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PAIN SUPPORT FROM FAMILY AND PROVIDERS IN THE DIABETIC AMPUTEE: A  
LIVED EXPERIENCE

by

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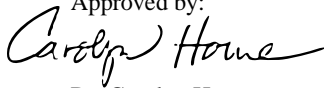
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### **Abstract**

Chronic pain after lower extremity amputation surgery has been reported in up to 80% of patients. Amputations, which are among the most debilitating chronic complication of diabetes have a variety of consequences including increased depression, inability to perform daily activities, and perceived inability to reintegrate into society. This study sought to understand the lived experience of chronic pain among those who have undergone a diabetes-related lower limb amputation. Researchers used a qualitative empirical phenomenology design. Private, semi-structured interviews were conducted on a purposive sample ( $N = 11$ ). Participants were primarily male (56%) with a mean age of 60.8 years ( $SD = \pm 15.4$ ). Interviews were transcribed verbatim. Transcribed interviews were read and re-read by each researcher separately and then compared to enhance credibility. Codes were identified for each participant separately and then across participants for common themes. Three major themes are highlighted by this research: 1) phantom pain is distinct from real amputation pain 2) sympathetic but not empathetic and 3) identification of a new normal. The first theme revealed that the amputee was hesitant to speak to others about their pain. Participants gravitated toward non-pharmacological treatments and discussed the need for alternatives. The second theme uncovered that family members had the desire to help but could not due to lack of understanding or knowing the experience of the amputee. Finally, identifying a new normal included the amputation being a choice and spirituality assisting with adjustment. This research has implications for how chronic neuropathic or phantom pain is managed among persons with amputations. More research is needed in identifying and teaching amputees alternative pain treatment beyond pharmacologic methods. This is especially important since amputees may be hesitant in discussing their pain with their healthcare provider and family if they feel the only solution is medication.

## **Introduction**

Diabetes is a disease that has ravaged much of the United States (US) population and has been extremely prevalent in the southeast (American Diabetes Association, 2016). Additionally, diabetes was the 7th leading cause of death in the US in 2010 (ADA, 2016). The American Diabetes Association (ADA) reports that 9.3% of the total US population have diagnosed diabetes (ADA, 2016). Diabetes in North Carolina is worse than the national average with 13.1% of the population diagnosed and an estimated 247,000 undiagnosed (ADA, 2014). Unlike an acute disease that is usually confined to one body system, diabetes is chronic and systemic, impacting many systems and often leading to debilitation (Diabetes North Carolina, n.d.). Complications from diabetes include chronic kidney problems, sleep apnea, strokes, heart attacks, and limb amputations (Diabetes North Carolina, n.d.).

Among the most debilitating chronic complication of diabetes is limb amputation. In 2010 alone, 73,000 non-traumatic lower-limb amputations were performed on adults older than 20 years as a result of diabetes (ADA, 2016). Approximately 54% of all amputations performed each year are due to a dysvascular cause with diabetes being the primary reason (Amputee Coalition, 2017). Amputations, are among the most debilitating chronic complication of diabetes and have a variety of consequences including increased likelihood of depression, inability to perform activities of daily living (ADL), differential treatment associated with chronic pain and perceived inability to reintegrate into society (Anderson et al., 2017; de Godoy, Braile, Buzatto, Longo & Fontes, 2002). Although prosthetics are becoming more effective at minimizing these complications they are still difficult to use, difficult to acquire, and often do not solve underlying psychological and pain problems (Hoffman, 2013). Thus, continued complications lead to a lifelong struggle to

maintain autonomy and function.

Diabetic individuals with an amputation often have daily chronic pain. It is estimated that approximately 80% of amputees end up with chronic pain (Hsu & Cohen, 2013). The pain is difficult to control and multidimensional. Neuropathic pain (phantom pain) can last a lifetime for the lower extremity amputee (Wooden, 2017). Unfortunately, control of neuropathic pain among amputees is unsatisfactory. Amputees report that their pain is not well controlled and many may stop seeking treatment due to its ineffectiveness (Kern, Busch, Muller, Kohl, & Birklein, 2012). In one study, 17 different pain management methods were mentioned by participants and only three had a greater than 50% success rate (Kern, et al., 2012).

