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IDENTITY DEVELOPMENT AND RECONSTRUCTION AMONG
CAREGIVERS

by

MACKENZIE KELLY

A thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Psychology
in the College of Sciences
and in the Burnett Honors College
at the University of Central Florida
Orlando, Florida

Summer Term, 2021

Thesis Chair: Steven L. Berman, Ph.D.

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Abstract

The goal of the current study was to assess possible changes in identity upon becoming a caregiver to another adult. Caregivers of adults (N= 9) completed an online, anonymous survey. A significant change in Identity Commitment was found from pre to post caregiving. Three participants went from a Foreclosed Identity Status pre caregiving to a Diffused Identity Status post caregiving, and one participant went from an Achieved Identity Status to a Moratorium Identity Status. However, no consistent trends in responses were found among these participants, suggesting further research with a larger sample size is needed.

Dedications

For my parents, who always stood by me especially when things got tough. Thank you for always being a shoulder to lean on and providing advice when I was stressed or overwhelmed. Without your support, I would not have achieved what I have in my college career. Thank you for cheering me on and helping me realize what I am most passionate about.

For my friend Jonathon and fellow researcher, who I probably asked a million questions. You were always there for me and willing to provide any resources you could. Thank you for all your help and motivation!

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INTRODUCTION

The effect of traumatic brain injuries (TBI) and the symptoms of TBI have been widely investigated. Rehabilitation and post-injury processes have been the primary focus of TBI research. The literature in previous research focuses on the effects of TBI on the process of identity change and re-development of self in people who have personally experienced TBI. TBI falls under the category of acquired brain injuries (ABI). ABI is defined as a brain injury that occurs after birth and can either be traumatic or non-traumatic (congenital versus degenerative; Palmisano et al., 2020). For the purposes of this study, we attempted to focus on stroke ABIs and people who, as a result, acquired aphasia. Aphasia is often a result of a stroke which is a TBI, therefore we might expect to see similar relationships and themes with previous research on the effects of TBI and a person's identity. Aphasia is a language disorder, where the injury has impacted a person's ability to communicate. Consequentially, acquired brain injuries can have an impact on the person with aphasia's relationships with family and spouses (Hutchinson, 1996). The extent of the impact on these relationships might lead to identity changes in the family members and caregivers of a person with aphasia. There has been past qualitative research on the changes and point of view of family members and caregivers of those with TBI. However, as Whiffin and colleagues (2019) noted, the caregivers of people with TBI are often considered witnesses to a patient's journey, rather than those who are also on a new journey. The changes that caregivers experience in their own lives due to caring for a family member or other person in their life with aphasia could lead to a possible change in self-concept. According to Ownsworth (2014), this possible change depends on the impact from the brain injury, the quality of relationships before the injury, and the amicability of the family members. Research done by de

Goumoëns and colleagues (2018) found that relatives of ABI survivors with chronic injury reported dissatisfaction with life and increased stress, which in turn impacted their emotional and physical health. They also reported poor family function which can impact all members of a family in different ways: feelings of burden, financial struggles, and readjustments in roles and responsibilities. Dillahunt-Aspillaga and colleagues (2013) define caregivers as people who provide care services to individuals that cannot take care of themselves and are not being paid to do so. For the purposes of this study, we use the general term of caregiver, although we expected most participants to be family members of the person with aphasia.

While social identity may be a significant part of one's identity, it is important to note that the focus of the present study is on the change of personal identity. According to Tajfel and Turner (2004), there is a distinction between the two identities. Personal identity deals with interpersonal situations and "personological variables" (Brown, 2000). In contrast, social identity is defined by group situations and can impart a different effect on personal identity or self-concept compared to personal identity. More specifically, in Brown's review of the Social Identity Theory (2000), a positive social identity can raise self-esteem, and in turn, people aim to keep this positive self-view of their social identity. Brown emphasizes the importance of community for both survivors of stroke and their family members. Past literature points to the social aspects of identity change, which can be studied in terms of Erik Erikson's psychosocial stages of development (1950, 1968).

Self-Concept and the Influence on Caregivers

Self-concept can be defined as overarching thoughts and emotions that a person feels about themselves (Beadle et al., 2016). The umbrella term of self-identity is more specifically

known as our own characteristics as we perceive them, which are always changing due to events in our life (Beadle et al., 2016). Berman and colleagues (2020) define identity as the collection of roles, goals, values, and beliefs about the world, which people adopt as a way of giving their lives a sense of direction and purpose.

Beadle and colleagues (2016) suggest four major life events that can cause a change in identity: (1) neurological damage, such as TBI or ABI, (2) major life transitions (e.g. becoming a parent, or suddenly having to take care of a child/spouse/parent with TBI), (3) social feedback from peers, and (4) psychotherapy or other interventions dealing with self-schema. It is already known that chronic illness can alter self-concept (Beadle et al., 2016), but the question in play is if this transition and emotional adjustment of the caregiver would also invoke identity change. The emotional changes that a caregiver of a person with aphasia experiences can be explained by the Self-Discrepancy Theory. According to Higgins (1995), self-discrepancy is a misalignment between the actual self (self-concept) and the ideal self (the person one wants to become). This misalignment creates a vulnerability to depression (Higgins, 1995). Higgins' theory further explains that a discrepancy between the actual self and ought self (self that is related to a person's responsibilities and roles) leads to a higher chance of anxiety. The event of changing a person's role (e.g. becoming a full-time caregiver) falls under the narrative of biographical disruption, explained by Whiffin and colleagues (2019) as one of four narratives used by family members of the patient to understand identity change. Biographical disruption is the process by which people reassess their current and future selves (Bury, 1982). Biographical disruption is entirely possible with a sudden responsibility as caregiver, which alters their current role and their potential future. This in turn could lead to possible diagnosis of anxiety or depression as explained by the Self-Discrepancy Theory.

