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PERSPECTIVES OF INDIVIDUALS WITH ACQUIRED NEUROGENIC  
COMMUNICATION DISORDERS AND CO-SURVIVORS ON PERSON-  
CENTERED CARE WITHIN SPEECH-LANGUAGE THERAPY

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LOGAN MACRAE ELLIS

Submitted to the Faculty of the Graduate School of  
Eastern Kentucky University  
in partial fulfillment of the requirements for the degree of

MASTER OF ARTS IN EDUCATION IN COMMUNICATION DISORDERS

2021

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## ABSTRACT

### *Main Argument*

Acquired brain injury impacts 2.8 million individuals each year in the United States (Taylor et al., 2017). Stroke, traumatic brain injury, tumor, infection, and other conditions cause life-altering changes to the way humans interact with each other. Social interaction and communication are important in many aspects of life, including but not limited to work, community, relationships, and mental health, etc. Damage to the brain often changes the ability to communicate drastically, which can impact all of the aforementioned aspects of life (Ardila & Rubilo, 2018).

Speech-language pathologists (SLPs) address the acquired neurogenic communication disorders associated with brain injury in order to enhance life participation. However, previous research indicated a difference between goals identified by clients versus SLPs (Foster et al., 2013).

Individuals with acquired neurogenic communication disorders prefer therapeutic goals related to activity and participation; however, goals addressed by SLPs are often impairment-based. This discrepancy impacts implementation of person-centered care (PCC). Person-centered care involves incorporating the client and his/her family/co-survivors into treatment using individualized techniques. Previous literature found that PCC enhances treatment outcomes, specifically life participation

(DiLollo & Favreau, 2010; Hersh et al., 2012). Current research investigated SLPs' perspectives of therapy as well as SLPs' and clients' perspectives on therapeutic goal-setting (Foster et al., 2013; DiLollo & Favreau, 2010; Brown, Worrall, & Howe, 2011; LPAA Project Group, 2001). However, limited literature is available investigating clients' and co-survivors' perspectives of the therapeutic process. Since PCC involves all those involved in an individual's life, SLPs must understand perspectives of co-survivors and clients with acquired neurogenic communication disorders. This information will enhance current practices of SLPs by meeting the needs of clients and co-survivors through PCC.

***Procedures*** The purpose of this study was to describe the perspectives of co-survivors and clients on PCC within speech-language therapy (SLT). The researcher aimed to answer one grand tour question with this study. How do adults with acquired neurogenic communication disorders and their co-survivors perceive the implementation of person-centered care in speech-language therapy? To answer this question, three focus group interviews, two with PWA and one with co-survivors, were conducted. Data was analyzed using open, axial, and selective coding processes, which resulted in categories that create a storyline.

***Findings*** The purpose of this study was to utilize qualitative measures to determine the perspectives of clients and co-survivors on PCC during



SLT. Findings revealed that client and co-survivor participants perceived components of PCC as being provided by SLPs during SLT services. The following components of PCC that these participants provided included treating the person as a whole, client and co-survivor involvement in therapy, life participation, and positive relationships between clients and SLPs.

The application of these findings can further support individuals with acquired neurogenic communication disorders by demonstrating the impact of incorporating PCC into SLT. Consequently, positive relationships are built between all parties, the individual is treated as a whole person instead of a diagnosis, SLPs provide support to clients and co-survivors, and life participation is priority.

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## **1. Introduction**

Acquired brain injury impacts 2.8 million individuals each year in the United States (Taylor et al. 2017). Stroke, traumatic brain injury, tumor, infection, and other conditions cause life-altering changes to the way humans interact with each other. Social interaction and communication are important in many aspects of life, including but not limited to work, community, relationships, and mental health, etc. Damage to the brain often changes the ability to communicate drastically, which can impact all of the aforementioned aspects of life (Ardila & Rubilo, 2018).

Communication impairments following an acquired brain injury are characterized by deficits in spoken language expression, spoken language comprehension, written expression, and/or reading comprehension (American Speech-Language-Hearing Association, 2020). Cognitive-communication disorders are also common following a brain injury. The American Speech-Language-Hearing Association (ASHA) defines cognitive communication disorders as “difficulty with any aspect of communication that is affected by a disruption of cognition” including memory, language, visuospatial skills, executive functions, problem-solving, reasoning, organization, and attention (ASHA, 2005). A deficit in any of these areas impacts speaking, listening, reading, writing, and/or pragmatic (social) skills, which adversely affects an individual’s participation and independence in basic activities of daily living as well as academic, social, and vocational performance (Northern Arizona University Communication Sciences and Disorders, 2020).

Speech-language pathologists (SLPs) are responsible for treating the residual cognitive and communication deficits associated with an acquired brain injury (also

known as acquired neurogenic communication disorders), specifically the impact on life participation. A systematic grounded theory study regarding SLP perspectives on therapy reported that “connecting with patients to meet their communication needs was the ultimate therapeutic goal” (Page & Howell, 2015, p. 19). However, it is important that the client, co-survivor, and clinician are all on the same page regarding treatment goals and expectations to enhance treatment outcomes. According to Sherratt et al. (2011), goals addressed by SLPs are impairment- and activity-based within the International Classification of Functioning, Disability and Health (ICF). However, Worrall (2011) found that clients prefer person-centered treatment goals spread across the components of the ICF with more focus on participation in activities. This discrepancy between client preferences and SLP practice patterns impacts application of person-centered care in addition to positive treatment outcomes.

