

SOCIAL SUPPORT AND WOMEN LIVING WITH SERIOUS MENTAL ILLNESS

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Project #23

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Social Support and Women Living with Serious Mental Illness

Executive Summary

The people in a social support network can help a person find solutions to problems, validate an individual's identity, direct the individual to helpful information, and provide comfort when that is all that can be done. Connection to others contributes to a sense of well being and gives meaning to life. It is no wonder that social support has been identified as one of the determinants of health, i.e., a factor believed to contribute to our overall health. Schizophrenia is an illness that can cause disorganized thinking, hallucinations, and delusions. It can cause a person to feel depressed or flat and lack the motivation to act. As a serious mental illness, at different stages it can inhibit the ability to make meaningful connections with others. Over time, due to the social stigma associated with serious mental illness, developing and maintaining relationships can be difficult. A support system is vital for people living with schizophrenia yet at the same time the illness places relationships at risk.

This project explored the social support in the lives of women living with schizophrenia. It was designed to build on an initial study, which examined the informational, and support needs as perceived by this population. In the initial study, women indicated there were a limited number of people in their lives. This present study focused on exploring with women their formal and informal sources of support, the kind of support people in their lives provided, and the kind of support women felt was lacking. Women were encouraged to talk about support in the context of their everyday lives, responsibilities, and sense of self, in light of having a serious mental illness.

Semi-structured interviews were conducted with fourteen women living in the community who self-identified as being diagnosed with schizophrenia. Most of these women were unemployed, lived in poverty, and relied on social assistance. Some lived with physical health problems as well. Most women had few responsibilities or activities to occupy their days, outside of limited social contacts and some structured activities. They relied on public transportation to get to appointments or other activities. The telephone was an important medium to connect them with members of their support system, especially in times of crisis.

Family members and mental health care providers were often identified as the most supportive people in their lives. Female friends with serious mental illness provided a meaningful source of connection to these women; however, the nature of the support was largely affective. Women conveyed a sense of reciprocity as they talked about their relationships and place within the community.

SUMMARY OF RECOMMENDATIONS:

- 1. An important source of support for women with serious mental illness is other women who have serious mental illnesses. Education and support is needed for women with serious mental illness who support each other.**
- 2. Families provide tangible, informational, appraisal, and emotional support over time, and at a distance. Education and support is needed for family members so they can be supportive.**
- 3. Women with serious mental illness could benefit from access to a health care worker who is knowledgeable about available resources, and can assist women in making choices about suitable resources in the community.**
- 4. Further development of intersectoral partnerships among agencies serving this population is needed.**
- 5. Access to female health care providers to discuss sensitive health care issues is recommended.**
- 6. Support for telephone service as part of social assistance is recommended, given the importance of the telephone in accessing members of the support system.**
- 7. Support for a bus pass as part of social assistance is recommended, given the need to rely on public transportation to access support systems outside the home.**
- 8. Support for the development of vocational training programs would be beneficial for women with serious mental illness.**

The findings, and the programming and policy implications that emerge, reinforce those reported elsewhere. A primary health care model, which is gender-sensitive and considers illness within the context of the individual's life, is best suited to meet the numerous needs of women living with serious mental illness.

Social Support and Women Living with Serious Mental Illness

Section 1: Introduction

A. BACKGROUND, PURPOSE AND RATIONALE FOR STUDY

Schizophrenia is a serious mental illness that can have a profound impact on people's lives. During acute phases of illness, delusions, hallucinations, and altered thought processing abilities are common. Women with schizophrenia often live stressful lives in poverty, and can have difficulties in maintaining relationships, an important source of support for women. The primary goal of this project was to explore the source and nature of social support with women with a serious mental illness.

Research to date suggests that a woman with schizophrenia is challenged to cope with the stress of losing life's achievements when an unpredictable and often chronic mental illness invades her life at a relatively young age. The average age of onset for women is 27 years (Gottesman, 1991). In order to control symptoms, such as hallucinations, delusions and altered thought processes, women are prescribed antipsychotic medications. These medications are known to cause side effects, such as unexpected weight gain, which can adversely affect body image and sense of self. Because schizophrenia can make it difficult to maintain a developed support system and to express needs, a woman with schizophrenia may have difficulty in independently negotiating around requirements in health, social, and financial needs.