Further literature concludes that it is not only trauma from brain injury that can disrupt the lives of caregivers and their social roles. According to Monk and colleagues (2017), Post-Traumatic Stress Disorder (PTSD) in veterans caused by an extended exposure to violence can lead family members and those in romantic relationships to experience secondary stress. This stress can come from a variety of factors including the illness itself, and higher rates of depression and substance abuse, all of which can have a negative impact on family members and those caring for the patient (Monk et al., 2017). There are other factors that can lead to emotional distress in caregivers and possible identity change. For example, the effects of aphasia occurring in a spouse can lead to a transition to the care-taker role and financial struggles depending on whose career has been impacted. According to Sabella & Suchan (2019), families may experience hardships when all their financial resources and time shift towards the medical treatment of a person with TBI. This could cause the family member who is now taking on the caretaker role to alter or lose their job completely. This loss of career or domain of their self-identity could lead to possible identity change (Waterman, 2020). Although the personal experiences of families following TBI have been recorded, its effects on the family's transformation and adaptation to function need further study (Sabella & Suchan, 2019). This alteration in daily life impacts the family as a whole and could cause enough psychological distress for identity change in the spouse/head of the family.

Importance of Community and Social Support

According to Ownsworth (2014), social loss (which could mean the loss of a relationship, job, or other social membership), can be one of the most painful human experiences due to the devaluation of the self and low self-esteem. Therefore, it is what we do and what we are involved

in that gives meaning to our identity. Our self-concept is largely up to us to create, and this meaning comes from our social interactions and group memberships (Ownsworth, 2014). This is in consonance with Beadle's (2016) third major life event: social feedback from peers. Positive social memberships boost our self-esteem and lead us to see a positive self-concept of ourselves. This positive social identity is one that people strive to achieve or maintain (Brown, 2000). Community memberships can include culture (Gracey et al., 2008), religious communities, political community, LGBTQ community, women's community, neighborhood, high school/college, place of employment, family, and friends (Stewart, 2013). There have been accounts from qualitative interviews that these places of community help by providing support from all areas of life, such as social and emotional relationships, and spiritual or religious support (Stewart, 2013). This can be applied to the caregivers as well, as their social memberships are likely to change with their new social role. The most evident social membership to change is the family dynamic. When a family member has taken on the role of caregiver, emotional supporter, or financial supporter, it can completely change their course of life. This can place significant strain and pressure on relationships (Gervasio & Kreutzer, 1997; Marsh, et al., 2002; Ownsworth, 2014). Psychotherapy can also be thought of as a community, which in many cases is used to improve social relationships, including marriage (Stewart, 2013).

Waterman's Taxonomy of Trauma Effects on Identity

According to Ownsworth (2014), the timing of TBI (childhood versus adulthood) can alter the outcome of the brain injury. Since there are different neural pathways in a child than in an adult, a stroke could cause certain cognitive or physical/motor skills to change. According to Waterman (2020) the timing of various traumas can also impact the effects on identity formation.

If the stroke occurs during childhood, then the child has time to recover from the trauma before critical identity formation occurs in adolescence. This effect can be summarized in Waterman's definition of identity resilience, the first of nine developmental impacts of trauma on identity in his taxonomy. The other impacts include Identity Affirmation, Identity Delay, Identity Threat, Identity Loss, Identity Alteration, Identity Replacement, Trauma-Shaped Identity, and Trauma-Centered Identity. Identity Resilience is a person's ability to maintain their identity and social commitments after experiencing trauma (Waterman, 2020), which is one of the many identity changes that can occur when the traumatic event occurs during or after adolescence. In Erikson's developmental stages, identity is seen as an adolescent issue that is usually resolved by the time a person reaches young adulthood. However, a trauma can disrupt previously established identities, such that the roles, goals, and values that previously formed one's identity may no longer seem viable under new circumstances. This is often the case with a stroke, in that the person may no longer maintain the same career, the role of being a caregiver might become reversed, and one might start to question assumptions about the world being a just place. Thus, the destabilization of identity in older adults will be the focus of this research project.

Waterman's taxonomy classifies and organizes the various impacts of traumatic injury on identity functioning into 9 possibilities. These effects are best measured in specific domains such as religious beliefs and other identity concerns (Waterman, 2020). The first of the taxonomy sequence is Identity Resilience as previously mentioned. This refers to people's ability to maintain their identity despite the changes caused by the traumatic injury. The second developmental impact of Waterman's taxonomy is Identity Affirmation. Identity Affirmation differs from Identity Resilience in that some traumas can actually reinforce and strengthen already present identity aspects such as beliefs, social roles, behaviors and goals. Waterman

provides examples of how a person may deepen their commitment to a chosen career field or religious community that the individual was involved in before the trauma. This closely ties with the work of Ownsworth (2014) and its focus on the importance of a person's relationship to their community. Identity Affirmation may be lost if there is a severe separation from community due to the stroke. This also aligns with Erikson's concept of Ego Identity (1950), more specifically how we look for continuity in our social roles and relationships with others in order to find meaning.

The separation from community that tends to occur following a traumatic injury may be associated with the inability to be involved in identity-related activities (such as career or religion). Waterman defines this time of distress as Identity Delay. Identity Delay is most likely to occur during the most prominent times of identity development, which is adolescence and emerging adulthood according to Erikson (1968) but may also occur during adulthood. When a trauma occurs, the adolescent/young adult might focus on the problem at hand, rather than identity-forming events or communities. For an adult, this time can also allow opportunities for new commitments, hobbies, etc., leading to a possible identity change.

