



# Methods: Measures



- Demographics
- Religious Coping
  - Brief RCOPE
- Spirituality – meaning, peace and faith
  - FACIT-sp
- Caregiver Preparation and Completion –
  - QUAL-E fam
- Caregiver Anxiety
  - POMS
- Caregiver Depression
  - CES-D
- Caregiver Grief
  - PG-12
- Subjective Caregiver Burden
  - Caregiver Reaction Assessment

# Caregiving Descriptors



- Caregiver Intensity
  - hours of caregiving / 24 hour period
- Duration of Caregiver Relationship
- Quality of Patient-Caregiver Communication-  
Personal Resource Questionnaire items
- Objective Burden –
  - Caregiver Reaction Assessment sub-scale

# Analyses



## Quantitative

- Examine feasibility of outcome measures pre and post intervention, examine initial patterns of change

## Qualitative

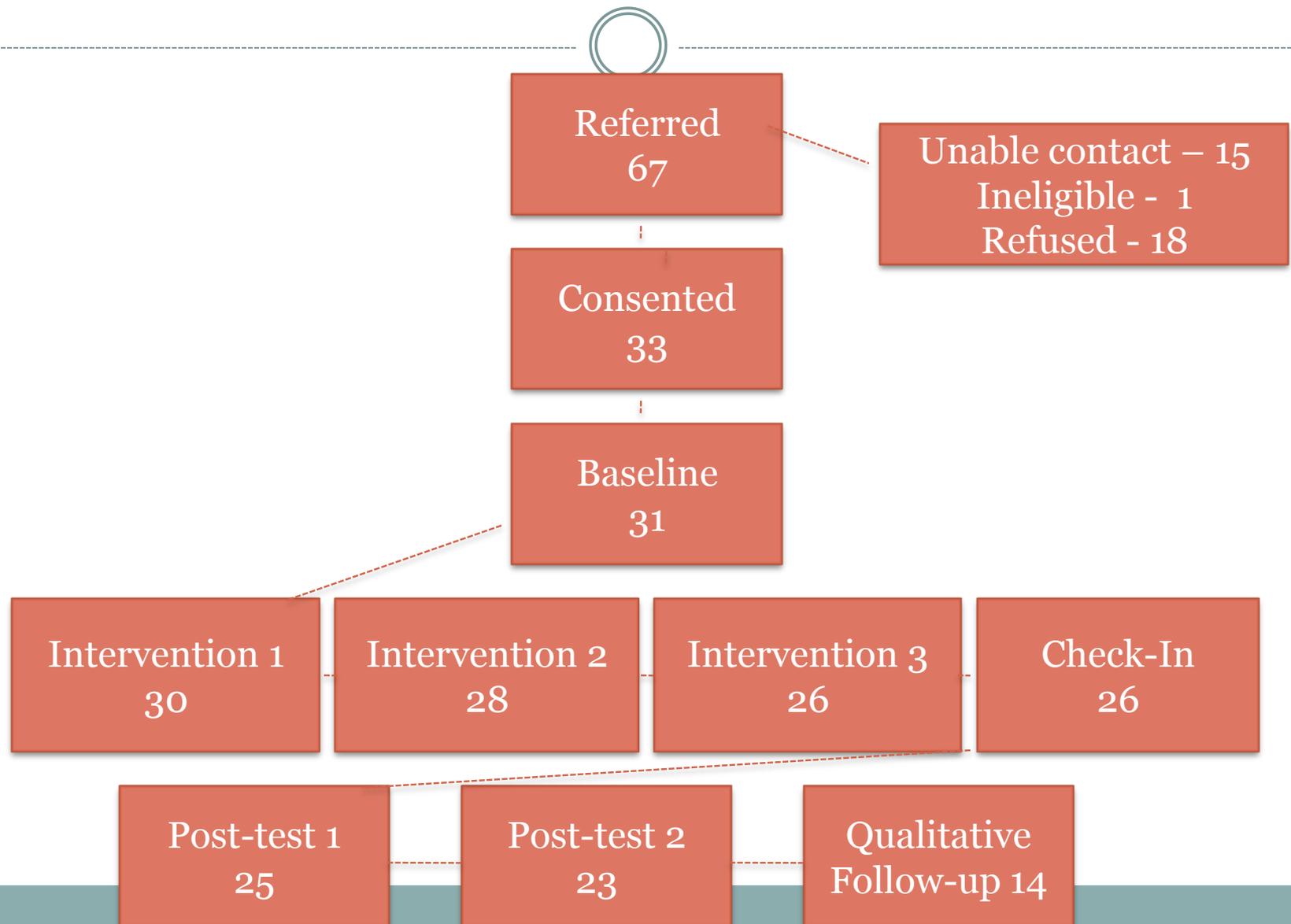
- Thematic Content
  - Open Coding
  - Compared by sub-groups
- Opportunity for spiritual assessment
  - Develop coding scheme

