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online continuing education for the life of your career

Supporting Clients and Families Living with Moderate to Severe Aphasia

Katie Strong, PhD, CCC-SLP

Moderated by:
Carolyn Smaka, AuD, Editor in Chief, continued



Need assistance or technical support?

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continued

How to earn CEUs

- Must be logged in for full time requirement
- Log in to your account and go to Pending Courses
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continued

Supporting Clients and Families Living with Moderate to Severe Aphasia

Katie A. Strong, Ph.D., CCC-SLP

Department of Communication Sciences & Disorders

Central Michigan University

continued

continued

- **Presenter Disclosure:** Financial: Katie Strong was paid an honorarium by SpeechPathology.com for this presentation. She is the owner of Strong Speech Consulting, Inc. Nonfinancial: Katie is a founding member of the Lansing Area Aphasia Support Group, on the "Virtual Connections for Aphasia" support group leadership team, and a regular host of the Aphasia Access Conversations Podcast.
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Learning Outcomes

After this course, participants will be able to:

- Explain at least two key factors and resources for collaborative goal setting for persons with moderate to severe aphasia.
- List at least three evidence-based intervention practices useful in working with people with moderate to severe aphasia.
- Identify at least two resources available to support clinicians in training family members and other partners in communicating with someone with moderate to severe aphasia.

Meet Steve

- Steve was 52 years old when he had his stroke.
- At the time of his stroke, he was:
 - Married and had 2 teen aged children.
 - Employed as a science teacher for a public high school.
 - Active in a golf league.
 - An avid reader of fiction.
 - President of his local Rotary club.
- After the stroke Steve is
 - Living with moderate to severe aphasia.
 - Unemployed.
 - Struggling with depression.
 - Doesn't see his friends or colleagues much.

Negative Impact of Aphasia (Simmons-Mackie, 2018)

Adverse impact
on quality of life

Negative impact
on community
engagement

Depression

Sense of
helplessness

Reduced
participation in
former activities

Reduced,
limited, or no
friends

Aphasia is
a chronic health condition

Life Expectancy

- Life expectancy in the U.S. =78.6 years (CDC, 2017)
- 34% of people hospitalized with stroke were younger than 65 (CDC, 2012)

At 52 years of age, Steve
could live 25+ years
beyond his stroke.

continued

Life Participation Approach to Aphasia (LPAA Group 2001)