Therefore, the purpose of this study was to understand the lived experience of pain among those who have undergone a diabetes-related lower limb amputation. More specifically, to understand the subjective experiences with chronic amputation pain and responses from family members, friends, and healthcare providers using a phenomenological approach.

## **Literature Review**

### **Search Process**

A review of the literature was conducted to determine the current state of research on pain perceptions and support among people with diabetes who have had a lower limb amputated. Searches were conducted in CINAHL, PubMed, and PsycInfo.

### **Major Findings**

**Living with diabetes.** The interactions between individuals with diabetes and their social support system have been examined in multiple studies. These studies demonstrated that those with chronic pain often feel disbelieved by close friends, family

members, and partners (Holloway, Sofaer-Bennett, & Walker, 2007; Monsivais, 2013; Rybarczyk, Nyenhuis, Nicholas, Cash, Kaiser, 1995; Toye & Barker, 2010). Diabetes often is stigmatized by society and thus individuals with diabetes often experience unpleasant representation from friends, family, and society related to their pain experience, their weight, and a perception of laziness (Della, Ashlock, & Basta, 2016; Horgan & MacLachlan, 2004; Kato et al., 2016). Members of society and family members often assume that the patient is in their current situation due to character failures. This can be so significant that individuals with diabetes report hesitation to tell others about their diagnosis because of a fear of others' perceptions (Della et al., 2016).

**Living with an amputation.** Lower-limb amputations decrease the ability to perform ADL because of physical limitations and chronic pain (Knezevic et al., 2015, Livingstone, Van De Mortel, & Taylor, 2011, Rybarczyk et al., 1995). Using the SF-36 instrument as a measure of quality of life, one study found that quality of life in amputees was unsatisfactory in six out of eight subscales (de Godoy et al., 2002) This is particularly important because performance of ADL is protective against depression (Anderson et al., 2017). Poor ADL functioning has been correlated with greater depressive symptoms and lower social support (Anderson et al., 2017). Social functioning is also impacted by amputation. Those with an amputation are often unable to participate in prior personal and professional activities (Knezevic et al, 2015), thus increasing differential treatment while simultaneously decreasing support (Hoffman, 2013). It is important to treat depression early and effectively due to the vicious cycle it can play in the social and daily active life of the individual.

**Impact of chronic pain and social support.** Disbelief of chronic pain can lead to

a feeling of lack of control. Studies demonstrate that those who experience chronic illnesses have a sense of helplessness and inability to get out of a metaphorical pit (Beattie, Campbell, & Vedhara, 2014; de Oliveria & Boemer, 2007; Knezevic et al., 2015; Livingstone et al., 2011). These feelings may lead to a decreased sense of self-worth and hesitation to participate in social activities (Kato et al., 2016). Furthermore, individuals with diabetes that are disbelieved or given differential treatment are more likely to have lower adherence to their treatment regimen (Kato et al, 2016). Thus, this helplessness, when combined with a lack of social support and decreased physical functioning diminishes quality of life and decreases the ability and desire to treat the original condition (de Godoy et al., 2002). Social support can have a valuable buffering effect against depressive symptoms and improve the ability to cope with an amputation (Anderson et al., 2017; Rybarczyk et al., 1995). Individuals with diabetes who have had an amputation must be treated using both social and physical approaches due to the complicated interaction between the physical and psychological aspects of their disease process (Livingstone, et al., 2011; Hoffman, 2013).

**Gap in the Literature.** While there is research that has examined experiences of people with chronic pain, diabetes, and amputation separately, there is a lack of research examining the experience of individuals with diabetes and chronic amputation pain. One study did examine the lived experience of diabetic amputees (Livingstone et al., 2011). Researchers created a grounded theory based on semi-structured interviews conducted with patients who had undergone a diabetes-related amputation. The three themes the authors discovered were: imposed powerlessness, adaptive functionality, and endurance. They focused on the patterns of feelings of insufficiency and lack of control as well as the positive

characteristics of seeking to find a way to make life manageable and never give up.

However, there is still very little research examining the lived experience of chronic pain management and interactions with others among those who have had a diabetes related amputation. This project seeks to expand on previous work by exploring these concepts.