Waterman's Identity Threat and Identity Loss are connected in that Identity Threat may or may not lead to Identity Loss. Identity Threat is the process in which those who underwent trauma begin to question their identity. The impact of such a severe injury can cause elements of our identity, such as belief in a god or gods, to be modified, lost, or replaced. The results of what happens to these elements of our identity encompasses Waterman's Identity Alteration, Identity Loss, and Identity Replacement. Identity Loss, then, is the aftermath of an individual not being able to successfully complete or maintain an identity forming social role, behavior, or personal goal. For example, starting and supporting a family may have been a goal of an individual but is

no longer feasible after the traumatic event. Giving up this goal, or Identity Loss, is only one possible way of coping for the person with aphasia or caregiver. As mentioned, the caregiver may also turn to Identity Alteration or Identity Replacement. Waterman's specific example of not being able to start a family then followed by Identity Loss can be related to Erikson's seventh stage of development: Generativity vs. Stagnation. According to Erikson (1950), this stage often takes place during middle adulthood, and in order to fulfill our identity we are meant to become productive individuals, give back to society (often by raising our children), and becoming connected to society. Identity Loss can compare to Erikson's stagnation, or the feeling of being disconnected.

Identity Alteration and Identity Replacement are key concepts in avoiding stagnation. With Identity Alteration, an individual can modify their goals and adapt the skills they already possess to that new goal. Although it is not the original goal or position they had envisioned, they are still contributing to society and reforming their identity. On the contrary, caregivers may choose Identity Replacement. Similar to Identity Alteration, these individuals are still finding commitments, goals, and beliefs to re-define their identity. The major difference, however, is that in Replacement, these identifying elements show no connections to pre-injury identity, whereas in Alteration, the connections can still be seen (Waterman, 2020).

According to Waterman, it is also important to note that the possible identity that comes from Identity Replacement does not relate to the traumatic event the individual experienced in addition to pre-injury identity. Instead, Waterman adds an alternative possibility to his taxonomy to account for such an occurrence called Trauma-Shaped Identity. This occurs when the new identity is directly related to the event that caused a change of identity. This new identity forming commitment could be a political cause or social outreach to support those who suffered

the same sort of event. There is a final, severe possibility named Trauma-Centered Identity (Waterman, 2020). In this case, the person's identity becomes centered wholly around the traumatic event, rather than just one aspect of their identity changing.

Each effect has been described as an impact on a specific identity domain, such as career and religion. These domains of caregivers can be affected, especially with the onset of the caregiver role or the personal trauma from witnessing the injury of the person who experienced the stroke. But to what extent do these changes impact actual personal identity, (i.e., cognitive processes and behaviors)? In addition, the specific impacts to Erikson's domains and stages of development such as Identity, Intimacy, and Generativity may be applied.

Rationale

The process of identity change after a traumatic event is very subjective, and past research has proven this with qualitative data concluded from interviews (Whiffin et al., 2019; Beadle et al., 2016; Gill et al., 2011; Cloute et al., 2008, Kroger, 2003). The outcomes of a brain injury/stroke are unique to each patient and their caregivers due to a combination of pre-injury, injury-related factors and post-injury processes/rehabilitation (Ownsworth, 2014). The outcomes of identity are unique to each person who has experienced TBI as expressed in Waterman's taxonomy. The experience of a stroke in a close family member is likely to have an effect on the outcome of the caregiver's identity, but also on their sense of community and social memberships during and after rehabilitation. These chronic and extreme stressors likely affect all caregivers, due to the long-term effects of a brain injury and their lasting ramifications for the caregivers who often need to change their roles, values, goals, and beliefs, in order to accommodate the new situation with a completely or partially incapacitated family member

(Ownsworth, 2014). This study aimed to focus primarily on the identity change of adult-aged (18+) caregivers of stroke survivors with aphasia. It was hypothesized that:

1. Changes from pre to post becoming a caregiver would be positively correlated with time since becoming a caregiver.
2. Identity variables would be significantly predicted by the degree of disruption that the injury has caused

METHOD

Participants

Participants included a sample of 9 adult-aged caregivers of individuals with an acquired expressive language disorder or other disorder ($M_{\text{age}} = 59.00$, $SD = 8.72$). The participants were recruited from several aphasia and TBI related groups, including the Feeling Aphasia Support Group, the Friday Only Club, the UCF Adaptive Community which consists of the Aphasia Choir and Aphasia Family, and online social media support groups for all caregivers. All 9 participants were female. The education distribution included 3 with a bachelor's degree, 2 with a graduate degree (MS or MA), 2 with an associate's degree, and 1 who completed some high school. The majority of the participants were White ($n = 7$), with 1 being Hispanic or Latino and 1 being a mixed ethnicity or other. The majority of the participants indicated being caregivers to their spouses ($n = 5$), with 2 being a caregiver to their partner, 1 person was a caregiver to a parent, and 1 was a caregiver to a sibling. Most (77.8%) of the caregivers reported living with the person to whom they gave care. Participant demographics are shown in Table 1.

Measures

A demographic questionnaire will ask the participant to report their age, gender, education, ethnicity, marital status, and relationship to the person with aphasia. Participants will also be asked about changes in identity variables and how these altered variables have affected them. These variables include career or financial difficulty, changes in philosophy, religious views and values, leisure/community activities, and changes in physical and mental health.

