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Discourse Intervention in Aphasia: Renegotiating Identity Post-Stroke

Tricia Olea Santos, PhD, CCC-SLP

Moderated by: Amy Natho, MS, CCC-SLP, CEU Administrator, SpeechPathology.com

continued

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continued

DISCOURSE INTERVENTION IN APHASIA: RENEGOTIATING IDENTITY POST-STROKE

Tricia Olea Santos, PhD CCC-SLP



LEARNING OUTCOMES

After this course, participants will be able to:

- Explain the concept of loss of identity in relation to aphasia.
- Identify one essential factor in renegotiating identity post-stroke.
- After this course, participants will be able to describe one discourse strategy that can be used to facilitate renegotiation of identity poststroke.

continued

FOUR PHASES OF CHANGE POST-STROKE (Kirkevold, 2002)

Initial surprise and suspense

Hard physical work during initial rehabilitation

Psychosocial and practical adjustment to daily life upon returning home

Getting on with life: minimizing effects of stroke on life individual's sense of self





RENEGOTIATING IDENTITY: "THERAPY WITH THE END IN MIND"

(Kagan & Simmons-Mackie, 2007)

• "The choice of aphasia assessment and intervention strategies should be directly influenced by outcome goals related to life participation in its broadest sense"

Addressing impairment/disease process

Facilitating participation: personally relevant activities, relationships, roles

Increasing access/reducing barriers to full participation in health care

Maximizing satisfaction and QoL



RENEGOTIATING IDENTITY: "THERAPY WITH THE END IN MIND"

- Life Participation Approach to Aphasia (LPAA Project Group, 2000, 2001)
- A Framework for Outcome Measurement (A-FROM) (Kagan & Simmons-Mackie, 2008)
- The link between QoL and identity



LIVING SUCCESSFULLY WITH APHASIA: SALIENT FEATURES

- Meaningful social relationships and support
- Positive way of life
- Perceived improvement
- Actively moving forward
- Meaningful activities
- * Importance of renegotiating self-identity

(Grohn, Worrall, Simmons-Mackie & Hudson, 2014; Brown, Worrall, Davidson & Howe, 2010; Hinckley, 2006; Holland, 2006; Boles, 2006; Cruice, Worrall & Hickson, 2006)

continued

IDENTITY AND IDENTITY RENEGOTIATION



IDENTITY

- A composite of roles, values, and beliefs acquired and maintained via social interaction (Shadden & Agan, 2004)
- Human language: the mediating tool through which we express and construct our identities (Edwards, 2009; Van Leeuwen, 2009)

continued

LOSS OF IDENTITY IN APHASIA

- Immediate reactions post-stroke aphasia
 - Period similar to bereavement (Müller & Code, 1989, p. 108)
 - "Crisis" fear, anxiety, frustration, and depression (Holland & Fridriksson, 2001)





LOSS OF IDENTITY IN APHASIA

- Most profound impact of aphasia: "Social dysfunction in life" - Alterations in roles and relationships (Shadden & Agan, 2004; Alaszewski, Alaszewski, & Potter, 2004; Lyon & Shadden, 2001)
 - Loss of social and occupational identity
 - Social isolation
 - Decreased roles
 - Limited communicative opportunities
 - Lack of community support systems

(Musser, Wilkinson, Gilbert, & Bokhour, 2015; Simmons-Mackie & Damico, 2007)



LOSS OF IDENTITY IN APHASIA

"Society often writes off stroke victims because they're not who they once were. As a result, stroke victims write themselves off—for the same reason. They're not the same person they once were. Worse, they don't know how to get that person back. The painful reality is that they will never get that same person back. But often over time—a better person will emerge."

(Serper, 2000, p. 19 in Hinckley, 2006)





RENEGOTIATING IDENTITY POST-STROKE: WHY ADDRESS IDENTITY IN APHASIA?