Recent literature that compares men and women with schizophrenia indicates that despite women having better psychosocial functioning than men, the social context of these women's lives can create a poor quality of life (Kulkarni, 1997). With illness onset, women are at risk for losing all that they have achieved - marriage, children, career. If women re-partner after their illness they are likely to connect with a man with a mental illness or find themselves with abusive partners, thus jeopardizing the quality of the intimate relationship (Mowbray et al., 1997). If a woman has children she risks losing custody of them, or has little support in caring for them and questions her ability to meet their needs (Miller and

Finnerty, 1996). The nature of the illness can limit the kind of employment she seeks, thereby increasing the likelihood of living in poverty (Kulkarni, 1997).

Living with stress, numerous losses, and a chronic mental illness can rob a woman of her self-esteem and confidence. Women tend to adhere to medication regimes and not require hospitalization as often as men do (Tamminga, 1997), therefore knowledge of community-based resources and the ability to access these become important in meeting a woman's health-related needs. However, after illness onset women are at risk of leading increasingly isolated lives (Seeman, 1998). Living with a chronic mental illness and the risk of isolation can put a woman's health and quality of life in jeopardy.

Determinants of health are those factors known to influence health. The focus of this project was the role of social support in the lives of women with a serious mental illness. At the same time it is acknowledged that the life context for a woman with schizophrenia is likely to include a number of other factors that can adversely affect health, such as living in poverty, the social stigma of living with a mental illness, unemployment, some personal health practices, and limited access to information.

B. REVIEW OF THE LITERATURE

Social support is a multidimensional construct and differentially defined (Weber, 1998). For the purpose of this research, social support was conceptualized as "perceived social support" which entails a cognitive appraisal of being connected to others (Barerra, 1986). Two key dimensions of perceived social support are perceived availability and perceived adequacy of supportive connections (Barerra, 1986). Social support networks as a determinant of health are believed to have a positive impact on health outcomes (Federal, Provincial, and Territorial Advisory Committee on Women's Health, 1993; Weber, 1998). Social support can provide a sense of well-being, serve as a source of information, act as a form of coping (Thoits, 1986), enhance self-esteem, or provide access to material needs (Bowling, 1991; Weber, 1998). Social network analysis studies a number of characteristics of the network, including size, composition, number of contacts, type of relationship, physical proximity of individuals to each other, and type of contacts. Social support analysis examines the perceived value or helpfulness of the support provided. Hence, in social support the perceptions of the recipient of social support are important in determining the effectiveness of support (Bowling, 1991).

Research to date that examines social support and individuals with serious mental illness is dominated by social network analysis. No doubt this is related to the objective methods associated with measuring networks as a form of connection with others. Pickens' (1999) review of the literature indicates that people with psychiatric illnesses tend to have smaller networks than people without psychiatric disorders. The networks of those with psychiatric illnesses also tend to include more family members. However, Holmes-Eber and Riger (1990) found for those individuals with chronic mental illnesses, when the frequency and length of admissions increase, there are fewer friends and relatives in their networks. Further, if the size of the networks remains the same, they are comprised of those met through the mental health system and based on short-term relationships.

The kind of support provided by others can be classified into multiple types, including: informational support, emotional support, appraisal support, and instrumental support (Weber, 1998). Informing an individual of the typical course of illness provides support through information giving. Expressing care and affection for someone provides emotional support. Providing evaluation about a person's ability to achieve a goal is appraisal support. Providing material resources such as food or money that assists a person is instrumental support.

A study of men with schizophrenia found that those with symptoms such as poor grooming, decreased motivation, flattened emotional response, and slower speech, had significantly smaller social networks and more dysfunctional relationships within their networks than men with less severe expression of these symptoms (Hamilton et al., 1989). The implication from this study was that behaviors that impaired the ability to relate to others were more responsible for difficulties establishing social contacts than hallucinations and delusions. Breier and Strauss (1984) found a shift in social needs during the year following a hospitalization for a psychotic disorder in their sample of men and women. During the convalescent phase, relationships with family members and contacts made in hospital (health care providers and patients) were important. During the rebuilding phase, there was a decrease in such relationships as people developed new social contacts.

Cogan (1998) interviewed 25 women receiving services from a community mental health centre about their relationship-based needs. This group of women identified needing assistance dealing with emotional abuse within relationships, sexual abuse, information about reproductive health, and child custody issues.