## **1.1. Literature Review**

Person-centered care (PCC) involves incorporating the client and his/her family/co-survivors into treatment using individualized techniques. White et al. (2008) described the primary components of PCC as “personhood, knowing the person, autonomy and choice, comfort care, and nurturing relationship” as well as a supportive environment. Previous literature found that PCC enhances treatment outcomes, specifically life participation (DiLollo & Favreau, 2010; Hersh et al., 2012; Kagan et al., 2008). Prior to engaging in PCC, the SLP must learn the client’s therapeutic preferences for goals and treatment.

### **What are clients' preferences for therapy?**

An in-depth analysis found that individuals with acquired neurogenic communication disorders want goals related to life participation (Brown et al., 2011; LPAA Project Group, 2001). However, Foster et al. (2013) reported a difference between the patient's goals and those set by the SLP. According to this research, PWA wanted more education while SLPs believed tailoring services to meet the needs of patients and families yielded more benefits (Foster et al., 2013).

Stroke education is not all that persons with aphasia (PWA) prefer in speech-language therapy. According to Worrall et al. (2011), individuals with aphasia not only wished to improve communication, but also wished to improve in the areas of social life, work, leisure, and altruism. Although these are not typically the primary targets in rehabilitation, patients also prioritized receiving information and gaining/maintaining dignity and respect. Patients in this study expressed a desire to return to life pre-stroke and having control and independence of their lives. PWA “wanted speech therapy that met their needs at different stages of recovery, that was relevant to their life,” (Worrall et al., p. 314, 2011).

### **What are current practices of SLPs?**

SLPs address the acquired neurogenic communication disorders associated with brain injury. Previous research indicates a difference between goals identified by clients versus SLPs (Foster et al., 2013) which impacts application of PCC. Individuals with acquired neurogenic communication disorders prefer goals related to activity and participation (i.e., improve word retrieval to communicate at work); however, goals addressed by SLPs are often impairment-based (i.e., improve word retrieval on 10



trained items) (Foster et al., 2013). More research is needed to examine the implementation of PCC in speech-language therapy, as perceived by adults with acquired neurogenic communication disorders and their co-survivors.

By using PCC, SLPs aim to use personally relevant and functional information in each individual's interventions. This means that each patient's therapy session will look somewhat different when PCC is used. However, researchers found that SLPs use more structured, task-oriented therapies than functional approaches (DiLollo & Favreau, 2010). Even under clinical supervision following classroom instruction about PCC, student clinicians failed to apply PCC (DiLollo & Favreau, 2010). For example, a SLP may target client comprehension through the utilization of "wh" questions (i.e., who, what, when, where, why). Asking questions about a standardized picture illustrates a typical task-oriented approach. A more functional approach may involve reading passages on a topic that the client is interested in or talking about a family photograph and asking "wh" questions to assess comprehension.

One example of person-centered service delivery is the Life Participation Approach to Aphasia (LPAA). The LPAA emphasizes functional, relevant goals within speech-language rehabilitation after acquired brain injury. The intent of LPAA is for persons with acquired neurogenic communication disorders to 're-engage into everyday society' from the assessment until the client elects to no longer have communication support (Chapey et al., 2000).

One method of measuring performance using the LPAA is the A-FROM model, derived from Living with Aphasia: Framework for Outcome Measurement. This framework creates a guideline for establishing individualized goals based on

interventions that focus not only on the patient's aphasia, but also on their environment, participation, personal identity, and emotions related to therapy. This being said, the A-FROM measures each of the following five domains: aphasia severity, participation, environment, personal, and life with aphasia. This allows the clinician, client and co-survivor to collaboratively create goals for each domain. In following the LPAA service delivery model, quality of life is measured by the A-FROM from a person-centered perspective (Kagan et al., 2008).

### **What are co-survivors' preferences for therapy?**

Co-survivors are also an important component of providing PCC. Familial co-survivors may include spouses, children, parents, friends, partners, or other individuals in the patient's support system. Co-survivor stress levels rise as the load of switching roles accumulates (Draper et al., 2007). Many parents, spouses, siblings, and children become full-time caregivers once brain injury occurs and they want the best care possible for their loved ones.

According to a study conducted by Howe et al. (2012), co-survivors and those included in the PWAs' support systems had several goals for rehabilitation. Analysis of interview data collected during this study revealed the following seven categories as potential goals created by co-survivors: "to be included in rehabilitation, to be provided with hope and positivity, to be able to communicate and maintain their relationship with the person with aphasia, to be given information, to be given support, to look after their own well-being, and to be able to cope with new responsibilities" (Howe et al., p. 515, 2012). This information provides an in-depth look at speech-language rehabilitation

through the eyes of co-survivors and allows SLPs to view their preferences for goal-setting.

### **How do SLPs involve co-survivors in therapy?**

Rehabilitation staff make the transition to the role of caregiving easier by offering social support to the co-survivor. SLPs provide education and counseling regarding the acute and long-term changes in persons with speech-language deficits associated with acquired brain injury (Draper et al., 2007) as well as communication strategies to lessen the caregiver burden and increase communication opportunities between clients and co-survivors. Foster et al. (2013) highlight the importance of the SLP providing family support, education, and hope, according to co-survivors. Because of circumstances and funding, however, these expectations are not always met to the fullest extent (Foster et al., 2013).

Techniques aimed to increase co-survivor involvement in therapy include communication partner training strategies. A systematic review of communication partner training reported positive outcomes for individuals with brain injury and the communication partners (Simmons-Mackie et al., 2016). Communication partner training is an evidence-based practice that improves communication between clients and their trained communication partners. Clients not only improved communication strategies, topic initiation, and the use of content words and sentences, but also demonstrated increased confidence, self-perceptions, and self-identity. Levels of depression decreased, knowledge of communication strategies improved, and participation increased in both clients and their co-survivors with the use of communication partner training (American Congress of Rehabilitation Medicine, n.d.).