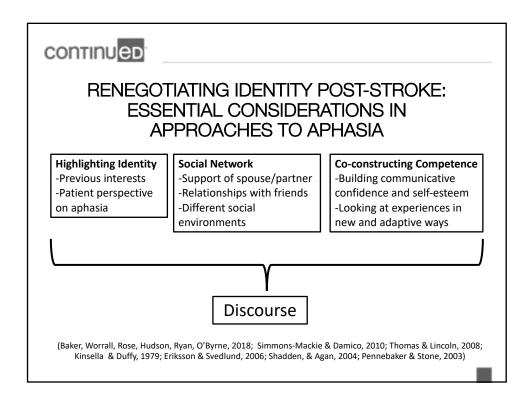
- Identity: a key component to improving QoL in aphasia (Corsten, Konradi, Schimpf, Hardering, & Keilmann, 2013; Shadden, 2005)
 - "Insider perspective" (Byng, Pound & Parr, 2000; LPAA, 2000; Simmons-Mackie, 1998)
 - Acceptance of a new image of self post-stroke (Musser, Wilkinson, Gilbert, Bokhour, 2015; Hinckley, 2006)
- Aphasia therapy should focus on promoting a positive social identity (Parr, 1996; Pound, 1996)

continued

RENEGOTIATING IDENTITY POST APHASIA

- Challenge: Making sense of life now and finding empowerment (Shapiro, 2011; Shadden, 2005)
- Outcome assessment: capture the entire spectrum from individual deficits to life participation (Simmons-Mackie & Damico, 2001)





DISCOURSE AND IDENTITY





DISCOURSE AND IDENTITY

- Discourse the core of renegotiating patient identity
 - Healing power (Hinckley, 2006; Shadden & Hagstrom, 2007)
 - Personal and social insights

(Fromm, Holland, Armstrong, Forbes, MacWhinney, Risko, & Mattison, 2011; Simmons-Mackie & Damico, 2010, 2009; Shadden & Hagstrom, 2007; Hinckley, 2006)

continued

HIGHLIGHTING IDENTITY: GETTING TO KNOW THE PWA

- Main Focus: Know who they are to create meaningful social environments that validate identity (Shadden, 2005)
- Who and what they were prior to the stroke (Shadden & Agan, 2004) —
 - Hobbies, Activities
 - Life, Interests and Values (LIV) cards
 - Social networks (Shadden & Agan, 2004; Ulatowska, Reyes, Santos, Garst, Vernon, McArthur, 2013)
- Discovering who they are now post-stroke



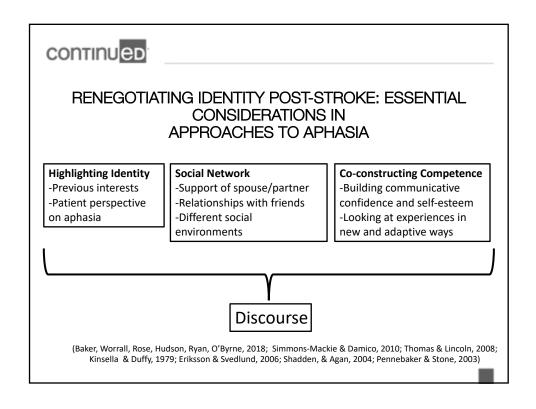
DISCOURSE AS A MEANS OF RENEGOTIATING IDENTITY POST-STROKE

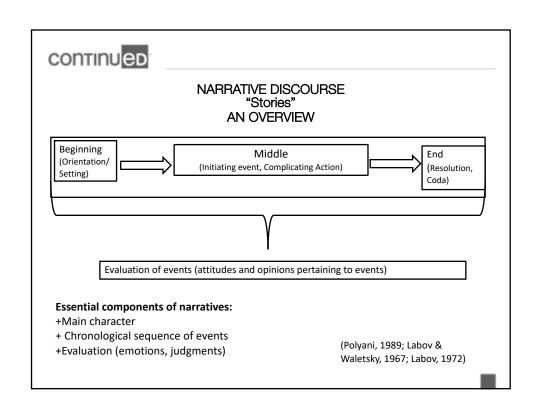
- Narrative discourse
- Procedural discourse
- Conversational discourse

