - ii. What steps did you take to manage the situation before seeking out your provider?
 - iii. What did you like and dislike about your last experience with a provider?
 - iv. What would you change if you could?
- II. Access to Information About Health Concerns
 - a. When you need to know something about a health concern, where do you get your information?
 - b. Tell me all the places that you go for information if you or someone in your family is sick or has a health concern?

- c. Tell me about the last time you were looking for information and all the steps you took to get the information.
- d. Who do you rely on the most when you need information about health problems?
- e. What changes have you noticed in how you get your information?
- f. How do you decide what information you use?
- g. Where/When have you tried to get information and not been successful?
- h. What barriers have you found when seeking information?
- i. What strategies have you found helpful when seeking information?

III. Formal Versus Informal Sources of Information/Services

- a. Who are the people in your life who you rely on for information?
- b. What types of information do you get from them?
- c. How much of a factor are they when you are looking for information about health?
- d. What would make you take/not take their suggestion over that of a health care provider?
- e. What impact do your support people have in how you choose a health care provider?
- f. How do you find out about what is available for services in your community?

Session #3

I. Barriers to Care

- a. Tell me about the last time you had difficulty when seeking health care?
 - i. What did you do about it?
 - ii. Who helped you?
 - iii. How successful were you in overcoming this difficulty?
- b. What obstacles have you run into when trying to get health care?
- c. How have you been able to overcome these obstacles?
- d. What do you think can be done to remove these obstacles?
- e. What type of impact do you feel you can have in making changes, removing obstacles?

II. Social Support System

- a. Who are the important people in your life, the ones who would help you if you needed it?
- b. What kinds of things do they do for you?
- c. How satisfied have you been with getting what you need?
- d. What kinds of support do you need that you are not getting?
- e. What opportunities do you have to add to /improve your social support system?
- f. How important are these people in helping you to maintain your health?
- g. What do they do to help you stay healthy?

III. Follow-up Probes

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