Current research investigated SLPs' perspectives of therapy as well as SLPs' and clients' perspectives on therapeutic goal-setting. However, limited literature is available investigating clients' and co-survivors' perspectives of the therapeutic process. Since PCC involves all those involved in an individual's life, SLPs must understand perspectives of co-survivors and clients with acquired neurogenic communication disorders. This information will enhance current practices of SLPs by meeting the needs of clients and co-survivors through PCC.

## **1.2. Purpose Statement/Research Questions**

The aim of this study was to utilize qualitative measures to determine the perspectives of clients and co-survivors on PCC during SLT. The principal investigator chose this information to not only provide SLPs with a clearer understanding of adults with neurogenic communication disorders and co-survivors but also to enhance the use of PCC during therapy.

The researcher aimed to answer one grand tour question with this study. How do adults with acquired neurogenic communication disorders and their co-survivors perceive person-centered care within speech-language therapy?

## **2. Research Methods**

The Eastern Kentucky University Institutional Review Board approved this pilot study and all participants signed informed consent prior to participating. This qualitative exploratory design utilized a grounded theory approach to answer the research questions through focus group interviews. The researcher chose this approach to reveal meanings, values, and opinions underlying co-survivors' and people with

acquired neurogenic communication disorder's experiences with SLT. The exploratory qualitative research design allowed a theory to emerge that is grounded in the words of the participants and that provides rich descriptions of the participants' current thoughts about SLT.

## **2.1. Participant Selection**

The selection of participants occurred through purposive sampling, which assisted in obtaining a wide array of perspectives regarding person-centered care within SLT. The principal investigator also utilized snowball sampling, which allowed participants to join through word of mouth from other participants. The individuals in the focus groups provided insight for the study's research questions. In order to recruit participants, the principal investigator emailed flyers to clinical and medical centers in Kentucky. The principal investigator posted an announcement on social media, as well, in order to recruit participants.

Participants included both adults with acquired neurogenic communication disorders and their co-survivors (see Table 1 for details). The sample size included six total participants, including four clients with neurogenic communication disorders and two of their co-survivors. In order to be eligible for the study, the clients must have been currently receiving speech-language therapy or have received speech-language therapy in the past. Co-survivors whose spouse, parent, child, sibling, or significant other experienced an acquired neurogenic communication disorder were invited to participate. For the purposes of this study, a "co-survivor" was defined as a family member or friend responsible for providing assistance with transportation, activities of daily living, or independent activities of daily living at least once a week.

**Table 1.** Participant Information

| <b>Client Participant Name*</b> | <b>Diagnosis/Reason(s) for Attending Speech-Language Therapy</b> | <b>Client Focus Group Type</b> | <b>Corresponding Co-Survivor Name* (if applicable)</b> | <b>Co-Survivor Focus Group Type</b> |
|---------------------------------|--|--------------------------------|--|-------------------------------------|
| Hattie                          | Cognitive Deficits   | Zoom                           | N/A  | N/A                                 |
| Ruth                            | Dysarthria, Cognitive Deficits                                   | In-Person                      | Joe  | Zoom                                |
| Sarah                           | Broca's Aphasia, Cognitive Deficits                              | In-Person                      | N/A  | N/A                                 |
| Valerie                         | Primary Progressive Aphasia                                      | Zoom                           | Henry  | Zoom                                |

\*Each participant was given a pseudonym as to protect participant privacy and confidentiality.

## **2.2. Data Collection**

Data collection occurred through focus group interviews both in-person and through Zoom. The researcher chose this data collection method because focus groups allow participants to interact and generate ideas and perspectives together (Redmond & Curtis, 2009). This type of research design is appropriate for topics with little known information (Corbin & Strauss, 2008). The interviews were guided by four open-ended questions (see Figure 1).

The principal investigator conducted three focus groups (two client and one co-survivor) with two participants in each group. One client focus group occurred in-person and the other client and co-survivor focus groups occurred through Zoom. The format for focus groups was based on participant convenience and preference given the current COVID-19 social distancing requirements. The principal investigator separated each focus group by participant title: co-survivor and client. This allowed for information to be kept independent so that responses more suitably matched each

appropriate role. Each interview was audio- and video-recorded and lasted 20-60 minutes. Following each interview, the principal investigator and research assistants transcribed the recordings verbatim.

**Figure 1.** Research Sub-Questions

- |   |
|---|
| <p>Sub-questions:</p> <ol style="list-style-type: none"><li>1. How do clients and co-survivors describe their experiences with speech-language therapy?</li><li>2. What influenced clients' and co-survivors' perceptions of speech-language therapy?</li><li>3. What were the outcomes of clients' co-survivors' overall experiences with speech-language therapy?</li><li>4. How did clients' and co-survivors' perceptions of speech-language therapy change over time?</li><li>5. What were the outcomes of clients' co-survivors' overall experiences with speech-language therapy?</li></ol> <p>How did clients' and co-survivors' perceptions of speech-language therapy change over time?</p> |
|---|

### **3. Data Analysis and Results**

Data was analyzed using open, axial, and selective coding processes, which resulted in categories that created a storyline. The creation of a storyline allowed emergence of a theory grounded in qualitative data (Birks, Mills, Francis, et al., 2009). The researcher chose this process because it limited gaps in the study, gave precedence to theory, and focused on the evidence rather than the researcher's possible external biases (Birks et al., 2009). This permitted the researcher to develop a descriptive theoretical perspective on participants' perceptions of PCC during SLT.

Focus groups were guided by the following questions (see Figure 2 for Client Questions and Figure 3 for Co-Survivor Questions). The principal investigator utilized verbal prompts to enhance participant responses and modified questions, as needed, to suit the unique needs of the participant groups.