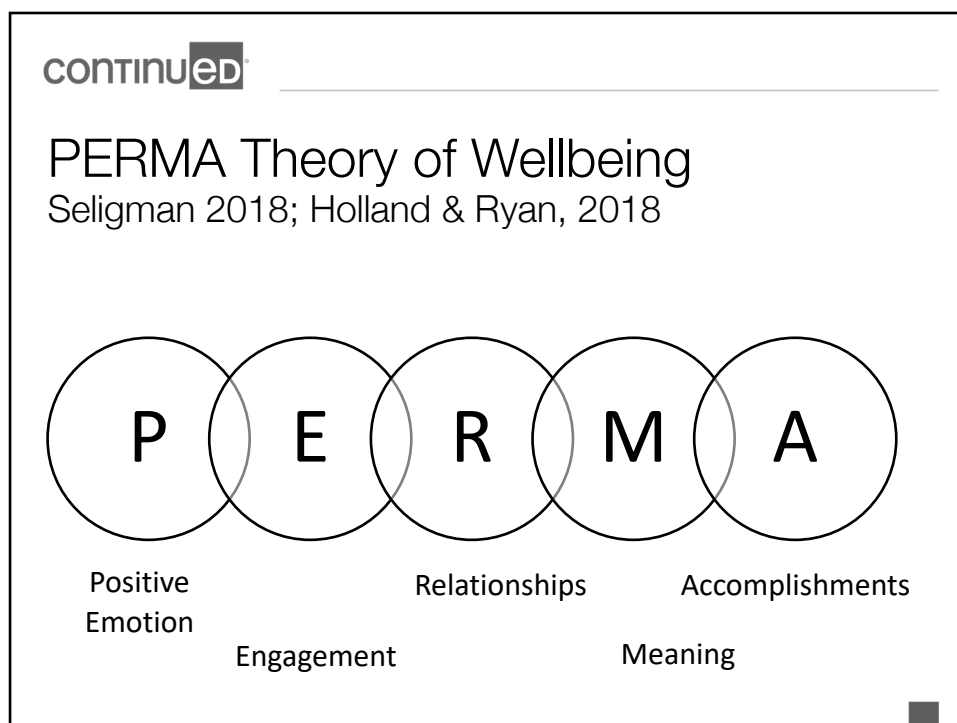
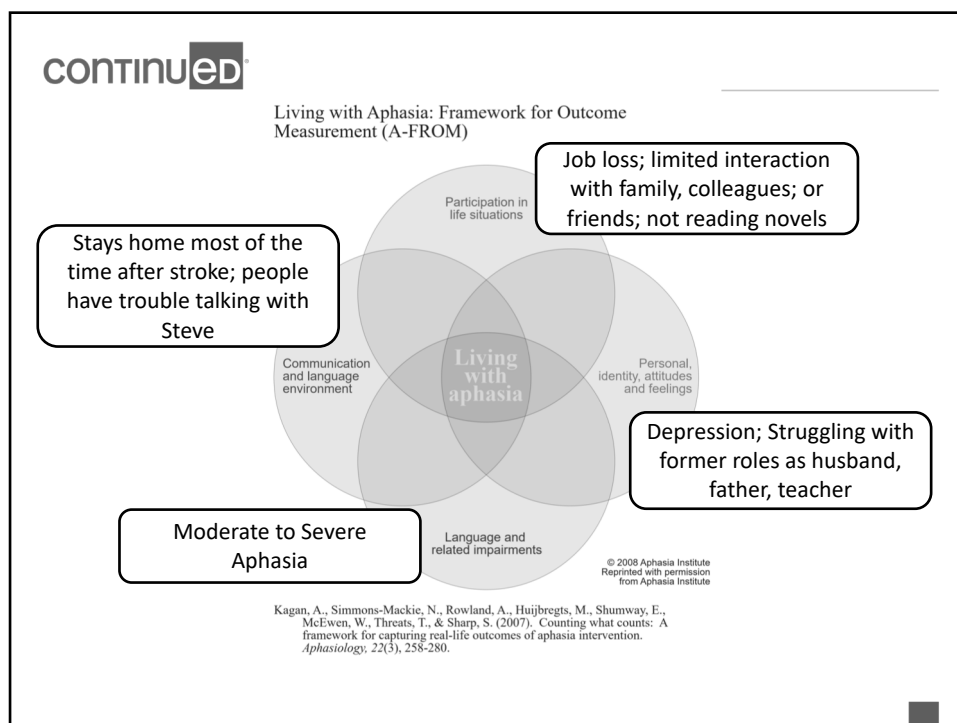
- Explicit goal is enhancement of life participation.
- Everyone affected by aphasia is entitled to service.
- Success measures include documented life enhancement changes.
- Both personal and environmental factors are intervention targets.
- Emphasis is on availability of services as needed at all stages of aphasia.

continued

What does embracing LPPA look like? (Simmons-Mackie, 2021)

- **Choice** - Closely tied to identity, requires listening to our clients about their hopes
- **Meaningful outcomes** - Reaching beyond language to participation; Meaningful is in the eye of the beholder
- **Environment** - Physical & social factors in home & community
- **Care Partners** - Involvement in therapy and support of their own wellbeing
- **Identity and Emotional Experience** - Psychosocial health, connection of language to identity

Q1



continued

Relationship-Centered Care

Worrall et al., 2010

- Relationship between client and clinician is at the heart of our care



continued

Collaborative Goal Setting

Focusing on Wellbeing and Relationship from the Beginning

continued

SMARTER Goals

Hersh et. al, 2012

- **S**hared
- **M**onitored
- **A**ccessible
- **R**elevant
- **T**ransparent
- **E**volving
- **R**elationship-centered