Weber's summative comments about the meaning of social support address the significance of relationships and perception in determining social support:

“Social support is about connection. It is about having needs recognized and acknowledged. It is about interdependence, accepting help when it is needed, and giving help when we are in a position to do so. It is about feeling connected to a community, so that as we go about our daily business, or face a crisis, we feel there are people who care about us, who value us, to be there when we need help and feel alone” (Weber, 1998:54)

C. METHODS

The study was designed using qualitative research methods, including semi-structured interviews as the primary data collection strategy. Women were recruited through health care providers who work with this population and self help groups, in Winnipeg and surrounding rural towns. A purposive sampling strategy was used to select women who:

- 1) self-identified as having schizophrenia for a minimum of five years,
- 2) were living in the community, and
- 3) were willing to discuss their support system.

Demographic data were collected to provide a description of the sample. Feminist research principles (Devault, 1990; Minister, 1991) guided the conduct of the interviews (see Appendix A for interview schedule). A woman with schizophrenia offered critical comments about the interview questions prior to its use. The overall research question was: What role does social support play in the lives of women with serious mental illness?

Sub-questions that guided data collection included:

- 1) What experiences have women with serious mental illness had in negotiating support from formal resources?
- 2) What experiences have women with serious mental illness had in negotiating support from informal sources?
- 3) What barriers are there to finding and accessing the support these women want and need to function in their chosen roles in the face of living with a serious mental illness?
- 4) What links do women make between social support, their feelings of self-worth, feeling in control of their lives, and feeling they have obtained information useful to them?

A semi-structured interview schedule was constructed that engaged women in an exploration of their perceptions of people they identify as supportive, including the nature of the support, and how at times supportive people may not be supportive. Women were encouraged to consider all types of relationships from family to health care professionals and group affiliations. The interview was constructed to include questions about the four kinds of support --informational, instrumental, affective and appraisal. Women were asked about the presence of a confidant in their lives, whom they can turn to for help in the face of

problems, and the overall perceived adequacy of their support system. Data were also collected from women about their past experiences with social support. Women were asked about changes in their support system over time, including the five-year period before the illness.

D. PARTICIPANTS

Fourteen women participated in the study including two from rural areas. Participants ranged in age from 40 to 73 years, with a median age of 45 years. Five of the women were married or living in a common-law relationship. Nine were single or divorced; three had boyfriends. Of the eight women who had children, two were raising children, two ex-husbands had custody, one's child was being raised by a relative, and three had grown children. During the course of the interviews, some women identified that they had other health concerns including: weight gain, high blood pressure, diabetes, anxiety, depression, substance use, and smoking.

Section 2: Findings

A. LIVING WITH A SERIOUS MENTAL ILLNESS

Nine of the women reported knowing their diagnosis for ten years or more. Several women lived with symptoms of illness and experienced hospital stays prior to the date of diagnosis they identified. Some women described receiving different diagnoses over time; others were not sure of the reasons, diagnostically, for their earlier hospitalizations; and, still others had symptoms without understanding why.

Finding the right drug to control symptoms was important to women. One woman described an “*awful*” experience with the side effects of one drug during a three-month hospitalization. However, after a three year experience with a new medication she stated:

“I can feel it working in my mind, ... It relaxes me, it soothes me, ... I can think more clearly, I am not so afraid”.

B. LIFE CONTEXT

Most participants in this study lived well below the poverty line. Eight women reported incomes of \$10,000 or less, while four lived on annual family incomes between \$10,000-19,999. Two women, whose husbands were actively employed, reported family incomes of over \$40,000. All the women themselves were unemployed or considered themselves retired from active employment.

The women participated in a range of structured activities in the community. Weight loss groups were popular. Church organizations, recreational groups and the Women's Program at the Manitoba Schizophrenia Society (MSS) were other activities commonly cited by this group of women. Different degrees of involvement in the activities were reported from occasional attendance to regular attendance and active participation. Generally, these women's lives were routine, and limited in activities and social contacts.

The women described experiences in which their safety was compromised. One woman had recently moved due to a robbery at her former apartment. Another lived in a group home populated by men. She described her feelings of "*discomfort*" and the limited connection she was able to make with any of the residents. Finding another place to live was a priority for her. However, she described the difficulties in finding suitable, supportive, and safe housing on a limited income.