**Figure 2.** Client Focus Group Interview Questions

- Client Questions:
1. Tell me about your experiences with speech-language therapy.
    - a. How often?
    - b. Where?
    - c. Group or one-on-one?
    - d. Describe some of the tasks.
    - e. What did you like about speech-language therapy?
    - f. What did you dislike about speech-language therapy?
  2. How were your goals determined?
    - a. Did the therapist ask about your goals for therapy?
    - b. Were the goals related to your interests, job, family, etc.?
  3. Describe a treatment session.
    - a. How involved are you in planning treatment with the SLP?
    - b. What tasks do you do?
    - c. Are the tasks individualized?
    - d. Do you bring supplies from home for therapy?
  4. If you receive(d) other therapies, how does speech-language therapy compare to the others in regard to person-centered care?
    - a. Does the SLP create goals related to your personal life?
  5. What advice do you have for future SLPs?



**Figure 3.** Co-Survivor Focus Group Interview Questions

Caregiver Questions:

1. Tell me about your experiences with the speech-language therapy services offered to the person in your care.
  - a. How often did the person in your care attend?
  - b. How often did you attend?
  - c. Where?
  - d. Group or one-on-one?
  - e. Describe some of the tasks.
2. How were you involved in treatment?
  - a. Actual communication partner training? If so, describe.
  - b. Did you bring materials from home?
  - c. Describe the homework and whether or not your loved one completed it. Why or why not?
  - d. Did you receive education and/or counseling?
3. Did the SLP implement tasks that target independence and/or quality of life?
  - a. What tasks?
4. What is your perception of your loved one's progress with speech-language therapy?
  - a. Do therapy tasks transfer to home and community?
5. What advice do you have for future SLPs?
6. If your loved one received other therapies, how does speech-language therapy compare to the others in regard to person-centered care?
  - a. Does the SLP create goals related specifically to your loved one's life?

Data collection and analysis occurred simultaneously to allow a continuous comparison of results (Corbin & Strauss, 2008). From these comparisons, the principal investigator modified the following focus group interviews by asking more in-depth questions about SLT tasks and how SLT activities are related to the clients' personal lives. Data collection ceased once all participants had been interviewed.

The principal investigator trained Eastern Kentucky University graduate students in the Communication Disorders program on the transcription process to 95% transcription reliability prior to the data analysis process. The principal investigator and research assistants transcribed the recorded responses of the video recordings verbatim. In order to ensure study reliability, two members of the research team each transcribed the data to provide consensus reliability. They noted any disagreements and discussed until a consensus was reached for each interview transcription.

Since this study followed grounded theory protocol, the principal investigator analyzed the data through open, axial, and selective coding (Corbin & Strauss, 2008). The coding process and findings are described below.

### **3.1. Open Coding**

The principal investigator utilized open coding to identify *in vivo* codes using words, phrases, or sentences from the focus group interviews. *In vivo* codes reflected direct words or phrases spoken by the participants. These codes determined common themes that emerged between participants about perspectives on speech-language therapy related to acquired neurogenic communication disorders and were identified by highlighting significant words, phrases, and sentences line by line from the transcriptions. During the open coding process, the principal investigator identified the

focus group participant who mentioned the code and then identified the transcribed quotation in a table. One table was used for each participant group (clients and co-survivors) in order to separate the data. The principal investigator counted the frequency of each code mentioned. The principal investigator also identified the total number of codes construed from the focus group interviews. The codes were arranged into categories based on similar ideas. Tables 2 and 3 provide examples of the open coding process.

**Table 2.** Example of Opening Coding Process

| <b>Code</b>            | <b>Data Extract</b>                      | <b>Participant</b> |
|------------------------|--|--------------------|
| SLP Commitment         | A lot of patience on you all             | Sarah              |
| Positive rapport       | As long as it's with her I'll be alright | Ruth               |
| Reason to continue SLT | That's why I'm still going               | Sarah              |

**Table 3.** Example of How Categories Emerged

| <b>Categories</b>  | <b>Code</b>  | <b>Data Extract</b>   | <b>Participant</b> |
|--------------------|--|---|--------------------|
| Client improvement | still got problems but better than she was   | She's still got problems, but I think she's better than she was.  | Joe                |
|                    | it helped her on talking a little more   | I think it helped her like on talking a little more   | Joe                |
|                    | people can understand better   | people can understand a little bit better.  | Joe                |
|                    | I can understand her better  | I think it helped her quite a bit. I can understand her better.   | Joe                |
|                    | It helped her speak a little better  | It just helped her speak a little better.   | Joe                |
| Client motivation  | very focused on doing the exercises and getting better   | Well, I think it definitely keeps her motivated. I mean, she's very focused on doing the exercises and getting better.  | Henry              |
| Positive outlook   | I think we've been lucky because it has been very slow.  | I think we've been lucky because it has been very slow.   | Henry              |
|                    | Overall, her situation is really good. I mean, the impact is still relatively mild.  | I overall, I mean her situation is so really good. I mean, it's still the impact is still relatively mild.  | Henry              |
|                    | I think I think it's one of the reasons why her situation is still relatively mild. I think it has helped it slowed the progression. | I think I think it's one of the reasons why uhh her situation is still relatively still fairly mild. I mean, I think it's, it has helped it has slowed the progression. | Henry              |

### **3.2. Axial Coding**

Axial coding involved defining the conditional relationships of the categories that emerged during open coding, by answering the questions what, when, where, why, how, and with what consequence (Corbin & Strauss 2008; Scott 2004). Axial coding consisted of creating a conditional relationship table for each participant group (Table 4). For example, the category, 'Improvements,' the first question 'what' was answered by creating a definition of each category. The second question was 'when did you have improvements?' The third question was 'where did you have improvements?' The fourth question was 'how did you have improvements?' The fifth question was 'what is the consequence of improvement?' This last question, consisting of consequences of each category, allowed relationships to develop between categories (Scott 2004). The axial coding process was completed for all categories, allowing a list of consequences to be created that connected all data.