Specific
Measurable
Achievable
Realistic
Time-bound

Q2

FOURC Model

Haley, Cunningham, Barry, & de Riesthal 2019

- Collaborative process for working with clients to identify and pursue self-identified goals, coordinate interventions, and achieve real life outcomes.
- <https://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals/fourc-model/>



continued

Life Interests and Values (LIV) Cards

Haley et al. 2010

- Facilitate goal setting in sessions and assessments
 - Client with aphasia, family member, friend
- Contain black-and-white drawings of life activities
 - Home and Community
 - Creative and Relaxing
 - Physical
 - Social
- Questionnaire for family or care partner
- <https://www.med.unc.edu/ahs/sphs/card/resources/liv-cards/>

Q4

continued

Goal Attainment Scaling (GAS)

Krasny-Pacini et al. (2016)

- Individualized outcome measure of success for each client but scored in a standardized way.
- Communication and collaboration with all team members
- Client involvement.
- Successful outcomes are agreed upon prior to intervention.
- <https://www.sralab.org/rehabilitation-measures/goal-attainment-scale>

Q5

continued

continued

GAS Steps

Turner-Stokes (Kings College)

1. Identify the goals
2. Weigh the goals (Weight = importance x difficulty)

Importance	Difficulty
0 = not at all important	0 = not at all difficult
1 = a little important	1 = a little difficult
2 = moderately important	2 = moderately difficult
3 = very important	3 = very difficult

3. Define expected outcome
4. Score baseline
5. Goal attainment scoring

Q5

continued

Goal Attainment Scaling (GAS)

Turner-Stokes (Kings College)

- Scoring:
 - +2 = much more than expected
 - +1 = somewhat more than expected
 - 0 = achieves expected level
 - -1 = somewhat less than expected
 - -2 = much less than expected

Q5

continued

Steve's Goals

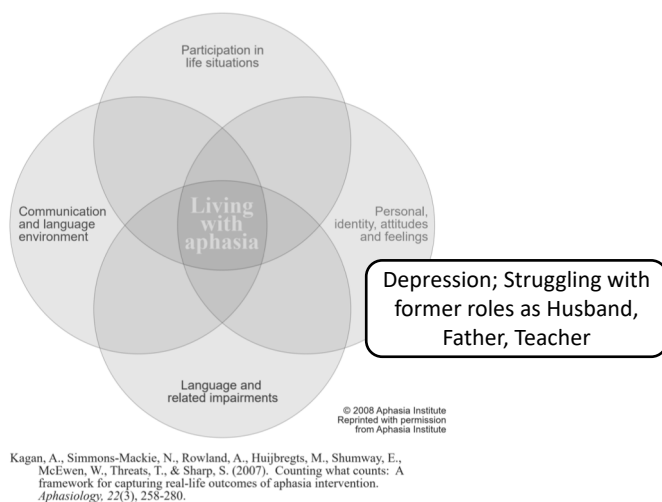
- LPAA and A-FROM used to see Steve beyond language impairment
- Used LIV cards during SMARTER goal setting with FOURC model to establish three areas to target.
 - Talk more to other people.
 - Feel more confident to go out for breakfast and talk with his golf league buddies.
 - Connect with family and Rotary friends through email.
- Use GAS to measure progress goals

continued

Evidence-Based Intervention Practices

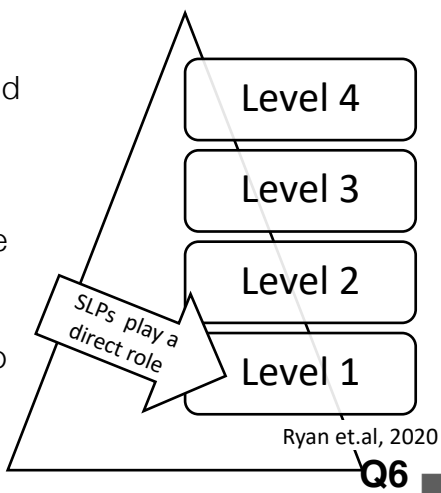
Targeting Identity and Environment Domains

Living with Aphasia: Framework for Outcome Measurement (A-FROM)



Stepped Psychological Care

- A framework for addressing mental health needs
- Matches the current needs and severity of symptoms to the appropriate level of care
- Levels 1 & 2: Include routine mood screening & appropriate interventions for mood symptoms.
- Levels 3 & 4: For moderate to severe depression.