Several women moved frequently. This meant the women had to adjust to new neighborhoods, and locate the resources they needed within that neighborhood. Moving also impaired the further development of relationships with others that had begun, but for which a strong tie had not yet developed. One woman described a friendship with a woman whom she saw often for Sunday brunch. The friend moved away and since then contact has ceased. Because many of these women tended to develop friendships with other people with mental illness, if they weren't moving, their friends were. The women relied on public transportation to get to members of their support system. For those on a limited income, the bus becomes a vital resource to attend support groups, and have in-person visits with friends.

C. WOMEN'S DEFINITIONS OF SOCIAL SUPPORT

Women were asked to define what the term “*social support*” meant to them. A number of women defined the term by describing the social aspect rather than the support aspect. For the others, the word “*help*” appeared in many of their personal definitions, suggesting the primacy of the instrumental aspects of support. For example, one woman defined social support as “. . . *somebody to help you develop different skills so you can live in the community*” while another woman said “. . . *its other people helping people.*” The appraisal aspect was also present in some of their definitions with statements like “. . . *to help them grow and expand...*” and “. . . *someone who interacts with you, helps you cope, and gives you the support to better yourself...*”.

D. WOMEN'S PERCEPTIONS OF THEIR SUPPORT SYSTEM

The emotional and informational forms of social support became more apparent when women began to describe their own support systems and how they were helpful to them. Women consistently ranked their family and mental health professionals among the top people in their support systems. Supportive actions among mental health professionals included: active listening, providing information, assisting in times of crisis (e.g., such as when a woman was feeling suicidal, needing someone to talk with), and providing referrals to other organizations (e.g., vocational rehabilitation). Long-term relationships with mental health care providers were valued by women as being most supportive. Women valued working with someone who had knowledge of them and their health needs.

Family members were key supporters. Many women lived at a distance from their supportive family and therefore contact with them was through regular phone calls. One woman described calling her sister in another province daily. Family members provided emotional and appraisal support, and frequently, when they were able, financial support. Not surprisingly, some women were ambivalent about the support they received from their families, either in the present or at a previous stage in their lives. One woman had her mother at the top of her “most supportive” list and “least supportive” list concurrently. This single parent received a great deal of instrumental support and tangible assistance from her mother in raising and caring for her children. However, the criticism and perceived interference she received on her parenting were not always appreciated and led to the participant’s feelings of being devalued as a mother. Another woman, described an ostensibly supportive sister as attempting to exert too much control over the participant’s life.

Not all families were considered supportive especially when there were issues of a parent's mental illness or a history of abuse. One participant's mother was being cared for by a sister who had no energy or patience left over to be supportive to the participant. Another woman described her mother, a substance abuser, as having a *"toxic influence"* on her life and chose to avoid contact whenever possible. Women demonstrated insight into the advantages and disadvantages of remaining in these relationships. They were thoughtful in making a conscious choice to limit contact in the face of problematic relationships.

For those women in intimate, sexual relationships, the emotional, appraisal, informational, and tangible support received in these relationships was described with a special sense of significance. As one woman described the importance of her relationship with a long-term boyfriend:

"If we went our separate ways I would be lost without him, because he knows somewhat more things, somewhat more people and more information than I know, he has a way of getting things done that I don't".

In talking about the support her husband provides, one woman stated: *"He's a very supportive person; he loves me; and things that I feel I have to keep secret, I can talk to him about"*. At the same time, issues faced within any intimate relationship were also present in this sample. One woman described differences between her own and her partner's needs for sexual contact. Another woman in the sample chose to continue to live in an abusive relationship due to the financial benefits of the relationship. Her discourse revealed her internal ambivalence between living in an abusive relationship and living with the effects of poverty.

Women's friendships, another important area for support, were often with other women with mental illness. The women voiced the significance that this connection meant to them. At the same time these relationships posed problems. The women struggled with valuing the relationship and recognizing that the support they wanted was not available when their friends were ill themselves. One woman identified her *"least supportive"* friend as her *"best friend"*. Her discourse revealed a connection with this friend at the same time as recognizing that her friend, who was often in much need herself due to illness, was not able to be the support she would like her to be.

The issue of reciprocity was evident in the women's reports about relationships with their support system and in the communities within which they lived. These women have a strong sense of community and family responsibility. The women talked about participating in or looking to participate in some type of

volunteer work. One woman talked about selecting food from the food bank in order to cook for other people. She also helped her brother who has AIDS by cooking for him and selecting clothing for him. Another woman talked about preparing food for people who helped her move to her new apartment. She talked about feeling she can ask for help from her neighbors in her apartment block, and that she will reciprocate in any way that she can.

