

# **Living with chronic illnesses: How are those with a chronic illness treated by their families since their diagnosis?**

## **Literature Review**

Chronic physical illness and chronic mental illnesses are reviewed separately here due to the tremendous differences in the two. In this study they will be compared against one another to cross analyze the differences and similarities in how the family member is treated depending upon their type of illness.

### **Chronic Physical Illness**

Chronic physical illnesses vary in types and intensity, but have one characteristic in common: they recur throughout time, usually at random intervals. The uncertainty that comes along with a diagnosis along these lines can greatly affect family communication and relationships.

**Marriage.** Marriage is the basis of most families in many cultures. Keeping the marital bond strong could be very difficult in the face of a chronic physical illness. A chronic physical illness could potentially change the daily lives and interactions of the entire marital relationship. It is important to discuss the communication that occurs around these illnesses in order to understand how those who have one have been treated since their diagnosis based on research already conducted around similar communication processes. Badr and Acitelli (2005) found that in couples that used relationship talk, or talking about the nature and direction of the relationship, chronically ill couples had more benefit than a couple that did not include someone who had a chronic physical illness did. This literature proves that in a situation where a spouse is chronically ill, it is important to use communication to make one another aware of certain things such as how one felt about a situation, or what one needs or expects from their partners. Talking

about the state of the relationship can be helpful for chronically ill people to express fears in relation to their illness and the marriage. Berg and Upchurch (2007) suggested that collaborative talk is the type of communication that is commonly correlated with positive results. This shows that it is important for married couples to talk about their situation together to keep their relationship strong since these tactics have been proven to be helpful for the couple. Shuff and Sims (2013) add on to this by stating that couples that are aware of their partner's expectations of communication in the marriage are more successful in supporting one another. Being aware of the partner's desires and being able to fill them is central to satisfaction in the relationships' functioning. Marital coping and sharing are not limited to relationship talk though. Another powerful way of sharing within the family is through narrative.

**Narratives.** Something that is strongly recognized and praised throughout literature on chronic physical illnesses is narratives. Several studies (Freeman & Couchonnal, 2006; Ott Anderson & Geist Martin, 2003; Walker & Dickson, 2004) stress the importance of narratives for the family healing process. Narratives are beneficial because they allow research to capture personal accounts of illness, and let the ill person be a gatekeeper to their own information about their illness. Ott Anderson and Geist Martin (2003) state that those with a chronic physical illness are more likely to actively share if their feelings and perceptions are confirmed by other people, especially friends and family. Some chronic illnesses have a negative social stigma to them, and confirmation that people will be respectful is important to getting the patient to open up about their experiences. Narratives and storytelling help families to communicate about changes that have taken place. Ott Anderson and Geist Martin (2003) conclude that the ever changing identity in the face of illness never stops, it is an endless development. Sharing through narrative in cases of chronic physical illness has the potential to better family communication

because the patient is able to clearly and concisely explain what is happening to them from their personal point of view. This can help the family identify what the patient has gone through, as well as understand new emerging identities. However, Lorde (1980) points out an important paradox where sometimes patients may be empowered by giving a narrative account of their story, while others may feel anxiety from reliving those moments of their life. According to Grotcher and Edwards (1990), when participants used communication to reduce their fear of their illness, they were likely to communicate about their illness more often. Walker and Dickson (2004) show that narratives are important in understanding and meeting the expectations of the family members when they are chronically ill. Often times people will have expectations for their family members without verbally expressing them, leaving family members more often than not confused about what direction to take. However, a narrative or forms of storytelling in the case of a chronic physical illness may reflect some of the patients unfulfilled needs, and help family members to identify them.

### **Chronic Mental Illness**

A chronic mental illness can be extremely hard for families to cope with given the negative social stigmas that exist about the illness in most societies around the world today. A chronic mental illness in a family member could lead to almost constant care and monitoring, depending upon the illness and the intensity. Families may find it difficult to cope with or come to terms with a family member's diagnosis of a chronic mental illness due to the many challenges it presents. Much of the literature surrounding mental illness in the family is psychology based, and there is a strong need for communication-based studies to better understand these unique families.