## **Methodology**

### **Research Design**

A qualitative empirical phenomenology design was used with semi-structured questions. Empirical phenomenology is characterized by its' emphasis on structure and the commonality of experiences between multiple participants (Hein & Austin, 2001). Unlike hermeneutic phenomenology which focuses on creating rich descriptions by inferring and uncovering information, the empirical method focuses on the exact words of participants and "relies on factual data collected" (Hein & Austin, 2001, p. 8). The structural nature of empirical phenomenology necessitates a stepwise approach in which the researcher is first immersed in the data and then assigns codes to the participant's words so that they can be combined into common themes (Hein & Austin, 2001).

### **Participants and Recruitment**

This study was approved by the University Medical Institutional Review Board (UMCIRB). Following approval, a purposive sample was recruited at a local Orthotics and Prosthetics office. Inclusion criteria were: (1) 18 years or older (2) have a diagnosis of diabetes (3) had a lower extremity amputation because of complications from diabetes at least 6 months prior to the interview and (4) English speaking. Exclusion criteria were: (1) less than 18 years of age, (2) had an amputation for a reason unrelated to diabetes (3) no diagnosis of diabetes and (4) non-english speaking. Office staff at the Prosthetics and Orthotics office selected individuals

who fit the above inclusion criteria and approached them about participating in this study. Participants who agreed to participate were then met by the principal investigator (PI) who explained the study and obtained consent for participation. Semi-structured interviews were conducted in a private room within the office. Participants were asked one over-arching question related to interaction with family and healthcare providers and their pain. Probe and follow-up questions were asked as needed to clarify responses. Each interview was audio recorded and transcribed. Field notes were recorded by the PI after each interview.

### **Sample**

A total of 14 individuals were approached. Three refused to participate. The final sample ( $N = 11$ ), consisted of 56% male with a mean age 60.82 ( $SD = 15.5$ ). Saturation was reached with the eleventh interview and recruitment ended. Participants were African American ( $n = 5, 49.5\%$ ), Caucasian ( $n = 5, 49.5\%$ ), and Native American ( $n = 1, 1\%$ ). All participants had an amputation done greater than six months prior to the interview.

### **Transcription and Analysis**

Initial immersion of the data was completed with transcription into word documents by the PI. The transcripts were re-read several times for reflection on the data. After re-reading several times and cross checking the recording with the transcribed document, codes were created from the transcripts. All transcripts were reviewed for commonalities and structure. Investigators completed this process separately and then compared results to enhance the credibility of the analysis. NVivo was also used to organize and validate coding of the data.

## **Results**



Three themes emerged from the data: 1) Phantom pain is distinct from real amputation pain 2) Sympathetic but not empathetic and 3) Identification of a new normal. Each of these themes had two subthemes. For the first theme: a) no associations of phantom pain with overall pain experience and b) belief that phantom pain can not be helped. For the second theme: a) friends and family: supportive but unable to help and b) healthcare provider: Listened but no other alternatives for treatment. For the third theme: a) hope and spirituality and b) independence and amputation as a choice. See Table 1 for further support for themes from interviews.

### **Phantom pain is distinct from real amputation pain**

The first theme revealed that the amputee was hesitant to speak to others about their pain. Two common reasons emerged from the data. First, participants did not associate the phantom pain sensations with their overall pain experience. Second, participants had a belief that their phantom pain could not be helped and thus chose not to speak about it.

**No associations of phantom pain with overall pain experience.** When asked, “What interactions have you had with family members related to your pain?” participants responded that they do not have pain. However, when asked probe questions about phantom pain they described the pain in detail and discussed its’ significant impact on their daily lives. One participant stated that the pain is “nonexistent except phantom pain”. Another stated, “really, I didn’t have that much pain with the amputation” and later stated that “[phantom pain is] not something you can associate with something really bothering you.” The participants in this study, associated overall pain with surgical pain and disassociated phantom pain from the holistic pain experience.

**Belief that phantom pain can not be helped.** A second subtheme centered on the feeling of helplessness in resolving or improving phantom pain. This feeling led to not discussing the pain experience with others. When asked about talking to his healthcare provider about phantom pain, one participant said he does not mention it because “nothing they can do about it... all amputees experience it.” Another participant said, “nothing you can do... like hitting yourself in the elbow in the funny bone with a hammer... just has to work itself out.” Participants stated that there was nothing that could be done once it started. One participant described it as just “ride it out”, while another stated “take something and keep going”. Overall, participants believed that phantom pain was something they needed to endure and not discuss because it was inevitable.