The Identity Distress Survey (IDS; Berman et al., 2004) focuses on unresolved identity issues and how they affect the participant's current distress. The 10-item survey uses a five-point

scale, with 1 meaning “Not at All” and 5 meaning “Very Severely” to rate the participants’ current struggles with distress, upset mood, and worrying in seven different domains of identity: long-term goals, career choice, friendships, sexual orientation, religion, values and beliefs, and group commitments. The IDS also asks to what extent distressing symptoms are impacting the daily functioning of the participants. Past research using this scale has shown an internal consistency of .84 with test-retest reliability of .82 (Berman et al., 2004). The current study found the measure to be reliable with a Cronbach’s Alpha of .90.

The Meaning in Life Questionnaire (MLQ; Steger, 2006) is a 10-item survey focusing on the active search of fulfillment in one’s life. Participants are asked to indicate how well they relate to each question and then assign a number from a Likert-type scale of 1-7, where 1 indicates the participant believes the prompt is “Absolutely Untrue,” and 7 indicates they feel the prompt is “Absolutely True.” The MLQ has two subscales, *Presence of meaning* and *Search for meaning* which both have a good reported internal consistency of .86 and .88, respectively. (Steger et al., 2006). The current study did not find the measure to be reliable with a Cronbach’s Alpha of .05.

The Dimensions of Identity Development Scale (DIDS; Luyckx et al., 2008) is composed of 25 items that measure five different identity development processes. These processes include Exploration in Breadth, Commitment Making, Ruminative Exploration, Exploration in Depth, and Identification with Commitments. The DIDS uses a 5-point Likert scale for questions in each dimension with 1 meaning “Strongly disagree” and 5 meaning “Strongly agree.” For our purposes, we will only use the Commitment Making Scale (questions 1-5) and the Exploration in Breadth Scale (questions 6-10). According to a study done by Luyckx and colleagues (2008), the Commitment Making subscale had an internal consistency reliability of .86 and the

Exploration in Breath subscale was .81. The current study found the measure to be reliable with a Cronbach's Alpha of .97 for commitment making and .93 for exploration.

The Trauma Impacts on Identity Functioning Scales (TIIFS; Waterman, 2020) is a mixed survey of multiple choice and Likert scale questions. This scale measures possible changes in development by asking retrospective questions, and noting if any changes to beliefs, goals, or values have changed since the time period in question. These changes relate to Waterman's taxonomy as previously discussed. This is a newly developed scale that has not yet been subjected to statistical analyses therefore internal consistency reliability will be determined with this study. The current study found the measure to be reliable with a Cronbach's Alpha of .95 for the impact of identity domains and .77 for identity functioning.

Procedure

After receiving approval from the University of Central Florida's Institutional Review Board (IRB), people who experienced a family member or other person's journey with traumatic brain injury will be recruited for this study. Participants will be asked to complete the anonymous survey in regards to how they felt about themselves before the person with aphasia's stroke and then complete the survey again after reflecting on their own experiences after the injury. Surveys will be completed online via Qualtrics in a location of the participant's choosing.

RESULTS

Preliminary Analyses

The means, and standard deviations for all study measures are shown in Table 1. The only statistically significant change on the measures from pre to post was in Identity Commitment which declined ($t_{(6)} = 2.71, p = .035$). A correlation matrix for all study variables is shown in Table 2. The only statistically significant correlation was Identity salience and identity functioning ($r = .90, p = .015$). This suggests that identity functioning is highly related to the degree of importance one attaches to their identity, but it does not indicate whether or not one is the direct cause of the other. Age did not significantly correlate with any of the study variables. Neither ethnic nor gender differences could not be analyzed. All participants were females.

Main Analyses

To test hypothesis one (Changes from pre to post becoming a caregiver would be positively correlated with time since becoming a caregiver) a bivariate correlation matrix was constructed between amount of time since becoming a caregiver and pre to post change scores for Identity Functioning, Identity Commitment, Identity Exploration, Identity Distress, and Meaning in Life. Time since becoming a caregiver was not significantly correlated with Identity Functioning ($r = .19, p = .668$), Identity Commitment ($r = .20, p = .674$), Identity Exploration ($r = .52, p = .230$), Identity Distress ($r = .43, p = .392$), or Meaning in Life ($r = .07, p = .901$).

To test hypothesis two (Identity variables would be significantly predicted by the degree of disruption that the injury has caused) multiple stepwise regression analyses were conducted. Gender and Age were entered on Step 1 with degree of disruption score entered on Step 2. Pre to post change scores for each of the identity variables (Identity Functioning, Identity Commitment,

Identity Exploration, Identity Distress, and Meaning in Life) served as the dependent measure in each separate regression analysis. The resulting equations were not significant for Identity Functioning ($F_{(2, 4)} = 0.68$; $R^2 = .25$; Adjusted $R^2 = -.12$; $p = .559$), Identity Commitment ($F_{(2, 4)} = 0.96$; $R^2 = .32$; Adjusted $R^2 = -.02$; $p = .458$), Identity Exploration ($F_{(2, 4)} = 0.89$; $R^2 = .31$; Adjusted $R^2 = -.04$; $p = .480$), Identity Distress ($F_{(2, 3)} = 0.55$; $R^2 = .27$; Adjusted $R^2 = -.22$; $p = .625$), or Meaning in Life ($F_{(2, 3)} = 0.14$; $R^2 = .09$; Adjusted $R^2 = -.52$; $p = .873$).