**Table 4.** Example of Conditional Relationship Table

| <b>Category</b>             | <b>What</b>                                       | <b>When</b>         | <b>Where</b>   | <b>Why</b>  | <b>How</b>  | <b>Consequence</b>  |
|-----------------------------|---|---------------------|--|---|---|---|
| Advice for SLPs             | Clients give SLPs advice about ST                 | during and after ST | Rehabilitation hospital, outpatient, university clinic | they don't know you messed up                               | open your kind of heart and mind, take your time, don't be hateful, treat your patient good, common sense, listen more, not nervous, not scared | treat with respect  |
| Appreciation                | we appreciate you                                 | during ST           | Rehabilitation hospital, outpatient, university clinic | work so hard  | willingness to help goes a long way   | we appreciate you   |
| Individualized intervention | speech is more individualized than the other ones | during ST           | Rehabilitation hospital, outpatient, university clinic | hers is aimed at improving and mine is aimed at maintaining | they're all a little different, tailored to me, my interests, my life, very carefully thought out   | never gotten the impression that somebody was following a script or workbook from speech therapy 101, much more individual, specific, directed; tailored to me, my interests, my life |

Further in the axial coding process, the consequences from the conditional relationship table were defined using a reflective coding matrix (See Tables 5 and 6 for the client and co-survivor reflective coding matrices, respectively). A core category was derived for each participant group. The core category is a consequence from the conditional relationship table that reflects all the other consequences (Corbin & Strauss 2008; Scott & Howell 2008). The core category that emerged for the client participant group was 'That's why I'm still going.' The core category that emerged for the co-survivor group was 'It definitely keeps her motivated. She's very focused on doing the exercises and getting better.' As described by Corbin & Strauss (2008), the reflective coding matrix included five areas: processes, properties, dimensions, contexts, and modes for understanding the consequences. Consequences that were mentioned most frequently (two times) became processes. For the client participant group, the five essential processes that emerged were: 'Complete opposite,' 'Helping me with my adaptive behaviors,' 'I've always been part of the treatment plan,' 'As long as I'm with her, I'll be alright,' and 'I wish I could have group therapy with more people.' For the co-survivor participant group, the two essential processes that emerged were: 'A big transfer to real life' and 'Still got problems but better than she was.' These processes represented the main actions of each participant group (Scott & Howell 2008).

The other consequences were used to fill in the rest of the reflective coding matrix. Properties defined each process listed in the table (Corbin & Strauss 2008). For example, in the client participant group, the process 'I've always been part of the treatment plan' was described using the properties of 'Never gotten the impression that somebody was following a script or workbook from speech therapy 101,' 'Much more

individual, specific, directed,’ ‘Tailored to me, my interests, my life,’ ‘Speech therapy is the most skill-focused,’ and ‘Trying to find solutions.’ For the co-survivor participant group, the process ‘Still got problems but better than she was’ was described using the properties ‘Still got the problems’ and ‘Documented that she’s got some issues still.’ Dimensions within the table provided variations of each process. For the client participant group process ‘I’ve always been part of the treatment plan,’ four dimensions provided variations as: ‘Everything you do for us is therapeutic,’ ‘Learned in different ways,’ ‘I had so much input,’ and ‘I chose that to work on.’ For the co-survivor participant group process ‘Still got problems but better than she was,’ dimensions used to provide variations were ‘Still got a few problems on words you can’t understand,’ ‘She can’t remember good,’ and ‘Progressive.’

Context was the environment in which each process occurred. For the client participant group process ‘Complete opposite,’ the context was ‘My problems only come after you’ve been around me for a little while.’ For the co-survivor participant group process ‘Still got problems but better than she was,’ the context was ‘Everyone’s situation is different.’ Modes for understanding consequences were the results of the consequences. For the client participant group process ‘As long as I’m with her, I’ll be alright,’ the results that emerged were ‘That’s why I kept going too’ and ‘We appreciate you.’ For the co-survivor participant group process ‘A big transfer to real life,’ the result was ‘It helped her on talking a little more.’ Each element of the two core categories were mentioned within each group’s codes, categories, conditional relationship tables, and reflective coding matrices.



**Table 5.** Client Reflective Coding Matrix

| <b>Core Category</b> <i>That's why I'm still going</i> |   |  |  |  |  |
|--|---|--|--|--|--|
| <b>Process</b>   | Complete opposite                                     | helping me with my adaptive behaviors                    | I've always been part of the treatment plan  | As long as I'm with her, I'll be alright   | I wish I could have group therapy with more people |
| <b>Property</b>  | They can see that I'm not good at this                | maintaining my speech and language stuff                 | Never gotten the impression that somebody was following a script or workbook from speech therapy 101 | It's nice to have an outside perspective tell me, "Oh, you think you're doing it this way, but this is actually what you're doing" | It's nice to socialize                             |
|  | I can't do a thing                                    |  | much more individual, specific, directed   | Even though you're getting graded on it, you still put all this effort into it to try and help me                                  |  |
|  |   |  | tailored to me, my interests, my life  |  |  |
|  |   |  | Speech therapy is the most skill-focused   |  |  |
| trying to find solutions                               |   |  |  |  |  |
| <b>Dimensions</b>                                      | I might not be as fast as other people                | helping me to come up with ways to maintain independence | Everything you do for us is therapeutic  | I wanted him all the time  | I wish I had more people that were similar to me   |
|  | didn't really understand what was wrong with my brain |  | learned in different ways  |  |  |