### **Sympathetic but not empathetic**

A second major theme related to the interactions between participants and those around them. Participants discussed feeling supported by friends, family members, and healthcare providers but did not feel that their pain experience was understood. Because of this gap in understanding, participants were unable to fully share their experiences or receive full support. While healthcare providers were quick to prescribe medications, participants gravitated toward non-pharmacological treatments and discussed the need for additional alternatives.

**Friends and family: supportive but unable to help.** Participants expressed that friends and family were very supportive. At the same time, they expressed that they either did not know how to help or got tired of hearing them talk about their pain. One explained that, “if it wasn’t for my personal support group, I couldn’t have done it.” Although, she later stated that some people “don’t let me have a pity party.” Another stated that his significant other is a “tremendous help, don’t know where I’d be if it wasn’t for her”, followed by stating that he will not “sit there

and go into a discussion about it [phantom pain]” because “people don’t want to hear what is going on with you.” Others stated that their family members simply did not understand why they were in pain or what it felt like. As one participant explained, “they can’t say anything or help because they can’t wrap their heads around it.”

**Healthcare Provider: Listened but no other alternatives for treatment.** Participants expressed frustration at the lack of treatment options for phantom pain. When asked what they do to relieve the phantom pain many stated that they could not do anything. Others mentioned that they pat or rub the residual limb, which helps to some degree. Another participant mentioned not wanting to manage the phantom pain primarily through medicine. One participant stated that he does not talk to his doctors about his phantom pain because “they prescribe something for me and I tell them right quick, I don’t want to take that.” Another spoke of a primary care provider who continually wants her to take narcotics despite her insistence that she wants to manage her pain through alternative methods. She stated that her healthcare provider believes “I’m crazy because I don’t want to be on narcotics.” Many participants stated that the side effects of traditional pain medications were worse than the pain itself and thus did not want to continue to take these medicines.

### **Identification of a new normal**

The final theme identified was the participants finding different ways to establish a new normal. Many discussed how their religious beliefs or hopeful outlook on life helped them to cope with this significant life change. Making a choice to have the limb amputated was also an important factor in giving participants a certain level of control which allowed them to find their new normal.

**Hope and spirituality.** Participants expressed that their hopeful outlook on life and faith helped them cope with their amputation and the pain they experience daily. Many expressed that they were “thankful” and “blessed.” One said that if it wasn’t for “the almighty God” he would be “down in the dumps.” Another stated that she keeps going because there is “always somebody worse off than you.” The overall attitude of the participants was expressed by one female participant who said she does not get down about it because she knows you just “do what you can at the moment to do things right.”

**Independence and amputation as a choice.** Participants recognized that when they chose to have the amputation, as opposed to the other options, it allowed for a positive recovery and return to a new normal since the decision was controlled by them. Two participants stated that deciding to get their leg amputated was the best decision they ever made. One said that it has allowed her to “get back to normal instead of letting others do stuff for me.” Another explained that she is constantly trying to get to the point of doing what she did before. Still another explained that she feels her pain is less severe than a friend who had a traumatic amputation because she made the choice to get it amputated and therefore had more time to prepare. Overall, the ability to be independent both in the decision to have an amputation and the recovery process seems to be significant.

## **Discussion**

The results of this study confirm previous research which had identified phantom pain one of the most significant consequences of a lower limb amputation and the significant effect which it has on daily life (Anderson et al., 2017; de Godoy et al., 2002) This is important because this interference with basic ADL can alter a person’s life, leaving them unable to

participate in basic social and functional activities and diminishing their quality of life (de Godoy et al., 2002).