CONTINU ED

NARRATIVE DISCOURSE AND IDENTITY











NARRATIVE DISCOURSE AND IDENTITY

- We are continually trying to create our life story (McAdams, 2008; 2001; Polkinghorne, 1988)
- Narratives allow us make meaning of experiences and create or maintain identity

(Ulatowska, Santos, Walsh, 2018; Strong, Lagerway, Shadden, 2018; Hinckley & Bourgeois, 2015; Corsten, Konradi, Schimpf, Hardering, Keilmann, 2014; McAdams, 2008; McAdams 2001; Bruner, 1987)



NARRATIVE DISCOURSE: RENEGOTIATING IDENTITY IN LIGHT OF STROKE

Healing power of stroke stories

(Santos, Ulatowska, Cuadro, 2016; Hinckley & Bourgeois, 2015; Corsten, Konradi, Schimpf, Hardering & Keilmann, 2014; Ulatowska, Reyes, Santos, et al, 2013; Davidson, Howe, Worrall, Hickson, Togher, 2008; Holland, 2007; Shadden, 2007; Shadden & Hagstrom, 2007; Hinckley, 2006; Holland, 2006; Simmons-Mackie and Damico, 2001; Coleman, 1999)

- Integrate disruptions into the life story
- Cope with impairment and understand its impact on identity and life goals

(White & Epston, 1990; Frank, 1997; Kleinman, 1988)

 Re-establish a more positive sense of self and develop an optimal identity

(Corsten, Konradi, Schimpf, Hardering, Keilmann, 2014; Ulatowska, Reyes, Santos, Garst, Vernon, & Mcarthur, 2013; Shadden, Hagstrom, & Koski, 2008; Holland, 2007; Hinckley, 2006; Pound, Parr, Lindsay, & Woolf, 2000; Brody, 1994; White & Epston, 1990 in Corsten, Konradi, Schimpf, Hardering, Keilmann, 2014)





NARRATIVE DISCOURSE AND IDENTITY: SOCIAL COMPONENT

- Establishes a relationship between the speaker and the listener
 - Listening with a humanistic ear vs. a linguistic ear (Hinckley & Bourgeois, 2015)
- Valuable sources of information: priorities, cultural views and values (Santos, Ulatowska, Cuadro, 2016; Hersh, 2015; Hinckley & Bourgeois, 2015)

continued

NARRATIVE DISCOURSE AND IDENTITY: THE SOCIAL COMPONENT

- Stories are influenced by the environment (Strong, Lagerway & Shadden, 2018; Ruth & Kenyon, 1996)
 - Co-constructing identity via narratives
 (McAdams, 2008)
 - SLP is a "co-constructor" (Strong, Lagerway & Shadden, 2018; Simmons-Mackie & Damico, 2010)





NARRATIVE DISCOURSE AND IDENTITY: WHERE DO WE BEGIN?

- Salient events in PWA's life prior to the stroke (Ulatowska, et al, Olness, et al)
 - Memorable experiences
 - Frightening experiences
 - Stroke story
- "Contextual Inventory of Key Life Activities Prior to the Onset of Aphasia." (Simmons Mackie & Damico, 2001)
 - Overview of essential communication contexts
 - Point of reference for intervention



NARRATIVE DISCOURSE AND IDENTITY: WHERE DO WE BEGIN?