|  |   |   |  |                             |                                  |
|--|---|---|--|-----------------------------|----------------------------------|
|  | helpful to me to just know why  |   | I had so much input<br>I chose that to work on |                             |                                  |
| <b>Contexts</b>                        | My problems only come after you've been around me for a little while                          | learn to use this machine   | I only want to try to help                     | I only want to try to help  | That's the worst part for me     |
|  |   | learn to try to put words together<br>The more I do it, the less I forget | I've worked on research types of skills        | treat with respect          |                                  |
|  |   |   | sing a song                                    |                             |                                  |
|  |   |   | learn my cell phone                            |                             |                                  |
| <b>Modes of Understanding Contexts</b> | This is what they're gonna be like and then you get in there and they're completely different | got up and prayed at church   | had opportunities to teach                     | That's why I kept going too | It's really hard to be that open |

|   |  |   |                   |
|---|--|---|-------------------|
| incredibly<br>brave that<br>everybody<br>goes to<br>speech<br>therapy | I don't forget<br>anymore  | it is helping me  | we appreciate you |
|   | now I remember<br>almost all of it<br>talk out loud at<br>home                     | I'm always getting or<br>giving feedback as to<br>whether this is working<br>Having been a therapist, I<br>would say definitely as<br>involved in speech therapy<br>as you would be in<br>individual counseling |                   |
|   | I love to cook,<br>and I've learned<br>how to adapt to<br>be able to cook<br>again | No one has ever done<br>anything with me,<br>therapeutically, that I was<br>like, "I don't like this."  |                   |
|   |  | I looked forward to it.   |                   |

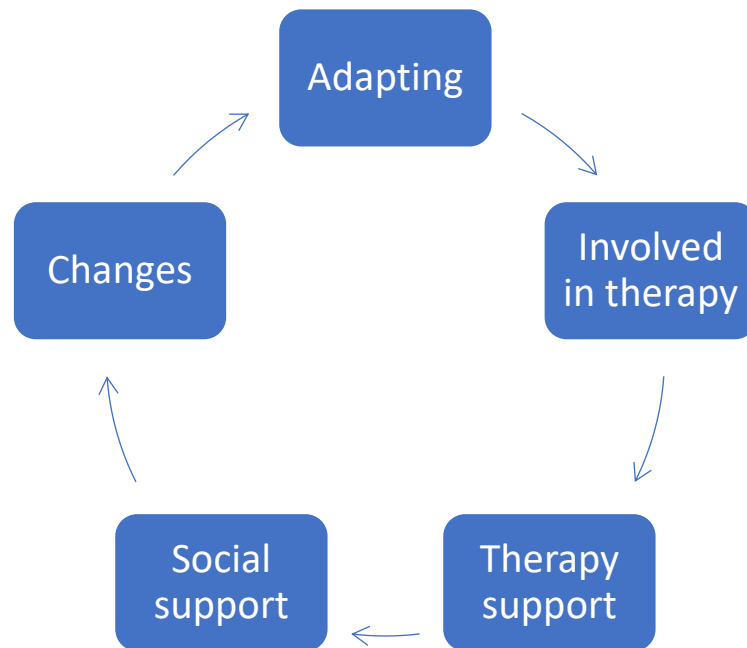
**Table 6. Co-Survivor Reflective Coding Matrix 4. Co-Survivor Reflective Coding Matrix**

|  |   |   |
|--|---|---|
| <b>Core Category</b>                   | <i>It definitely keeps her motivated. She's very focused on doing the exercises and getting better.</i> |   |
| <b>Process</b>                         | A big transfer to real life   | Still got problems but better than she was  |
| <b>Property</b>                        | Had a real sort of real-life component  | still got the problems  |
|  |   | documented that she's got some issues still   |
| <b>Dimensions</b>                      | you need to know what problem you're dealing with and how to address it                                 | still got a few problems on words you can't understand                              |
|  |   | she can't remember good   |
|  |   | Progressive   |
| <b>Contexts</b>                        | did a pretty good job completing homework   | everyone's situation is different   |
|  | showed everyone how to plant seeds  |   |
| <b>Modes of Understanding Contexts</b> | it helped her on talking a little more  | people can understand   |
|  |   | Overall, her situation is really good. I mean, the impact is still relatively mild. |
|  |   | She's definitely learned from that to manage those issues                           |

### 3.3. Selective Coding

During the selective coding process, the principal investigator organized and related the core categories, consequences, and processes to create a storyline. These data collection and analysis processes allowed the principal investigator to group similar responses together in order to develop a theory (Damico et al., 1999). The descriptive theory that emerged described co-survivors' and clients' perceptions of person-centered care within speech-language therapy for adults with acquired neurogenic communication disorders. That theory is described below, using direct quotations from the participants.

**Figure 4.** Emergent theory: That's why I'm still going.



Individuals with acquired neurogenic communication disorders experience changes. These changes may be related to cognition, communication, swallowing, personality, physical ability, emotional stability, social status, work, medical changes, and more. To address these changes, clients become involved in SLT and wish SLPs would recognize all of these changes. However, they appreciate being involved in therapy and learning how to adapt in order to participate in life and previously enjoyed activities. Clients reported that therapy is an avenue of support but they also value support from other individuals with acquired neurogenic communication disorders.