### **Phantom pain as a part of the holistic, treatable pain experience**

Phantom pain has been well documented as a complication of lower limb amputation in many patients (Hsu & Cohen, 2013). This complication is one that can lead to significant consequences both physically and socially. Previous literature has not significantly addressed the differences between surgical pain and phantom pain for the lower limb amputee. While both concepts have been studied, most previous literature has focused exclusively on one or the other and thus has not compared the patient view of both. This study suggests that those who have had a lower limb amputated because of a diabetes-related complication may view phantom pain as something that is inevitable and separate from their overall pain experience.

de Godoy et al. (2002), discussed the concept of helplessness, specifically stating that lack of social support and decreased physical functioning can impact treatment long term. The findings from this study add to that by suggesting that a perception of phantom pain as an untreatable complication of amputation may decrease desire to seek treatment. We know that there is a complex psychological aspect to treatment of individuals with diabetes and an amputation (Livingstone et al. 2011; Hoffman, 2013). This study reveals that phantom pain is not currently viewed as a manageable or treatable complication and, thus, identifies a need for further patient education in this regard.

### **Social support and management of phantom pain**

Many previous studies have focused on the importance of positive social support for the individual with diabetes, chronic pain, or a lower limb amputation (de Godoy et al., 2002; Della

et al., 2016; Hoffman, 2013; Horgan & MacLachlan, 2004; Kato et al., 2016). While much focus has been on the perception of stigma and differential treatment, this study had greater focus on ability to help. While the social support was present and others desired to help, there was a lack of true support because of failure to follow through. While there are many explanations for this, participants in this study identified the reason as a lack of understanding of the patient experience. In response to this, individuals who have had an amputation may close off and stop discussing their pain with others. The inability of their social support system to provide meaningful help may lead them to feel like a burden or that others do not want to hear about their experiences.

Current pain management methods for phantom pain are often insufficient to improve quality of life in the individual who has had a lower limb amputation (Kern et al., 2012). Because chronic pain is one of the primary factors which decreases quality of life and social functioning in the individual with an amputation more efforts are needed to address this issue (Knezevic et al., 2015, Livingstone et al., 2011, Rybarczyk et al., 1995). While much research is being conducted regarding alternatives to medication for the management of chronic phantom pain, this study indicates that there may be a gap in getting these alternatives to the patient. In addition, there seemed to be a lack of education on alternatives for pain management which meant that participants were unaware that they had the option of trying other approaches to control their pain. Furthermore, traditional pain medications have a variety of unpleasant side effects, many individuals may decide not to take them. There is a need for alternative and complementary treatments for those who choose not to take pain medications or desire an additional treatment to manage phantom pain.

### **New beginnings after an amputation**

Anderson et al. (2017) identified lower limb amputation as a significant life event which can lead to depression and anxiety in those who are unable to find a new normal. This research confirms these findings and identifies ways some individuals may cope with the dramatic life changes of a lower limb amputation. In nearly all cases, participants found hope despite very difficult circumstances and expressed that they felt they still had it better than others. Spirituality played a role in this transition which has not been significantly studied previously in this population. For many participants, there appeared to be a better ability to cope with pain following an amputation because of an optimistic and hopeful perspective on life and the situation.

Livingstone et al. (2011) found that endurance and adaptation were important factors in recovery for the individual with a diabetes related lower limb amputation. This research confirms those themes and builds on them by identifying independence as a potential factor that differentiates diabetes related amputations from traumatic amputations. The ability to choose an amputation over other treatment options appears to have been a significant psychological factor for participants in this study as it allowed them to feel more in control of their recovery process. Returning to a new normal and finding alternatives to the activities that are physically impossible after a lower limb amputation was confirmed in this research to be a significant challenge.

### **Summary of discussion**

This research contributes to the growing knowledge of the lived experience of individuals who have undergone a lower limb amputation related to diabetes. Following a similar methodology to Livingstone et al. (2011), it seeks to continue to understand the perspectives of these individuals. There is increasing need for education and treatment about the phantom pain experience both for patients and their social support system. There is also increasing need for

alternative and complementary therapies for these individuals. Having a lower limb amputated is a very significant life event and requires great resiliency to return to a new state of normal life. This study confirms previous research which identifies hope and independence as important factors in making this transition.

### **Implications for Practice**

This research highlights the need for better education of patients about phantom pain. While participants understood what phantom pain was, they seemed to have misconceptions about whether it was considered a real part of their pain experience. Better education should be provided both at discharge, through recovery and rehabilitation related to phantom pain being part of the holistic pain experience and, thus, should be reported and treated. Individuals with amputations should know that phantom pain is real pain and can be treated, thus they should communicate with their healthcare team all experienced pain through the recovery process.