Descriptive Analyses

As seen in Table 3, three participants stayed within the same identity status, three participants went from a Foreclosed Identity Status to Diffusion, and one participant went from an Achieved Identity Status to Moratorium. Table 4 reports change scores by participant on each measure. The same participants who experienced a change in identity status all had a decrease in Identity Commitment from pre to post. One other participant also experienced a decrease in Identity Commitment, but apparently the pre caregiving identity was sufficiently strong that this drop did not result in a change of Identity Status. One other showed no change in Identity Commitment and one had a very slight increase. Most notable is participant 3 who appeared to have experienced post-traumatic growth with improvements in identity functioning, meaning in life, identity exploration, identity commitment, and a decrease in identity distress. For each identity domain, participants were asked if there was change from pre to post caregiving. If they answered yes, they were then asked to what degree the change was disruptive to their life and to what degree they saw things as better or worse as a result of the changes. These scores are listed by participants in Table 5. The identity domain most affected was Hobbies/Leisure Activities/Community Involvement, with all participants reporting disruption. For 3 it got better,

for 2 it stayed the same, and for 4 it got worse. The next two most affected domains were Physical Health and Relationships with Friends, both with 8 out of 9 participants reporting disruption. For Relationship with Friends, 2 saw it as getting better, 3 reported it to be the same, and 3 said it was worse. For Physical Health, 3 said it was better, 3 said the same, and 3 said worse.

DISCUSSION

In this study, identity salience and identity functioning were correlated, but it is not clear whether feeling that your identity is important to you leads it to function better, or whether better functioning leads to feelings of greater importance, or for that matter, whether both are reflective of healthy identity development but neither having a direct effect on the other. Longitudinal studies might yield better evidence in regard to which aspects of identity precede others. Age did not correlate with any identity variables, which is consistent with Erikson's theory that identity is relatively stable after adolescence/young adulthood. Changes in identity in older adulthood are usually due to idiosyncratic outside influences (trauma, family changes, economic changes, etc.) rather than developmental change.

Gender differences could not be explored as all participants were female. Further research is warranted in order to more deeply explore all study variables, especially the family dynamic which has been aforementioned as the most evident social membership to change after becoming a caregiver (Stewart, 2013). Variation in gender of the participants is needed in order to fully understand the strain and pressure that becoming a caregiver can place on relationships within the family. There were not much ethnic variation among the few participants, therefore we cannot ascertain the degree to which it might impact the experience of becoming a caregiver. Changes in religion, politics, and philosophy of life was only seen in two participants. Further research with a larger more diverse sample is necessary to conduct gender and ethnic/racial analyses of the data.

Career and romantic relationships were two identity domains that were highly impacted by becoming a caregiver. With a larger sample, further investigation could be conducted into the impacts of a change in career and how this affects caregivers economically as suggested by

Sabella & Suchan (2019), as well as investigating the changes in romantic relationships in regard to Erikson's Ego Identity (1950) and the need to find meaning in our social roles.

Four participants witnessed a change in Eriksonian ego identity status. All other participants remained at the same identity status, either Achieved or Foreclosed. Foreclosed identity status means the individual has accepted identity commitments (politics, beliefs, values, etc.) without much exploration, typically based on parental influence and what they were told to commit to. They conform to an identity without exploring or critically evaluating it. An Achieved identity status also represents individuals who have made identity commitments but through their own introspection and exploration. A Diffusion identity status, on the contrary, is representative of an individual who does not have any strong identity commitments nor has any interest in exploring identity possibilities. Lastly, a Moratorium identity status follows someone who is in the process of exploring their identity but are not yet ready to make commitments. Thus it would appear that 3 of the participants who were in the Foreclosed identity status prior to becoming a caregiver, were unprepared to deal with the threats to identity that this challenge presented. Not having developed the tools of critical thinking in regard to identity development when they were younger, it would seem that they are now left in a state of diffusion. The participant in Achievement, on the contrary, had already experienced the process of exploration and critical examination necessary to establish a sense of identity, which might explain why she is now in a state of Moratorium, searching for a new and renewed sense of identity, rather than languishing in diffusion.

Limitations of the Study and Future Research

As with all studies, this research has limitations that will be discussed. The first major limitation was the small sample of participants. The extreme difficulty in recruiting participants may have been due to a lack of motivation to participate in the survey since there was no academic or financial compensation. In addition, the survey was given to a population who may have already felt overwhelmed due to caregiver responsibilities and thus did not have the time nor energy to participate in uncompensated research. Another possible reason for lack of participation could be due to the fact that data collection was done during the Covid-19 pandemic, and caregivers may have been facing increased levels of caregiver burden and fatigue from both their normal caregiver responsibilities and added stressors and responsibilities from the pandemic.

This absence of compensation may have also had an effect on survey answers, since many questions were repetitive in order to measure pre to post changes in identity upon becoming a caregiver. Several of the participants did not complete all the surveys suggesting that the battery might have been too long and the repetitive nature of questions too off-putting. In addition to a small sample of participants, and perhaps because of it, there was a lack of variation in gender and ethnicity. This in turn means that the data cannot be generalized and that further research is needed with a wider pool of participants. This study aimed to measure the impact on becoming a caregiver quantitatively, rather than use qualitative data which most past research has done. In order to have significant quantitative data, a larger sample is required. If a larger sample is not available, future research might benefit from continuing to use qualitative interviews in addition to quantitative measures in order to get a richer understanding of the numbers as well as to actively mitigate against survey fatigue.

Future research may also benefit from administering the survey in-person in order to encourage greater participation and reduce drop out (those who didn't fully complete the survey battery). This was not possible for this study, as the Aphasia support groups were not held face-to-face due to Covid-19.