- Erikson's stages of psychosocial development (Erikson, 1980)
 - Intimacy (20-40s)
 - Generativity (40-60s)
 - Integrity (60+)
- Reminiscence Bump (Rubin, Rahhal & Poon, 1998)
 - Events from late adolescence to early adulthood: one's "memory bump" (first job, first marriage, first child, first pet)



NARRATIVE DISCOURSE AND IDENTITY: THE ONGOING NARRATIVE

- Ongoing narrative: Reconstructing the past and imagining the future (McAdams, 2008)
- Discussing "Who I am with Aphasia" is critical to living successfully in the longer term

(Kagan & Simmons-Mackie, 2007; Hinckley, 2006)

• "My Story" study - restore one's life pre, peri- and post-stroke (Strong, Lagerway, Shadden, 2018; Strong 2015)

continued

PROCEDURAL DISCOURSE AND IDENTITY





RENEGOTIATING IDENTITY POST-STROKE: ESSENTIAL CONSIDERATIONS IN APPROACHES TO APHASIA

Highlighting Identity

-Previous interests -Patient perspective on aphasia

Social Network

- -Support of spouse/partner-Relationships with friends
- -Different social environments

Co-constructing Competence

-Building communicative confidence and self-esteem -Looking at experiences in new and adaptive ways

Discourse

(Baker, Worrall, Rose, Hudson, Ryan, O'Byrne, 2018; Simmons-Mackie & Damico, 2010; Thomas & Lincoln, 2008; Kinsella & Duffy, 1979; Eriksson & Svedlund, 2006; Shadden, & Agan, 2004; Pennebaker & Stone, 2003)

continued

PROCEDURAL DISCOURSE "Procedures"

- A description of steps to perform an activity in a specific order
- Characteristics
 - Goal-oriented: concrete, highly structured
 - Chronological/temporal structure
 - Based on script knowledge of familiar/learned routines (Ulatowska, North, Macaluso-Haynes, 1981, Ulatowska, Doyel, Freedman-Stern, Macaluso-Haynes, North, 1983; Ulatowska, Reyes, Olea Santos, Garst, Davis, Seok, Kim, 2013)
- Primary purpose: to inform or instruct (Longacre, 1981)





WHY STUDY PROCEDURAL DISCOURSE IN APHASIA?

(Ulatowska, Reyes, Santos, Garst, Davis, Seok, Kim, 2013)

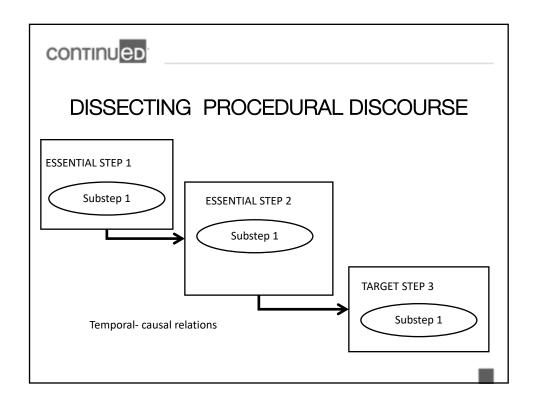
- Supported context
- Diagnostic tool
- Verbal rehearsal as a strategy to complete essential ADLs
- Fostering patient identity

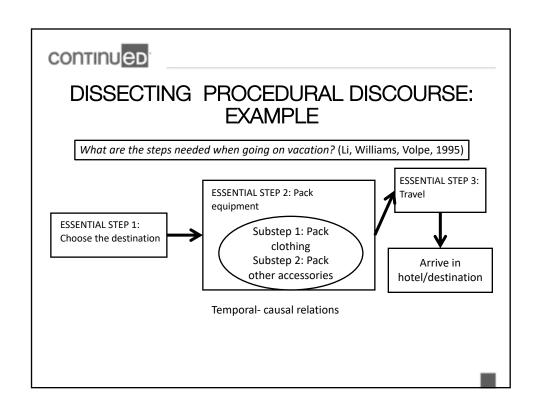
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HOW DO I ELICIT PROCEDURAL DISCOURSE?