# Results



- Feasibility and acceptability
  - Participation rates
  - Participant characteristics
- Caregiver discussion themes
- Was the intervention something to be integrated with spiritual assessment and chaplaincy care?
  - Chaplain acceptability
  - Integration with chaplaincy work

# Participation Rates: Study Flow



# Participant Characteristics



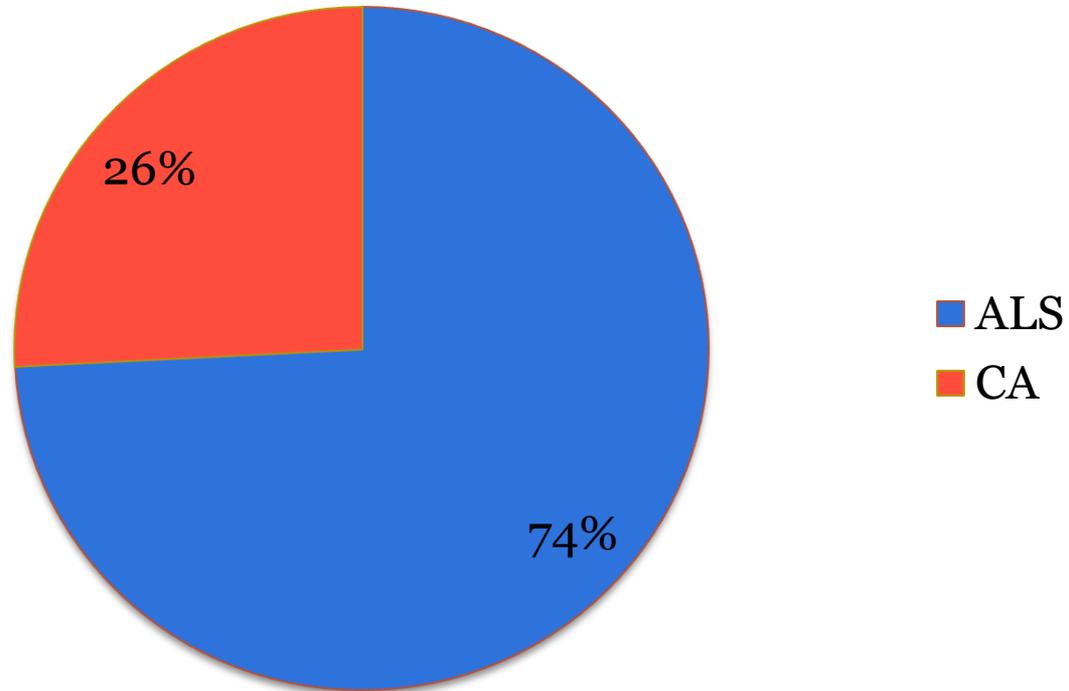
<b>Gender</b>	<b>Female</b>	<b>Male</b>	<b>Total - 31</b>	
	55%	45%		
<b>Marital Status</b>	<b>Married/Liv Together</b>	<b>Div/Sep/Wid/Single</b>		
	84%	16%		
<b>Age</b>	<b>Mean (years)</b>			
	60.5			
<b>Race</b>	<b>African American</b>	<b>Caucasian</b>		
	16%	84%		
<b>Relationship to patient</b>	<b>Spouse/Partner</b>	<b>Daughter/Son</b>	<b>Mother/Father</b>	<b>Other</b>
	74%	13%	3%	3%

# Caregiver Characteristics (cont.)



<b>Education</b>	<b>&lt;=12 years</b>	<b>Some post HS</b>	<b>College or Post Grad</b>	
	32%	23%	45%	
<b>Financial situation</b>	<b>Having difficulty paying bills</b>	<b>Can pay bills after cutting back</b>	<b>Can pay bills but little spare money</b>	<b>After paying bills have money left over</b>
	7%	23%	26%	53%