### **3.3.1. Changes.**

First, it is important that SLPs recognize the client as a person. SLPs must view the client as a whole by learning their interests, lifestyle, support system, etc. Clients shared a variety of personal changes physically, mentally, and emotionally following injury and diagnosis. Clients also noted changes to speech, cognition, and socialization. Clients reflected on these difficulties, acceptance, and working to overcome them. For example, Hattie stated, “My problems only come after you’ve been around me for a while.” Sarah reported, “I can’t do a thing.” Clients believe it essential that SLPs realize that their changes are not only related to communication but to all aspects of life. By acknowledging the client as a person, SLP can better provide person-centered care.

### **3.3.2. Adapting.**

To assist with some of the differences that clients may experience, SLPs introduce adaptive, compensatory strategies. For example, Valerie stated, “I love to cook, and I’ve learned how to adapt to be able to cook again.” Cooking is a personal interest of Valerie’s so her SLP made sure to include this aspect of her life into her

therapy program. Ruth is learning to use an AAC device to help her communicate with others. She reported, “I got up and prayed at church.” Church is a very important aspect of her life and speaking in front of the church was a familiar practice for Ruth. After her injury and resulting communication disorder, Ruth transformed from an outgoing jokester to being a shy individual. Her AAC device has allowed her to adapt and get back a part of her old self.

### **3.3.3. Involved in therapy.**

Client participants reported involvement in goal planning and treatment ideas. Hattie reported, “I’ve never gotten the impression that if somebody was just following like a script or a workbook from, you know, speech therapy 101.” Valerie stated, “I’m always getting feedback or giving feedback.” Both of these statements illustrate the importance of including the client in making decisions about their treatment. By allowing open communication about targets and ideas, trust and rapport can be built amongst the client and SLP.

### **3.3.4. Therapy support.**

Building positive relationships with clients is an essential component of having a positive experience with speech-language therapy. Hattie stated, “Sometimes it’s nice to have like an outside perspective tell me, ‘Oh you think you’re doing it this way, but this is actually what you’re doing you know.’” Concerning student clinicians, Valerie stated, “Even though you’re getting graded on it, you still put all this effort into it to try and help me.” Clients appreciate the clinicians’ extra effort to ensure their needs are met. Because of such a strong relationship with her SLP, Sarah reported, “That’s why I

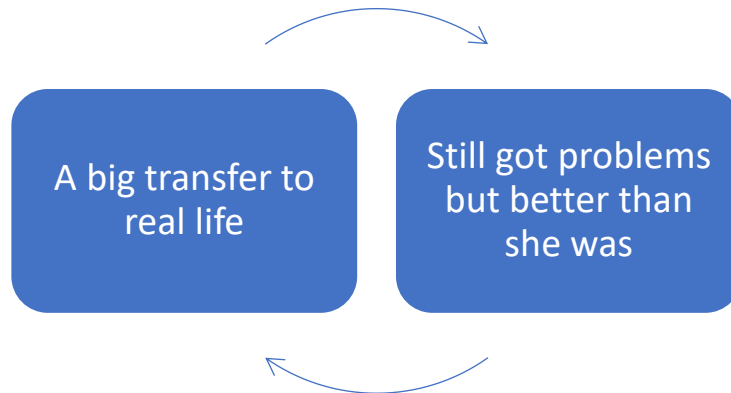
kept going too.” Feeling validated and at ease with the SLP increases the motivation and willingness to work at the therapy goals agreed upon.

### **3.3.5. Social support.**

Lastly, clients reported wishing they could attend speech-language therapy with other individuals going through similar experiences. Hattie explained, “I do wish that I had more people that were a lot more similar to me.” Clients wish for more support from others going through similar trials. Group therapy and support groups can bring similar people together to allow them to discuss their similarities and differences, as well as to allow them to work together on their treatment goals. However, group therapy is not offered for everyone and, moreover, clients may not always have closely similar individuals to talk with. For example, there may be five individuals attending group therapy together but only one who experiences a brainstem stroke and the effects from that. While all of the individuals may experience acquired neurogenic communication disorders, no two people will ever be the same. While this is important for clients to realize, it can be difficult to come to terms with. SLPs may address this concern by offering more group therapy options for potential clients. Another way is by continuing to advocate for our clients experiencing acquired neurogenic communication disorders and decreasing some of the stigmas surrounding them.



**Figure 5.** Emergent theory: It definitely keeps her motivated. She's very focused on doing the exercises and getting better.



Co-survivors may come in many forms, such as spouse or significant other, parent, sibling, child, friend, or other individual in their support system. Co-survivors usually know their loved ones before and after the diagnosis of the acquired neurogenic communication disorder. As discussed above, many changes can occur within the client. These changes can be minimal to maximal and can affect several areas of life. The co-survivor may be given additional responsibilities following the client's diagnosis, such as providing transport to appointments, assisting with activities of daily living (ADLs), and being a constant provider of support. Co-survivors report that their loved ones who receive SLT services following the diagnosis of an acquired neurogenic communication disorder continue to demonstrate problems following treatment but continually show improvements. They also report that SLT provides a significant transfer to the personal lives of their loved ones.

### **3.3.6. A big transfer to real life.**

The co-survivor group had another perspective with different opinions to share. They reported that speech-language therapy has had “a big transfer to real life” for their

loved ones. Henry stated that speech-language therapy has “had a real sort of real-life component” for his loved one. Person-centered care focuses in on the interests and activities that each client enjoys. Because this has been an important component of speech-language therapy that the co-survivors have noticed, it can be noted that person-centered care has been implemented in some form.

### **3.3.7. Still got problems but better than she was.**

The co-survivors also reported that their loved ones still have some issues going on that need to be worked on. Joe stated that his loved on has “still got the problems,” but went on to report that she has improved and “people can understand” what she says when speaking. Henry noted about his loved one that it is “documented that she’s got some issues still.” Although both of the co-survivors conveyed that their loved ones still have issues, it is important to note that both also stated that they’ve observed improvements in each of them.