The telephone was of paramount importance in many women's lives. Several women relied primarily upon this medium to connect them to their support systems. One woman, with physical concerns in addition to her mental illness, described calling her clergy for help and her best friend during a time of feeling suicidal. She phones her doctor and her mental health worker regularly. Her definition of support included those people who "*phone her back*". Another had family and friends in Eastern Canada, who were most supportive in her life, next to a crisis line and her mental health worker.

Knowledge of resources was developed over time, and depended upon whom each woman knew (friend, community mental health worker). There were varying abilities among women to get what they needed from the system. Some lived with minimal formal social support. It was unclear if these women did not know about other resources or they did not have the energy or motivation to contact the right agency. On the other hand, a few women described needing extra money and successfully making a case with social assistance workers for this added support. Others found ways to get basic needs met outside the formal system. For example, a few women were able to identify whom they could borrow a few dollars from, or where they could get food or a meal if needed.

E. ADEQUACY OF SUPPORT SYSTEM

Most women stated that they were satisfied with their social support system. This seems different from findings based on an earlier study in which women expressed the need for more people in their lives, in particular, friendships (Chernomas, Clarke and Chisholm, 2000). Those who were able to identify desired improvements talked about wanting trustworthy friendships and people to engage in social activities.

Section 3: Implications and Recommendations

There are several recommendations for women's health policy and programming based on the findings of this study.

- 1. Provide support for community-based services, activities, and supports specifically for women with serious mental illnesses, by women, that offers a range of programming geared to this population.**

Women sought out structured activities that serve health and social needs, such as weight loss programs and church support groups. Weight loss programs cost money and women located them on their own. While there are advantages to women seeking out their own resources, a program that addresses a range of needs could be designed specifically for women with a serious mental illness. The Women's Program located at the Manitoba Schizophrenia Society offers programming that addresses social support, education across a variety of health and social topics, opportunity for skill development, and social/recreational activities (Clarke, Chernomas, and Chisholm, 2001). The educational sessions offer topics directed at the needs of this group including: relationships, domestic violence, and menopause. Educational sessions that are offered through an organization aware of the special needs of this population are advantageous. For example, understanding the effects of illness and medications when a woman is menopausal, could be considered in offering such a session.

Part of the design of this type of programming is to involve women in planning the activities. For example, women raising children live with the fear of losing custody of their children. The needs for education, parenting skills, understanding legal rights and options, and for support in light of this possibility could be easily incorporated into a flexible program design. Skill development is possible with such programming as well. For example at the Manitoba Schizophrenia Society, one woman assumes responsibility for constructing and circulating a newsletter. Circulation for this communication tool is to about 100 women and health care professionals.

Financial support for this program, since it began in 1999, has come from different sources in the form of one-time contributions. At this time, there is no ongoing funding for this women-centered program, which makes its future sustainability and further development tenuous.

2. Education and support for women with serious mental illness who support each other.

Most of the female friendships women had were with women with a mental illness. Access to other women with serious mental illness through a women's program can provide a safe way to develop friendships and a support network for these women. Programming that takes into account a woman's ability to be supportive and her need for support would help women develop the skills to engage in reciprocal relationships with their friends. This idea can be made a part of the gender-sensitive community-based program described above.

3. Education and support for families, in particular, for those at a distance.

When family members provided support, it was highly valued. At the same time when there was understanding of the illness and its impact, women could feel more understood by their family. This made relating easier. The need for education and support for family members is frequently noted in the literature, and its need is reaffirmed in this study.

4. Access to a health care worker who is knowledgeable about available resources, and can assist women with mental illness in making choices about suitable resources.

Given the variety of needs that this population has, comprehensive programming through one resource is unrealistic within the current structuring of the health and social systems. The women suggested that they were navigating the health and social systems primarily on their own. A health care professional who is knowledgeable about a continuum of available resources would be equipped to discuss with the woman her needs and assist her in selecting and getting appropriate resources. This health care professional would need to have assessment and communication skills, an understanding of health needs in the context of mental illness, an understanding of women's health issues, and an ability to work with women with full appreciation of the circumstances of their lives

5. Further development of intersectoral partnerships among agencies serving this population is needed.

Building and strengthening partnerships between the mental health community and women's health community would help to address women's health issues within this population. This study did not evaluate the extent and quality of health and social services in these women's lives other than to investigate the women's own perceptions of their experiences with self-identified forms of support. However, a mechanism to better link resources with one another would facilitate meeting the health and social needs of this population in a more comprehensive manner.