Longitudinal studies could also be helpful in investigating the long term effects on identity of becoming a caregiver without relying on recall and memory. Despite the many shortcomings of this study, it does reinforce the idea that the effects of becoming a caregiver go beyond stress, exhaustion, and financial strain, and can in fact disrupt a previously established sense of identity. Further research into the effects on identity could prove useful in developing prevention and intervention programs for caregivers to mitigate these grave potential problems.

APPENDIX A: TABLES

Table 1 Means, standard deviations, and significance of change from pre to post measures of all study variables

	Pre-test <i>M (SD)</i>	Post-test <i>M (SD)</i>	<i>t(df)</i>	<i>p</i>
Identity Salience	4.20 (.32)	3.31 (1.07)	1.79(5)	.133
Identity Functioning	2.96 (.19)	2.78(.54)	.76(6)	.479
Meaning in Life	4.08 (.60)	4.21 (.57)	-1.36(5)	.231
Identity Commitment	4.54 (.51)	3.26 (1.12)	2.71(6)	.035
Identity Exploration	3.23 (1.18)	3.06 (1.24)	.56(6)	.593
Identity Distress	1.43 (.84)	2.00 (.91)	-1.62(5)	.165

Table 2 *Correlation Matrix of All Study Variables*

	Identity Saliency	Identity Functioning	Meaning in Life	Identity Commitment	Identity Exploration
Identity Functioning	.90*				
Meaning in Life	-.04	.08			
Identity Commitment	.80	.75	.34		
Identity Exploration	.03	.27	.06	-.06	
Identity Distress	-.57	-.19	.17	-.42	.30

Note: * $p < .05$

Table 3 *Participant Demographics*

Participant	Age	Ethnicity	Education	Relationship	Years as Caregiver	Identity Status Pre	Identity Status Post
1	45	H	AA	Sibling	3.75	Achieved	Achieved
2	46	W	MA	Spouse	4.50	Foreclosed	Diffuse
3	65	W	MA	Spouse	5.00	Foreclosed	Foreclosed
4	55	W	<HSD	Partner	1.83	NA	NA
5	64	W	AA	Spouse	1.83	Foreclosed	Diffuse
6	62	W	BA	Spouse	6.00	Foreclosed	Diffuse
7	65	M	NA	Partner	2.00	Achieved	Moratorium
8	70	W	BA	Parent	20.00	NA	NA
9	59	W	BA	Spouse	7.00	Achieved	Achieved

Note: W = White, non-Hispanic; H = Hispanic or Latino/a; M = Mixed Ethnicity or Other

AA = Associate’s Degree; MA = Graduate Degree, BA = Bachelor’s Degree; HSD = High School Degree; <HSD = less than High School Degree; NA = no answer provided

NA Identity Status is due to unfinished questions by participant

Table 4 *Difference scores from pre to post by participant for all measures*

Participant	Identity Functioning	Meaning in Life	Identity Commitment	Identity Exploration	Identity Distress
1	+0.13	-0.03	0.00	0.00	0.00
2	-1.53	+0.50	-3.20	+0.40	+1.43
3	+0.20	+0.30	+0.20	+0.40	-0.29
4	-	-	-	-	-
5	-0.40	0.00	-1.00	-1.80	+0.14
6	+0.27	-0.10	-1.40	-0.60	-0.29
7	0.00	-	-2.60	0.00	-
8	-	-	-	-	-
9	+0.07	+0.10	-1.00	+0.40	+1.86

Table 5 Degree of Disruption and Result Ratings for Each Identity Domain

Participant	Job/Career	Family Income	Relationships with Friends	Relationships with Other Family Members	Romantic Relationships	Hobbies/Leisure Activities or Community Involvement	Long-term Goals	Religious views/beliefs/values	Role as Parent/Caregiver to Another Person	Physical Health	Mental Health
1	NA	NA	4 / 4	NA	NA	5 / 4	NA	NA	NA	4 / 4	4 / 5
2	5 / 3	5 / 4	5 / 3	3 / 4	NA	5 / 2	4 / 2	NA	NA	3 / 4	4 / 4
3	NA	NA	3 / 2	NA	NA	3 / 4	NA	NA	NA	NA	NA
4	NA	NA	NA	NA	5 / 3	5 / 3	3 / 3	NA	NA	2 / 3	NA
5	3 / 3	NA	3 / 3	NA	NA	3 / 3	2 / 3	NA	NA	4 / 3	2 / 3
6	3 / 2	3 / 2	3 / 2	3 / 2	NA	4 / 2	4 / 2	NA	NA	3 / 2	NA
7	5 / 1	4 / 1	4 / 2	NA	5 / 1	5 / 1	5 / 2	3 / 2	4 / 2	3 / 2	3 / 2
8	4 / 2	3 / 2	3 / 3	NA	3 / 3	4 / 2	4 / 2	NA	NA	4 / 3	NA
9	3 / 1	4 / 5	4 / 4	3 / 4	NA	4 / 4	4 / 2	3 / 3	NA	3 / 4	4 / 4

Note: NA response means participant did not believe this domain to be affected by the trauma

Degree of Disruption Rating: (1) = Not at all; (2) = Mildly; (3) Moderately; (4) = Severely; (5) = Very Severely

Result of Disruption: (1) = Much Worse; (2) = Worse; (3) = About the Same; (4) = Better; (5) = Much Better

APPENDIX B: IRB APPROVAL LETTER



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board

FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

June 16, 2021

Dear Bailey Wagaman:

On 6/16/2021, the IRB determined the following submission to be human subjects research that is exempt from regulation:

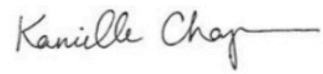
Type of Review:	Modification / Update
Title:	Identity and Caregivers of People with Aphasia
Investigator:	Bailey Wagaman
IRB ID:	MOD00001963
Funding:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • Identity_of_Caregivers_Form_251.pdf, Category: Faculty Research Approval; • Identity of caregivers_HRP-255 .docx, Category: IRB Protocol; • IRB Wagaman 3040 HRP-254 Explanation of Research.pdf, Category: Consent Form; • IRB Wagaman 3040 Recruitment Email (1).docx, Category: Recruitment Materials; • IRB Wagaman 3040 Survey.docx, Category: Survey / Questionnaire;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Research (HSR) Standard Safety Plan with permission from your Dean of Research or submitted your Study-Specific Safety Plan and received IRB and EH&S approval. Be sure to monitor correspondence from the Office of Research, as they will communicate when restrictions are lifted, and all in-person research can resume.

Sincerely,

A handwritten signature in cursive script that reads "Kamille Chap". The signature is written in black ink and includes a horizontal line extending to the right from the end of the name.

Kamille Birkbeck
Designated Reviewer

APPENDIX C: SURVEY BATTERY

Identity of Caregivers Survey

Demographic Questionnaire:

AGE: What is your current age? _____

SEX: Indicate your gender

- Male
- Female
- Transgender
- Other (explain): _____

EDUCATION: Indicate year highest degree obtained

- · High school
- · Some college
- · Associate's degree
- · Bachelor's degree
- · Graduate degree (MA or MS)
- · Doctorate, Law, or Medical
- · Other (explain): _____

ETHNICITY: Select the ethnic/racial identifier that best describes you:

- White, non-Hispanic
- Black, non-Hispanic
- Hispanic or Latino/a
- Asian or Pacific Islander
- Native American or Alaskan Native
- Mixed ethnicity or Other (Specify): _____

MARITAL STATUS:

- Single
- Married
- Co- habitating
- Separated
- Divorced
- Widowed
- Other (specify)

What is your relationship to the person to whom you give care?

- Spouse

- Parent
- Sibling
- Adult Child
- Other Family Member (specify)
- Friend (not related)
- Other (specify)

How long have you been a primary caregiver to this person?

On average, how many hours a week do you give care to this person?

Do you live with this person?

- Yes
- No

What is the condition of the adult that requires care? _____

Changes in Identity Variables:

Did taking care of this person result in any of the following changes in your personal life?

Change in job or career:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Reduction in family income:

- Yes

- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in relationships with friends:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in relationships with other family members:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in romantic relationships:

- Yes
- No

If yes, please explain

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in hobbies, leisure activities, or community involvement:

- Yes
- No

If yes, please explain

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in long-term goals

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes in religious views/beliefs, values, spirituality, or philosophy of life:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes to your role as a parent, caregiver, etc. to another person (other than this person):

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes to your physical health:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

Changes to your mental health:

- Yes
- No

If yes, please explain:

How disruptive was this in your life on a scale of 1 to 5:

Not at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

Compared to when you first began taking care of this person, how is this area of your personal life **currently** on a scale of 1 to 5:

Much Worse	Worse	About the same	Better	Much Better
1	2	3	4	5

*Has anything else changed as a result of the injury? If yes, please explain below:

In this survey we will ask about your “Identity” and how it might have changed from before you became a caregiver to this person.

Your identity involves the roles, goals, and values that give your life a sense of direction and purpose. These include your career, education, religious beliefs, political beliefs, relationships, and community memberships

TIIF:

How important was each of these things to your sense of identity BEFORE you became a caregiver to this person?

Not At All Important	Somewhat Important	Moderately Important	Very Important	Extremely Important
1	2	3	4	5

- A. Your work, job, or career _____
- B. Your religion or spirituality _____
- C. Your philosophy of life _____
- D. Your personal relationship with a romantic partner _____
- E. Your personal relationship with your closest friend _____
- F. Your ethnic or racial identification _____
- G. Your immigrant status _____
- H. Your hobbies, sports, or leisure activities _____
- I. Your role as a parent or caregiver to another person _____
- J. Your politics or views on a specific social issue _____
- K. Your gender _____
- L. Your sexuality _____
- M. Your physical health _____
- N. Your mental health _____
- O. Your community involvement, volunteer activities, or community service activities _____

For the following questions, think about how you felt about your sense of identity BEFORE you became a caregiver to this person.

Not At All True	Somewhat True	Moderately True	Very True	Extremely True
1	2	3	4	5

12. My identity was clear and unambiguous before I was a caregiver to this person. ____

13. I felt very positively about my identity. ____

14. My identity provided me with a sense of meaning in my life then. ____

15. My identity was an important part of who I was then. ____

16. My identity was a source of personal satisfaction in my life then. ____

17. My identity was central to how I thought about myself then.

18. My identity seemed to relate to most things I was doing at the time.

19. I spent a great deal of time then engaging in activities relating to my identity.

20. I believed my identity would remain pretty much the same in the years ahead.

IDS:

Please respond to these statements the way you think you would have BEFORE you became a caregiver to this person. To what degree, at that time, were you upset, distressed, or worried over any of the following issues in your life?

None at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

___ 1. Long term goals? (e.g., finding a good job, being in a romantic relationship, etc.)

___ 2. Career choice? (e.g., deciding on a trade or profession, etc.)

___ 3. Friendships? (e.g., experiencing a loss of friends, change in friends, etc.)

___ 4. Sexual orientation and behavior? (e.g., feeling confused about sexual preferences, intensity of sexual needs, etc.)