CONTINUED



Level 1 Intervention provided by SLPs (Ryan et. al, 2020)

- Biographic Narrative Therapy (Corsten et. al, 2015)
- Psychosocial group support focused on sharing of personal experience with other people with aphasia (Brumfitt & Sheeran, 1997)
- Aphasia Action Success and Knowledge (ASK) therapy (Ryan et al., 2017)
- Solution-focused brief therapy (Northcott et. al, 2015)
- Modified motivational interviewing (Holland et al, 2017)

Q6

CONTINUED

Power of Story in Supporting Identity Strong & Shadden, 2020; 2021

- Stories are powerful tools in moving life forward post stroke and with aphasia.
- Supporting the development of personal narratives to allow identity reconstruction falls within LPAA/A-FROM
- SLPs are well-suited to support identity renegotiation in persons with aphasia through narrative reconstruction

Q7

CONTINUED

continued

Taking the PULSE of Those Living with Aphasia

Strong & Shadden 2020, 2021

- Partnerships
- Uniqueness
- Listening
- Supporting
- Exploring



continued

Connecting People Living with Aphasia

With Other People Living with Aphasia.....

Support Groups

continued

continued

Support Group Finders

- American Heart Association
 - <https://www.stroke.org/en/stroke-support-group-finder>
- National Aphasia Association
 - www.aphasia.org
- **ACTION STEP:** You can also REGISTER your own support groups on these websites.

Q8

continued

Online Communities

Connecting people living with aphasia with other people who are living with aphasia

continued

continued

Aphasia Recovery Connection

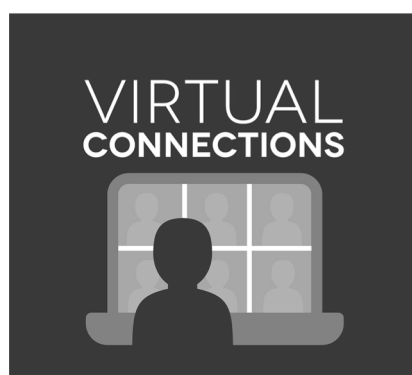
- 10,000+ members on Facebook Community
- Group members can:
 - Meet others with aphasia and their caregivers & families
 - Help new group friends stay in touch
 - Learn the latest information about aphasia
 - Help each other through difficult times
- <https://www.aphasiarecoveryconnection.org/>



Q8

continued

Virtual Connections



Aphasia Recovery Connection
& Lingraphica

- New collaboration since COVID-19
- Goal – ending isolation of aphasia
- 2-3 groups daily, 7 days per week
- <https://devices.aphasia.com/virtual-connections>























Q8

continued

continued

Recent weekly offerings

<https://devices.aphasia.com/virtual-connections>

<div>  VIRTUAL CONNECTIONS Aphasia Recovery Connection & Lingraphica </div> <div> JULY 27 - AUGUST 2, 2020 <small>ALL TIMES ARE IN THE EASTERN STANDARD TIME ZONE</small> </div>						
MON - 27	TUES - 28	WED - 29	THURS - 30	FRI - 31	SAT - 1	SUN - 2
11 AM LET'S TALK! ENTERTAINMENT 	10 AM CAREGIVER SUPPORT GROUP 	11 AM MIND AND SPIRIT 	11 AM WHAT ARE YOUR FAVORITE THINGS? 	11 AM MOVE TO THE MUSIC 	11 AM RHYTHM & MELODY 	1 PM THROUGH THE DECADES 
2:30 PM TV CLUB: 	12 PM COFFEE CHAT 	1 PM MUSIC 	7 PM CAREGIVER OPEN CHAT 	1 PM BOOK CLUB 	1 PM THRIVING WITH APHASIA 	3 PM OPEN CHAT 
4 PM WOULD YOU RATHER? 	1:30 PM COMMUNICATION RAMPES FOR APHASIA 	6 PM OPEN CHAT 		2:30 PM THINK POSITIVE! APHASIA SUPPORT CLUB 		