6. Provide access to female care providers.

Some women noted that being able to discuss sensitive topics with a female health care provider, educated in mental health and women's health, was the preferred context.

7. Support for telephone service as part of social assistance.

The telephone was an important tool to reach key supportive people in their lives, notably, psychiatrists, mental health workers and family, many of whom live at a distance. For these women at risk and living in poverty, the telephone becomes a lifeline. Given the significance of the telephone in the lives of these women, financial support for this service is strongly recommended.

8. Support for a bus pass as part of social assistance.

In light of the level of poverty, public transportation becomes the only option for women to reach their support system outside the home. The ability to access activities in the community beyond walking distance could be facilitated by a bus pass. While the availability of programming that meets the needs of this population is advantageous, opportunities to interact with people outside of illness-related services are needed to provide integration with the broader community.

9. Development of vocational training programs for women with serious mental illness.

The desire to contribute to the community and to engage in meaningful activity was expressed by this sample of women. The women talked about either participating in or looking for volunteer work. They recognized the limitation that the illness and its treatment imposed on their ability to seek and maintain full time employment. Vocational training programs that provide gradual reintroduction into meaningful work while at the same time recognize the impact of illness and its treatment on a woman are needed.

SUMMARY

Our findings with programming and policy implications from this study reinforce those cited in other discussions promoting gender-sensitive health policies and programs (Morrow and Chappell, 1999; Thielen-Wilson and Hinton, 2001). A primary health care model of health service, that is gender-sensitive, and views the illness within the context of a woman's life, seems best suited to meet the health and social needs of this high-risk group. Such a model encourages intersectoral cooperation, addresses illness treatment and health promotion aspects of health care, addresses the impact of all the determinants of health, and support services that are based in a person's community. In order to facilitate connection with resources across sectors, both health and social, a health care worker knowledgeable about the woman's community has been recommended.

A health care worker able to make comprehensive and timely referrals ensures that health and social needs are being addressed. Others advocating a women-centered, primary health care approach for women with serious mental illness have also identified the recommendations cited in this report. Developing innovative ways to facilitate the implementation of the recurrent themes in these recommendations would support a woman with serious mental illness during recovery and re-integration.

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Appendix A

INTERVIEW SCHEDULE

1. Explore meaning of social support
Probes: What does social support mean to you?
2. Who is part of your support system at the present time?
(Identify all people including family, friends, neighbours, health care professionals, clergy).
Specify their role/place in your life and how long they have been part of your support system.
3. Can you tell me how each person is supportive?
Probes: How does that person affect how you feel, in general and about yourself?
What does that person do that is helpful?
4. Do you have someone you feel you trust and can confide in? If yes, can you tell me about this person?
How often do you talk with this person? Can you describe a situation in which this person was helpful
- how was the person helpful? How important is having this person in your life?
5. If you had a problem and didn't know what to do? Is there someone you could talk to about it?
If you were feeling too ill to shop for food, is there someone you could ask to pick up a few necessities
for you?
6. Sometimes the supportive people in our lives are not supportive? For each of the people identified in
#2, explore if there are at times when they are not supportive. What do they do/say that is not
supportive? How does this affect your feelings, in general, and about yourself? How does this affect
your ability to do the things you have to do each day?
7. Was there a time when you needed help and didn't know who to ask, or the person you usually ask was
not available? Please describe, (encourage the following data: when, what happened, how did you feel)
8. Overall, how adequate do you think your support system is? (Probes: are you satisfied with the number
and quality of your friendships, your intimate relationship, relationships with family, etc...)
9. I would like to go back in time and think about whether or not your support system has changed. Has
your support system changed in the last few years? If so, describe. How about now compared to 5
years ago, when you were X years old, 10 years ago, etc...(This question will be participant -
dependent. For example, a 55 year-old participant would have a longer time period to cover than a 30
year-old it is a general sense of change, how much change, and what might have precipitated the change
in support system that is being sought).
10. Think about the period 5 years before you received a diagnosis. What was your support system like
then? Who were the most important supportive people in your life? (To explore with participant: are
those people still in your life, if not, what happened).