___ 5. Religion? (e.g., stopped believing, changed your belief in God/religion, etc.)

___ 6. Values or beliefs? (e.g., feeling confused about what is right or wrong, etc.)

___ 7. Group loyalties? (e.g., belonging to a club, school group, gang, etc.)

MLQ:

Please take a moment to think about what made your life feel important to you BEFORE you became a caregiver this person.

Absolutely Untrue	Mostly Untrue	Somewhat Untrue	Can't Say True or False	Somewhat True	Mostly True	Absolutely True
1	2	3	4	5	6	7

1. I understood my life's meaning. ____
2. I was looking for something to make my life feel meaningful. ____
3. I was always looking to find my life's purpose. ____
4. My life had a clear sense of purpose. ____
5. I had a good sense of what makes my life meaningful. ____
6. I had discovered a satisfying life purpose. ____
7. I was always searching for something to make my life feel significant. ____
8. I was seeking a purpose or mission for my life. ____
9. My life had no clear purpose. ____
10. I was searching for meaning in my life. ____

DIDS:

Please respond to these statements with how much you agree or disagree with them BEFORE you became a caregiver this person.

1	2	3	4	5
---	---	---	---	---

Strongly disagree	Disagree	Neither disagree / Neither agree	Agree	Strongly agree
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

TIIIF-2:

Now, **CURRENTLY**, how important is each of these things to your sense of identity:

Not At All Important	Somewhat Important	Moderately Important	Very Important	Extremely Important
1	2	3	4	5

- A. Your work, job, or career _____
- B. Your religion or spirituality _____
- C. Your philosophy of life _____
- D. Your personal relationship with a romantic partner _____
- E. Your personal relationship with your closest friend _____
- F. Your ethnic or racial identification _____
- G. Your immigrant status _____

- H. Your hobbies, sports, or leisure activities _____
- I. Your role as a parent or caregiver to another person _____
- J. Your politics or views on a specific social issue _____
- K. Your gender _____
- L. Your sexuality _____
- M. Your physical health _____
- N. Your mental health _____
- O. Your community involvement, volunteer activities, or community service activities _____

For the following statements, think about the way you CURRENTLY feel about your sense of identity.

Not At All True	Somewhat True	Moderately True	Very True	Extremely True
1	2	3	4	5

- 12. My identity is clear and unambiguous. _____
- 13. I feel very positively about my identity. _____
- 14. My identity provides me with a sense of meaning in my life then. _____
- 15. My identity is an important part of who I am. _____
- 16. My identity is a source of personal satisfaction in my life. _____
- 17. My identity is central to how I think about myself. _____
- 18. My identity seems to relate to most things I do. _____
- 19. I spend a great deal of time engaging in activities relating to my identity. _____

20. I believe my identity will remain pretty much the same in the years ahead. _____

IDS-2:

Please respond to these statements the way you think you now feel CURRENTLY. To what degree have you *recently* been upset, distressed, or worried over any of the following issues in your life? (please select the appropriate response, using the following scale).

None at all	Mildly	Moderately	Severely	Very Severely
1	2	3	4	5

- ___ 1. Long term goals? (e.g., finding a good job, being in a romantic relationship, etc.)
- ___ 2. Career choice? (e.g., deciding on a trade or profession, etc.)
- ___ 3. Friendships? (e.g., experiencing a loss of friends, change in friends, etc.)
- ___ 4. Sexual orientation and behavior? (e.g., feeling confused about sexual preferences, intensity of sexual needs, etc.)
- ___ 5. Religion? (e.g., stopped believing, changed your belief in God/religion, etc.)
- ___ 6. Values or beliefs? (e.g., feeling confused about what is right or wrong, etc.)
- ___ 7. Group loyalties? (e.g., belonging to a club, school group, gang, etc.)

MLQ-2:

Please respond to these statements with how you feel CURRENTLY.

Absolutely Untrue	Mostly Untrue	Somewhat Untrue	Can't Say True or False	Somewhat True	Mostly True	Absolutely True
1	2	3	4	5	6	7

- 1. I understand my life's meaning. _____
- 2. I am looking for something that makes my life feel meaningful. _____
- 3. I am always looking to find my life's purpose. _____
- 4. My life has a clear sense of purpose. _____

5. I have a good sense of what makes my life meaningful. _____
6. I have discovered a satisfying life purpose. _____
7. I am always searching for something that makes my life feel significant. _____
8. I am seeking a purpose or mission for my life. _____
9. My life has no clear purpose. _____
10. I am searching for meaning in my life. _____

DIDS-2:

Please respond to these statements with how much you agree or disagree with them CURRENTLY.

	1 Strongly disagree	2 Disagree	3 Neither disagree / Neither agree	4 Agree	5 Strongly agree
6. I have decided on the direction I am going to follow in my life.	1	2	3	4	5
7. I have plans for what I am going to do in the future.	1	2	3	4	5
8. I know which direction I am going to follow in my life.	1	2	3	4	5
9. I have an image about what I am going to do in the future.	1	2	3	4	5
10. I have made a choice on what I am going to do with my life.	1	2	3	4	5
6. I think actively about different directions I might take in my life.	1	2	3	4	5
7. I think about different things I might do in the future.	1	2	3	4	5
8. I am considering a number of different lifestyles that might suit me.	1	2	3	4	5
9. I think about different goals that I might pursue.	1	2	3	4	5
10. I am thinking about different lifestyles that might be good for me.	1	2	3	4	5

Thank you for your participation in this Survey. It is much appreciated!

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