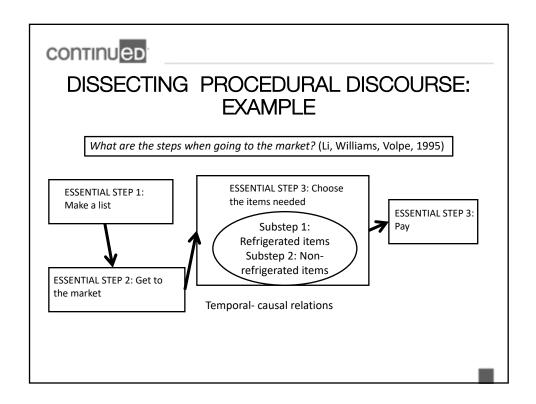
- "How do you <u>make a ham sandwich (procedure)</u>. Give the steps as though explaining it to someone who has never done it before." (Ulatowska, Reyes, Santos, et al, 2013)
- "What are the steps in <u>making a ham sandwich</u> (<u>procedure</u>). Give them as though explaining it to someone who has never done it before." (Ulatowska, Reyes, Santos, et al, 2013)













ANALYSIS OF PROCEDURES: WHAT ARE WE LOOKING FOR?

(Ulatowska, Reyes, Olea Santos, et al, 2013; Ulatowska, North, Macaluso-Haynes, 1981, Ulatowska, Doyel, Freedman-Stern, Macaluso-Haynes North, 1983)

- Coherence: Does it make sense?
 - Is there a strict temporal-causal structure (script)?
- Language Structure
 - Simple vs complex sentence structure
 - Are there referential errors?
- Information structure
 - What are the essential steps and substeps? How many of these were mentioned? – <u>Best to assign these a priori</u>
 - Essential steps necessary steps to complete the procedure
 - Substeps additional steps which support the essential steps
 - ARE THERE NON-RELATED STEPS?





STUDIES ON PROCEDURAL DISCOURSE IN APHASIA

- Preserved script knowledge (Ulatowska, Reyes, Santos, Garst, Seok, Kim, 2013; Ulatowska et al. 1992; Ulatowska, Allard, Chapman, 1990; Armus et al. 1989)
- Individuals with mild-moderate aphasia severity levels:
 - Well-structured procedures
 - Simple language and errors at the sentential level (Ulatowska, et al., 1981)
 - Greater number of sub-steps in tasks involving familiar topics (Li, Williams, Volpe, 1995)
 - Reference difficulties with more complicated social procedures (Ulatowska, Reyes, Santos, Garst, Seok, Kim, 2013)

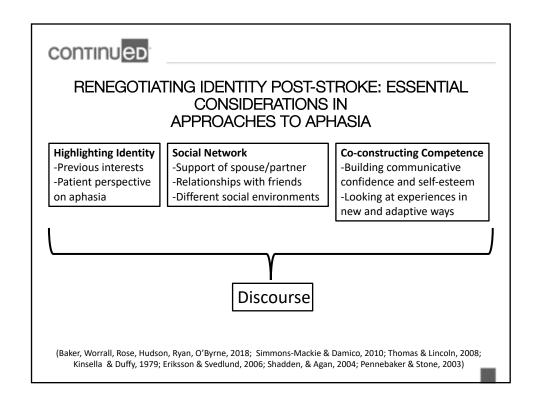
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HOW DOES PROCEDURAL DISCOURSE RELATE TO IDENTITY?

Incorporating meaningful activities in therapy



CONVERSATIONAL DISCOURSE AND IDENTITY







CONVERSATIONAL DISCOURSE

- Conversation is the "heart of human communication" (Armstrong and Mortensen 2006; Oelschlaeger & Damico, 1998)
 - The root of relationships (Simmons Mackie and Damico, 2007; Lock, et al., 2001)

continued

CONVERSATIONAL DISCOURSE IN THE CONTEXT OF APHASIA

(Hengst & Duff, 2007; Simmons-Mackie, 1998; Simmons 1993, Simmons-Mackie 1993, 1994; Simmons-Mackie & Damico 1993)

- Goals of communication
 - Information exchange
 - Social interaction
- Context: Conversation and natural interaction (vs discrete elements of language)
 - Authentic, relevant, natural contexts
- Idea of communication: dynamic, flexible, multidimensional
 - Collaborative communication (vs. PWA)
 - Adaptations to impairment