Further education is needed to help patients cope with the pain through alternative means. Patients who have had an amputation may refuse to discuss pain with their family or healthcare provider if they feel that there is no solution or the only treatment is medications. Alternative methods of pain control should continue to be studied and these options should be presented to patients who choose not to take pain medications or need additional pain control. In addition, healthcare providers should ensure that they are communicating to their patients that they are willing to work with them in developing a satisfactory pain management plan, inclusive of medication, alternative therapies, and complementary therapies.

### **Conclusion**



As the number of people impacted by diabetes and its' comorbid sequela, such as amputations, grow, there is a need for understanding of how to treat chronic neuropathic pain. Although much research has been conducted about diabetes, amputations, and social support, there is less research seeking to understand the lived experience of these patients. Studies like this may provide a richer understanding of the lived experience of pain and provide implications for how the healthcare team treats and responds to persons who have undergone a lower limb amputation.

**Table 1: Participant statements for themes and subthemes**

**Theme 1: Phantom pain is distinct from real amputation pain**

- No associations of phantom pain with overall pain experience
  - “Pain nonexistent except phantom pain”
  - “When they cut it off they cut the pain off too”
  - “Really didn’t hurt except the phantom pain”
  - “Didn’t have a lot of pain”
  - “I have a high pain tolerance”
  - “I didn’t have real pain, I had infection all the time”
  - “don’t have none [pain]”
  - “[phantom pain] not something you can associate with something really bothering you”
  - “I didn’t have no pain ... [phantom pain] feels sharp, like some pinching; especially in the toes”
- Belief that phantom pain can’t be helped
  - “I take something and keep going”
  - “[I have] high pain tolerance”
  - “We will endure a lot...have to keep faith... [I] still have feeling... [I’m] still a man.... still rely on my strength”
  - “Nothing you can do [about phantom pain]”
  - “Like hitting yourself in elbow in funny bone with hammer; just has to work itself out.”
  - “Don’t do nothing, just ride it out”

**Theme 2: Sympathetic but not empathetic**

- Friends and family: supportive but unable to help
  - “[husband] very supportive...I keep pretty much to myself”
  - “[wife tells me] bear with it”
  - “[others tell me] sorry buddy, can’t do nothing about it”
  - “They don’t let me have a pity party”
  - “They’re trying to take care best they know how but I really don’t care”
  - “I keep to myself...why lay it on someone else when they can’t do nothing?”
  - “I don’t sit there and go into a discussion about it; people don’t want to hear what’s going on with you”
  - “They understood; nothing they could do but they sympathized; they can’t say anything or help because they can’t wrap their heads around it; can’t tell how to correct if never been in the situation”

- Healthcare Provider: Listened but no other alternatives for treatment
- “Some thought I was “putting on”...I was grunting and flinching, they thought I was messing, “but I won’t”...they found out that’s the way it was...couldn’t tell me anything”
- “they prescribe something for me and I tell them right quick, I don’t want to take that”
- “[healthcare provider believes] I’m crazy because I don’t want to be on narcotics”
- “Don’t really talk about pain [with HCP]”
- “Doesn’t hurt that that bad to take medicine”
- “Don’t mention anything [about phantom pain to HCP] ... nothing they can do about it... all amputees experience it”

### **Theme 3: Identification of a new normal**

- Hope and Spirituality
  - “I’m thankful” “I’m blessed, I’m alive”
  - “I thank God I’m still here”
  - “Do what you can at the moment to do things right”
  - “Don’t let it depress you”
  - “The almighty God, other than that I think I’d be down in the dumps”
  - “I can make jokes... fortunate to walk, some can’t”
  - “Keep going... there is always somebody worse off than you”
  - “I cry out to Jehovah so I’m good”
  - “We’ve been fortunate”
- Independence and amputation as a choice
  - “Accept it, it’s happened...go on and live”
  - “Don’t let it worry you”
  - “Kinda a hard decision... I hated it so bad but I told him to take it off”
  - “[you have] good days and bad days regardless of if you have an amputation”
  - “I said “no more. Take it ...best thing I ever did”
  - “Trying to get to the point of doing what I did before...have to get over fear of doing new things”
  - “My decision to have amputation... could have saved my leg but would have had more problems”
  - It was my choice... best choice...I’m free to do what I want...get back to normal instead of letting others do stuff for me”

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