## **4. Study Rigor**

Several steps to the verification process were used in order to validate the study rigor. During the transcription process in the initial phase of data collection, two to three trained individuals compared transcriptions of the videos of the focus group interviews. If any discrepancies were found, revisions were agreed upon and made by the research team. To ensure the verification of data analysis, *in vivo* codes were used. In order to ensure credibility, member checking was used. The researcher shared a brief summary of the study’s findings with each of the research participants in order to confirm that their views were expressed accurately. A second person compared the transcriptions to the audiotapes. If any discrepancies were found, revisions were made.

One final verification procedure that was used was an audit trail. The audit trail was maintained to confirm that an accurate record of codes and categories were kept.

## **5. Discussion**

The purpose of this study was to utilize qualitative measures to determine the perspectives of clients and co-survivors on PCC during SLT. How do adults with acquired neurogenic communication disorders and their co-survivors perceive person-centered care within speech-language therapy? Findings revealed that individuals with acquired neurogenic communication disorders and their co-survivors provided specific information related to PCC within SLT.

As described by White et al. (p. 116, 2008), the essential features of PCC are “personhood, knowing the person, autonomy and choice, comfort care, and nurturing relationship, (and a) supportive environment.” The reasons provided in this study relate directly to the features specified by White and colleagues (2008). These reasons related to personal changes following diagnosis, adaptations, therapeutic involvement, positive client-SLP relationship, and social support, all of which relate to the central focus of PCC. Clients valued building positive relationships with not only the SLPs, but also others going through similar experiences. For the most part, the clients liked having a hand in choosing their therapy goals and seeing how their targets related to each of their personal lives.

The co-survivors acknowledged that their loved ones continue to exhibit issues with cognitive communication during and following SLT but that the services they received transferred to life outside of therapy. This is important to note as person-centered care aims to include clients and their support systems in goal-setting, therapy

implementation, and communication partner training not only during therapy sessions but also in generalized settings.

These findings describe a process of the perspectives of individuals with acquired neurogenic communication disorders and their co-survivors about implementation and use of person-centered care in speech-language therapy. “That's why I'm still going” and “It definitely keeps her motivated. She's very focused on doing the exercises and getting better” describe the processes that individuals with acquired neurogenic communication disorders and their co-survivors have about their experiences and opinions of speech-language therapy.

## **6. Clinical Implications**

Because speech-language pathologists have the responsibilities of screening, assessing, diagnosing, and treating persons with neurogenic communication disorders, this study is clinically significant. In order to better understand and improve the current practices of speech therapy, SLPs require a clear understanding of caregivers' and clients' views. By learning the perspectives of those directly involved in and impacted by SLT for individuals with acquired neurogenic communication disorders, SLPs can reflect on their therapeutic approaches and how they are viewed by others. As a result, life participation can be enhanced through PCC.

As discussed previously, PCC is comprised of including the client, family, co-survivors, and support system into the goal planning and intervention processes. Throughout this entire process, intervention is individualized to complement the client's life and personal interests. The SLP should first recognize the client for who he/she is as a whole person, not just after their diagnosis. SLPs need to recognize what the client

was like prior to the neurogenic communication disorder and how they may have changed. By knowing the client that is being treated, positive rapport and trust is fostered. Building a positive relationship with the client and their support system is foundational in providing and implementing PCC effectively. Once a positive relationship is established, a certain trust is also established and must be maintained. SLPs can do this by providing extensive support to their clients and loved ones. This can be completed by not only providing personally relevant therapy materials and approaches, but also by supplying counseling and education that pertains to the diagnosis, speech-language characteristics, treatments, advocacy, and helpful information for situations outside of the therapy setting.

Because client participants reported enjoying group therapy and support groups, SLPs should work to implement these groups into their facilities as best they can. Group settings can provide clients and their loved ones with an environment of support, advocacy, education, camaraderie, and understanding that otherwise would not be provided elsewhere. By giving clients the opportunity to build relationships with others experiencing similar trials, a sense of community is built.

## **7. Limitations and Future Research**

This study may be limited in that all participants were located in the central Kentucky area. Three of the client participants were familiar with the researcher so this could have affected focus group interview responses. Another limitation is the reduced depth of the study as data saturation was not met. Secondary to the COVID-19 pandemic reaching the United States during the recruitment process and data collection phase, fewer participants chose to participate than expected prior. Therefore, this study

will act as a pilot study for future research examining the perspectives of PCC in SLT. All of the client participants were presently attending SLT at the time of data collection. Although the clients had attended for varying periods of time, three of them were still in the chronic therapy phase and one of the clients was in the acute therapy phase. None of the clients had completed SLT and graduated from services. Findings may vary depending on differing therapy phases. Because this is a pilot study, continued research is needed in order to obtain more accurate, reliable results across locations, settings, therapy phases, and participants.

## **8. Conclusion**

The purpose of this study was to utilize qualitative measures to determine the perspectives of clients and co-survivors on PCC during SLT. Client and co-survivor participants perceived components of PCC as being provided by SLPs during SLT services. The following components of PCC that these participants provided including treating the person as a whole, client and co-survivor involvement in therapy, life participation, and positive relationships between clients and SLPs. The application of these findings can further support individuals with acquired neurogenic communication disorders by demonstrating the impact of incorporating PCC into SLT on those involved. Through the implementation of PCC through SLT, positive relationships are built between all parties, the individual is treated as a whole person instead of a diagnosis, SLPs provide support to clients and co-survivors, and life participation is priority.

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