CONVERSATIONAL DISCOURSE IN THE CONTEXT OF APHASIA

- Fundamental to self-identity (Fox, Armstrong, Boles, 2009; Simmons-Mackie & Damico, 2007; Shadden, 2005; Schiffrin, 1988, 1994; Simmons-Mackie, 1998; Tannen, 1994)
 - Develop and maintain a notion of self
 - Meet emotional needs
 - Construct social relationships

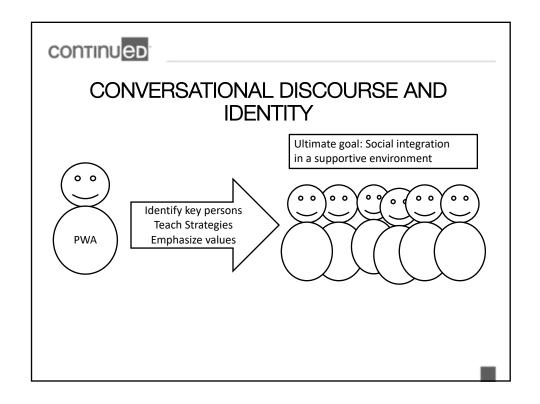


CONVERSATION AND IDENTITY: FOOD FOR THOUGHT

- Improvement in language does not translate to improved QoL (Franzén-Dahlin, Karlsson, Mejhert, & Laska, 2010; Simmons-Mackie & Holland, 2011) in Corsten, Konradi, Schimpf, Hardering, Keilmann, 2014)
- Decreased QoL results from a loss of identity

(Ayerbe, Ayis, Wolfe, & Rudd, 2013; Brown, Worrall, Davidson, & Howe, 2012; Hilari, Needle, & Harrison, 2012; Cruice et al., 2010; Hinckley, 2006) in Corsten, Konradi, Schimpf, Hardering, Keilmann, 2014)





CONVERSATIONAL DISCOURSE AND IDENTITY: PARTNERS MATTER

 PWAs who are surrounded by willing and supportive communication partners are more likely to engage in social activities post-stroke and aphasia

(Dalemans, De Witte, Wade, Van Den Heuvel, 2010)





CONVERSATIONAL DISCOURSE AND IDENTITY: PARTNERS MATTER

- Identify the PWA's social support system
 - Key individuals who may support the PWA and improve communication
 - Essential role of the family (Brown, Worrall, Davidson, & Howe, 2011; Ch'ng, French, & Mclean, 2008)
- Observations and Interviews (Simmons Mackie & Damico, 2007)
 - Significant others
 - Social network analysis
- ASSESS (Simmons Mackie & Damico, 2007; Simmons-Mackie & Damico, 2001, 1996 in Simmons-Mackie & Damico, 2007)
 - Collaborative discourse characteristics
 - Features of relevant contexts
- Train Partners

(Simmons-Mackie, et al., 2010; Simmons Mackie & Damico 2007; Hopper, Holland, Rewega, 2002; Simmons-Mackie & Damico, 2001; Worrall, McCooey, Davidson, Larkins, & Hickson, 2002; Holland, 1998; Parr, et al., 1997, 2003; Simmons-Mackie, 1998)



CONVERSATIONAL DISCOURSE AND IDENTITY: BUILDING BLOCKS

- Strengths-based approach: natural interactions between PWAs and communication partners
- Essential features (Worrall, 2014)
 - Turn taking
 - Repairing communicative breakdowns
 - Managing topics
 - Maintaining topics



CONVERSATIONAL DISCOURSE AND IDENTITY: APPROACHES

- Supported Conversation for AphasiaTM
- Conversational Coaching
- Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC)
- Counseling
- Education

*Script training

continued

CONVERSATIONAL DISCOURSE AND APHASIA: SAMPLE STRATEGIES

PWA

- Using various modalities (gesture, drawing, writing, verbalization)
- Requesting for help
- Requesting for more time

Communication partner

- Decreasing interruptions
- Facilitating comprehension
- Encouraging use of various modalities
- Rephrasing PWA utterance during communication repairs