Q8

continued

Getting Online for People with Aphasia

- New resource from the Stroke Association
- <https://www.stroke.org.uk/what-is-aphasia/communication-tools/getting-online-people-aphasia>
- Guide has 14 sections including
 - Online Basics
 - Online Safety
 - Connecting to wifi
 - How to send an email
 - Using Google maps
 - Social media
- Adding videos with step by step guidance

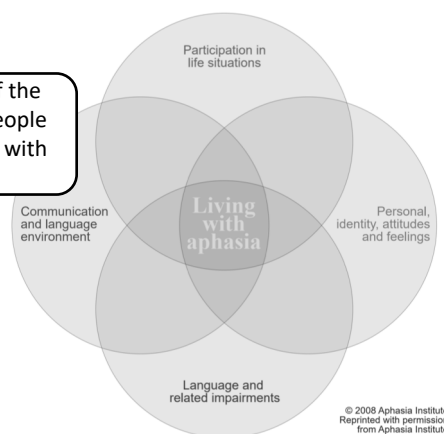
Q8

continued

continued

Living with Aphasia: Framework for Outcome Measurement (A-FROM)

Stays home most of the time after stroke; people have trouble talking with Steve



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Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E.,
McEwen, W., Threats, T., & Sharp, S. (2007). Counting what counts: A
framework for capturing real-life outcomes of aphasia intervention.
Aphasiology, 22(3), 258-280.

continued

Resources to support clinicians in training families

continued

Communication Partner Training

Has been shown to be an effective approach for **improving communication activities** and/or **participation** of some communication partners.

Level 1 Evidence to support Communication Partner Training (Simmons-Mackie et al., 2010)

Q9

Who is a communication partner?

- Family
- Friends
- Physicians, Nurses, other rehab team members
- Mental health professionals
- Direct care providers such as patient care technicians
- Community members (restaurant servers, barbers, nail technicians, etc)

Q9

continued

Supported Conversation for Adults with Aphasia (SCA) Kagan et al 2001

- The goals of SCA are:
 1. Acknowledge the competence of the adult with aphasia.
 2. Help the adult with aphasia to reveal his or her competence.
 - a) Getting the message IN
 - b) Getting the message OUT
 - c) VERIFYING the message
- Introduction to SCA E-learning Module Aphasia Institute (New Module)

<https://www.aphasia.ca/home-page/health-care-professionals/knowledge-exchange/>

continued

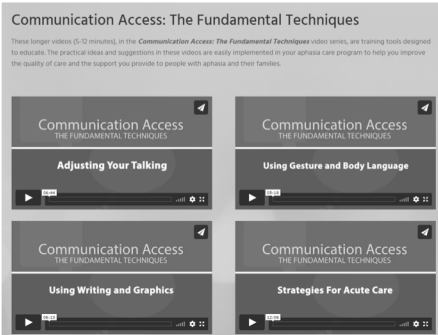
ParticiPics Aphasia Institute

- Free searchable database of pictographic images designed specifically for people with aphasia to be used in conversation.
- <https://www.participics.ca/>

Training Videos

Training tools designed to educate people in becoming better communicators with people with aphasia.

<https://www.aphasiaaccess.org/videos/>



Making Information Accessible

- A.K.A. 'Aphasia Friendly'
- Stroke Association
- Accessible Information Guidelines: Making Information Accessible for People with Aphasia

