

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

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Abstract

This study aims to figure out what the relationship and meaning of the ways that a family treats a family member with a chronic mental or physical illness. The exploration of the way those with a chronic illness are treated since their diagnosis is important to understand the perceptions, behaviors, and communication that surrounds illness. Chronic mental illness will be analyzed against chronic physical illness to assess similarities and differences in family behaviors. Participants included individuals selected from local support groups based on their illness as well as family structure. An ethnographic study would be used to compare both the verbal and nonverbal relationship between the ill family member and the rest of the family.

Introduction

This study aimed to focus on both physical chronic illnesses and mental chronic illnesses and their effects on family communication, particularly surrounding the diagnosis of the illnesses.

Family has a large impact on the perceptions of illness. In recent times, the publicity around individuals with chronic illnesses, both mental and physical, has increased dramatically in the media. From the production of films about those with physical chronic illnesses to celebrity diagnosis of a mental illness, illness is something our society is beginning to talk about more frequently. However there are certain stigmas attached to these illnesses that make it harder for patients and their families to cope with their situation. Most often because of the portrayals of chronic illness that romanticize illnesses and do not necessarily show all of the effects of these illnesses on the patient or their family.

Both mental and physical chronic illnesses are much more complex than how they are portrayed in the media. These illnesses often produce copious amounts of side effects that bring a whole new level of challenges to the patient's struggle through their daily life and readjustment after diagnosis. One effect that is often not publicized as much as others is the relationships that exist between the patient and their family. These family relationships may change drastically with the diagnosis of and grappling with a chronic illness, changing how family members perceive one another, how they act, and even how they communicate. All of these things depend upon the nature of the family, and the illness and produce different changes. However, through all different types of families and illnesses, communication in situations like these is essential to

understanding one another. According to Rosland (2009), several interviews and focus groups showed that family members lowered stress, and are central to patient success. In most instances, the family is the primary caregiver to someone with a mental or physical chronic illness, and the family relationship is important in the healing process due to proximity and the support received from family members. The diagnosis of a chronic illness has the potential to change the fabric of the family dynamic to help accommodate to the family member who is ill.

While it is clear that families often change to accommodate, it is unclear how family members communication changes since the diagnosis of a chronic illness, if change is present at all. Which begs the question: How are those with a chronic illness treated by their families since their diagnosis? Little research exists regarding the potential changes associated with the new found illness. Answering this question will help to make those in a family with one or more person who is chronically ill more aware of their own behavior, and will also shed light on the patients perception of their illness, and how that has been influenced by the family's communication about the illness.

This study is essential to the communication field, particularly health communication, because it adds to the ongoing conversation about how to understand people who are chronically ill and treat them in a world where in 2012, 117 million people had one or more chronic health issues (Ward et al., 2014). This study will explore both chronic physical and mental illness in the context of the family, focusing on marriage, parent-child relationships, and the use of narratives. This will help assess the problems that come with illness, and find out what happens to family communication when a family member gets diagnosed with a chronic illness.

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 effect 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 is 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, Schmalin 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 schemata 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 may 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 families 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 Schrod (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 Schrod (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.

Methodology

To answer the given research question, qualitative methods would be most appropriate to find an answer. Literature on related topics suggests that qualitative methods are most appropriate (Badr & Acitelli, 2005; Berg & Upchurch, 2007; Chadda, 2014; Freeman & Couchonnal, 2006; Hamond & Schrodt, 2012; Ott Anderson & Geist Martin, 2003; Richardson et al., 2013). An ethnographic study should be used because as Keyton (2011) states, it "...allows the researcher to observe and understand how communication is generated and responded to in a particular context" (p. 300). This would aim to aid researchers' in their quest to understand the relationship of participants who are ill in relation to their family members. This would involve a nonrandom sampling strategy to get the combination of characteristics needed for the study. Specifically,

purposive sampling, to be able to get close and personal enough with the participants to have them share details about their personal lives.

This purposive sample depends upon researchers knowing what is typical and atypical of the populations they are studying. A sampling frame of an exhaustive list of chronic physical and mental illnesses will be created, and participants will be selected based on whether or not they, or someone in their immediate family, has one of the listed illnesses. The sample will be selected by going to local support groups for individuals with both mental and physical illnesses. A wide array of illnesses will be selected, and age will be as varied as possible. Participants who are selected will be contacted via e-mail or phone call to ask them to participate in the study.

Once participants respond and confirm their consent to take part in the study, the researcher will begin to go into the family home and talk to family members. Since ethnography is similar to a participant observation study, the researcher needs to build a relationship with the families being studied, especially with those who have the mental or physical illness, if possible, to assess the changes that have occurred in behavior since the diagnosis. Once trust is established, the researcher can come in and begin recording the conversations about the diagnosis time, and how participants felt. This data will be compared to stories from before the diagnosis period, for both mental and physical illness affected families. A list of operationalized concepts such as: love, affirmation, avoidance, and fear, will be created to classify the nonverbal actions towards the ill family member. Collecting both verbal and nonverbal accounts can give a better representation of the true behaviors of family members' actions, both verbally and nonverbally towards the chronically ill family member. An analysis of the responses in relation to the stories around the diagnosis and before the diagnosis will be compared to the observed actions of the families in relation to the ill family member. Once this has been done for both chronic mental illness and chronic physical illness, the

results will be cross analyzed to compare and contrast the different verbal and nonverbal communication styles. Using ethnography will allow for an in depth and lengthy analysis of these different families, and the effects of mental illnesses and physical illnesses on family communication.

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