CONVERSATIONAL DISCOURSE AND IDENTITY: EVALUATING INTERACTIONS

 The Measure of Skill in Supported Conversation (MSC) – rates the conversation partner

(Kagan, Simmons-Mackie, & Shumway, 2018; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004, Kagan et al, 2001)

 Measure of Participation in Conversation (MPC) – rates the level of participation of PWAs

(Kagan, Simmons-Mackie, & Shumway, 2018; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004, Kagan et al, 2001)



CONVERSATIONAL DISCOURSE AND IDENTITY: EVALUATING INTERACTIONS

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(Kagan, Simmons-Mackie, & Shumway, 2018; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004, Kagan et al, 2001)

Explicit Acknowledgment of Competence	Implicit Acknowledgment of Competence
"I know that you know"	Natural tone of voice
Acknowledging frustration	PWA is an intelligent adult





CONVERSATIONAL DISCOURSE AND IDENTITY: EVALUATING INTERACTIONS

 Measure of Participation in Conversation (MPC) – rates the level of participation of PWAs

(Kagan, Simmons-Mackie, & Shumway, 2018; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004, Kagan et al, 2001)

Getting the message IN	Getting the message OUT	Verifying
•Using various modalities (gestures, writing, pictures) •Using simple sentences	•Yes/No questions (general- specific) •Fixed choice questions	•Gestures/written key words
•Observing PWA's facial expression, body posture	•One question at a time •Sufficient time to respond	•Repeating message / Recapping conversation
•Eliminating distractions	•Using various modalities to express self (gestures, writing, pictures)	•Expanding on what the person might be trying to say



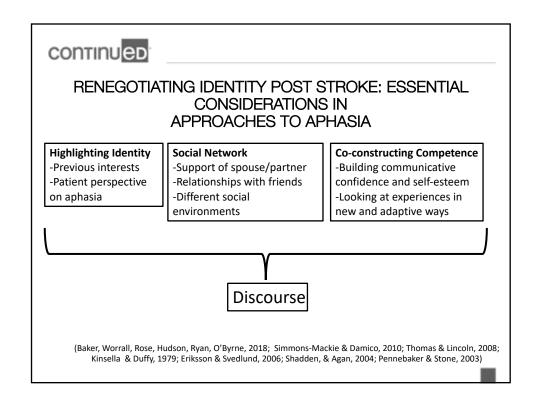
CONVERSATIONAL DISCOURSE AND IDENTITY: SAVING FACE

(Kagan, Simmons-Mackie, & Shumway, 2018; Simmons Mackie & Damico, 2007; Kagan, Winckel, Black, Duchan, Simmons-Mackie, & Square, 2004, Simmons-Mackie & Elman, 2004; Simmons Mackie & Schultz, 2003; Simmons Mackie & Kagan, 1999; Kagan et al, 2001; Goffman 1959, Gumperz 1982, Tannen 1984, Shiffrin 1987)

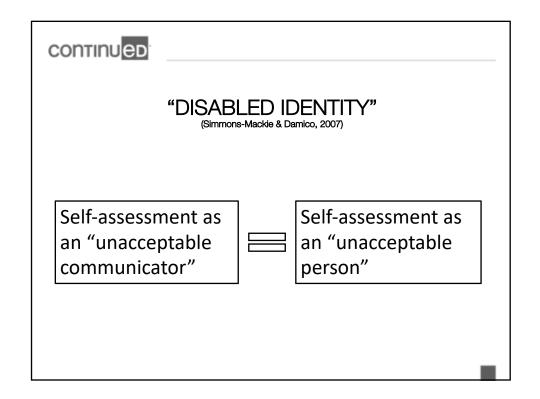
- Saving face vs making meaning
 - Accept and accommodate to the communicative style of PWA (Use all modalities with the PWA)
 - Use humor
 - Identify trouble spots
 - Avoid "Face threatening" behaviors
 - Openly correcting
 - Carrying on extended repair
 - Lacking interest/attention
 - Using overly complex language
 - Failing to demonstrate understanding