The Five Steps

There are **Five Steps** to follow

Step 1: A short message

Step 2: Clear sentences

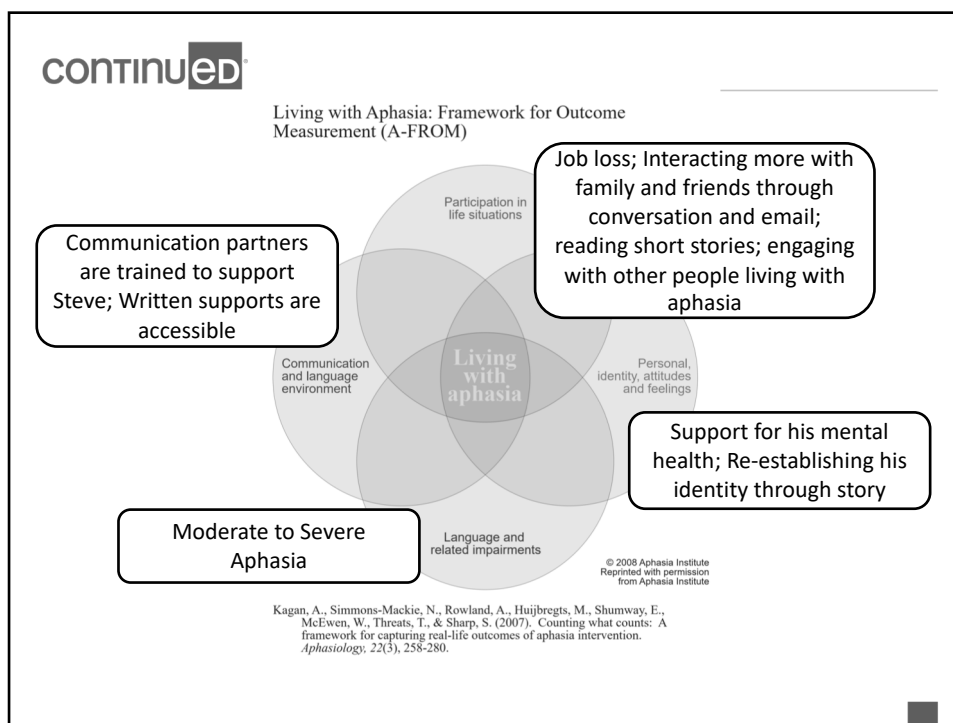
Step 3: Easy words

Step 4: Good layout

Step 5: Make a set

https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf

Q10



continued

Interested in learning more about applying LPAA to your practice?

- Ep 52 - Online Communication Partner Training
- Ep 48 Goal Attainment Scaling
- Ep 42 Importance of Aphasia Advocacy
- Ep 35 SMARTER Goals
- Ep 34 Stepped Care
- Ep 25 L!V Cards
- Ep 23 Relationship-Centered Care
- Ep 19 Environment
- Ep 5 Identity

52 Episodes and counting

AphasiaAccess CONVERSATIONS

Podcast

<https://aphasiaaccess.libsyn.com/>

Concluding Thoughts

- LPAA, A-FROM, PERMA
- Collaborative Goal Setting for Meaningful Outcomes beyond Language Impairment
 - SMARTER goals; FOURC; LIV Cards; GAS
- Intervention targeting identity
 - Stepped Care
 - Being open to support story
- Intervention targeting environment
 - Communication Partner Training
 - Making information accessible
 - Connecting with other people living with aphasia

Thank you!

- Questions?

Resources

- PERMA – Positive Psychology <https://ppc.sas.upenn.edu/learn-more/perma-theory-well-being-and-perma-workshops>

Collaborative Goal Setting

- FOURC Model - <https://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals/fourc-model/>
- Life Interests Values (LIV) Cards - <https://www.med.unc.edu/ahs/sphs/card/resources/liv-cards/>
- Goal Attainment Scaling - <https://www.sralab.org/rehabilitation-measures/goal-attainment-scale>

Aphasia Access

- Training Videos <https://www.aphasiaaccess.org/videos/>
- Podcasts - <https://aphasiaaccess.libsyn.com/>

Aphasia Institute

- ParticiPics <https://www.participics.ca/>
- Introduction to SCA E-learning Module Aphasia Institute <https://www.aphasia.ca/home-page/health-care-professionals/knowledge-exchange>

Resources

Stroke Association

- Getting Online for People with Aphasia <https://www.stroke.org.uk/what-is-aphasia/communication-tools/getting-online-people-aphasia>
- Accessible Information Guidelines: Making Information Accessible for People with Aphasia https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf

Support Group Finders

- American Heart Association <https://www.stroke.org/en/stroke-support-group-finder>
- National Aphasia Association www.aphasia.org

Online Aphasia Communities

- Aphasia Recovery Connection <https://www.aphasiarecoveryconnection.org/>
- Virtual Connections <https://devices.aphasia.com/virtual-connections>

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