**Marriage.** An important aspect of the family dynamic is marriage. It is the foundation of most families, and gives people feelings of stability. Communication is essential to marriage, but little literature exists exploring the communication around a diagnosis of a mental illness. However, much literature exists on its effects on marriage. Perry (2014) focused on social networks and stigma in relation to those with a serious mental illness. A spouse is a very prominent and strong part of a married person's social network. If someone is entering or exiting a marriage, their social network changes in many different ways. Perry (2014) found that the stigma of a mental illness had contact with the social network and the relationship between the two works ambiguously together. Meaning that the social network responded to the mental illness through their own thinking, and proving that spouses typically control family conversations. Spouses decide the climate of the family views and values towards different topics as they raise their offspring, if they choose to have any. Segrin (2006) shows that there is a strong call for communication scholars to explore the way that families interact, especially about mental illness, and that a positive or a negative attitude can set a precedent for what future family communication will be like based off of how spouses interact. The different communication processes that couples partake in set examples for children to interact based on. Adding mental illness to the mixture, Schmaling and Jacobson (1990) show that wives that are depressed are more likely to make an aggressive comment to their husbands than wives that are not depressed would, and depressed wives have less positive discussions than their counterparts. These aggressive statements could likely become a stressor for the marriage or produce a negative schema of marriage for children or adolescents in the family. Segrin (2006) offers that depression has a large impact on the family, and usually just creates more problems that tends to

result in fueling depression. However, this assertion could also be true of the communication patterns surrounding many other types of mental illnesses in the family.

**Parent-Child.** Looking at the parent-child relationship in reference to mental illnesses, it is known that parents are the primary caregivers to children and adolescents with chronic mental illnesses. Literature mainly focuses on the illness from the parents' perspective, rather than the child's, suggesting that little is known about children's perceptions of their parents' mental illnesses. Richardson, Cobham, McDermott, and Murray (2013) explained that parent's feelings of loss about an adult child with a mental illness focuses on grieving about ambiguous losses, like the child's loss of self or identity. This loss and grieving process has the potential to shape the family's behaviors and patterns of communications. Since there are usually no tangible effects of a mental illness, parents may often find it hard to cope with a diagnosis and come to terms with it. Even harder for families to process is the fact that in most cultures and societies in the world, there is a negative social stigma to having a mental illness. Richardson et al. (2013) also noted that parental grief over the child's mental illness was not socially acceptable. Several studies (Richardson et al., 2013; Chadda, 2014) discussed this notion that parents felt as though the illness or their own grief should be hidden because it is not socially acceptable. Most of the struggles that parents in this situation face are with the topics of self-concepts and identities, with variance to whether it is their own, or their child's'. Richardson et al. (2013) found that the child's illness changed the parents own identity. Since the identity and self are such fluid concepts, it is important to understand the self and different identities as well as the changes that occur with the two in accordance to both the parents, and the children. There is little literature in regards to mental health's effects on self-concepts and identities. Aside from the self, another important factor to contend when discussing mental illness between the parents and children is

parenting styles effects on these children with mental illnesses. Hamond and Schrodt (2012) explored the effects of the different parenting styles on children's mental health and concluded that there was no statistically significant evidence that the different styles had an effect on mental health. However, Hamond and Schrodt (2012) continued by noting that findings indicated that acts of affection and authority make limited, but important, improvements to the child's mental health. When it is the parent in the relationship who is mentally ill, the communication process is entirely different. As found in Van Loon, Van de Ven, Van Doesum, Witteman, and Hosman (2014), where adolescents internalizing and externalizing behaviors were correlated to parents mental illness. Parents with mental illnesses were found to have a negative effect on the adolescent or child, the whole family, and even the parent and child's interactions (Van Loon et al., 2014). This literature exemplifies that parental mental illness controls more channels of communication than a child or adolescent's mental illness does. While much literature exists about families and mental illness, unfortunately very few scholars focus on the talk that occurs about the family member with the illness, and the communication around this topic.

Reviewing the literature leads back to the question: how are those with a chronic illness treated by their families since their diagnosis? Analyzing both mental and physical illnesses and the family communication processes around them are essential to furthering the conversation that communication scholars are creating to understand these unique families.