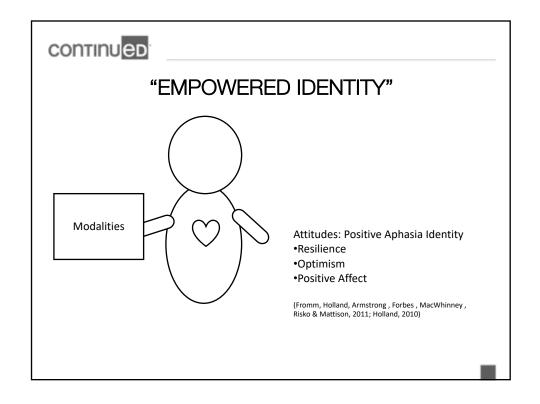


CO-CONSTRUCTING COMPETENCE: THE EMPOWERED IDENTITY











CO-CONSTRUCTING COMPETENCE

 Communication partners must not only have the communication tools but also develop values and beliefs that support communication access (Simmons Mackie and Damico, 2007)

continued

CO-CONSTRUCTING COMPETENCE: VALUES AND BELIEFS THAT SUPPORT CHANGE

- 1. The PWA is a competent person and given the appropriate support, can be a competent communicator
- 2. The PWA has something to contribute to the conversation
- 3. All parties within the interaction bear responsibility for supporting participation and access
- 4. Suitable strategies or supports can be identified through cooperative exploration
- HENCE: PWA and communication partner adopt a new framework
 - · Respect for the PWA
 - Cost of communicative participation is worthwhile



PUTTING IT ALL TOGETHER: SAMPLE CASES

CONTINUED

RENEGOTIATING IDENTITY: OTHER CONSIDERATIONS





EVALUATING THE JOURNEY POST-STROKE

- Reflecting on one's identity post stroke: reshaping one's new social identity (Musser, Wilkinson, Gilbert, Bokhour, 2015; Shadden & Agan, 2004)
 - "Thinking about this time after your stroke, what do you think has helped (or not helped)?" (Grohn, Worrall, Simmons-Mackie & Hudson, 2014)
 - Use of metaphors in describing one's life pre- and post-stroke (Fromm, Holland, Armstrong, Forbes, MacWhinney, Risko, Mattison, 2011; Shadden & Agan, 2004)

continued

EVALUATING THE JOURNEY POST-STROKE

- "How do you think your speech is these days?" (Fromm, Holland, Armstrong, Forbes, MacWhinney, Risko, Mattison, 2011)
 - Values the PWA's opinion
- Needs of PWA s change –continually evaluate the changing needs over time (Wood et al., 2010)





SOCIAL APPROACHES TO IDENTITY: THE BIGGER PICTURE

- 1. Aphasia groups
 - Ideal forum for renegotiation of identity for PWAs and their significant others

(Grohn, Worrall, Simmons-Mackie & Hudson, 2014; Robison, Wiles, Ellis-Hill, McPherson, Hyndman, & Ashburn, 2009; Shadden & Agan, 2004; Lyon & Shadden, 2001 in Shadden & Agan, 2004; Shadden, 1994; Shadden, 1988)

- 2. Other communities
 - 'Mainstreaming' into different social environments (Musser, Wilkinson, Gilbert, Bokhour, 2015)

continued

CONCLUSIONS

- Begin with the end in mind: Promoting a positive social identity (Kagan & Simmons-Mackie, 2007)
 - Empowerment is essential to communicative participation (Simmons 1993, Parr 1996) Simmons-Mackie, 1998
- Implement activities that transition the PWA and families from a therapy context to a social context (Shadden & Agan, 2004)
- Assist PWAs as they renegotiate and reevaluate needs across time (Grohn, Worrall, Simmons-Mackie & Hudson, 2014; Wood, Connelly & Maly, 2010)



ACKNOWLEDGMENTS

- Dr. Hanna Ulatowska
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