# Patient Diagnoses



# Time Spent Caregiving



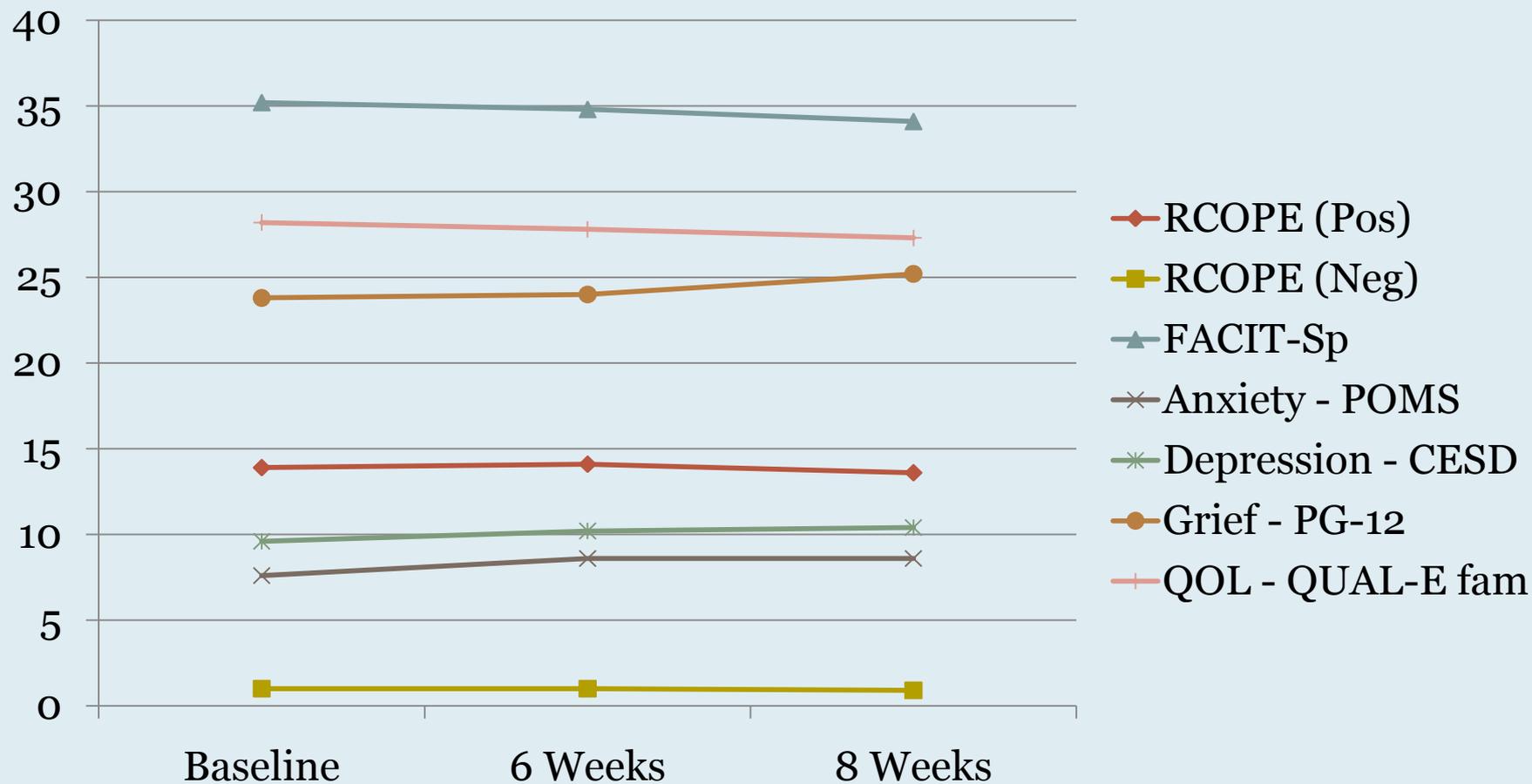
<b>Yrs spent caring for loved one</b>	<b>&lt; 1 year</b>	<b>&gt;=1 but &lt; 3 yrs</b>	<b>&gt;=3 but &lt; 5 yrs</b>	<b>&gt;=5 yrs</b>
	52%	16%	19%	13%
<b>Hrs/day spent on duty for pt</b>	<b>&lt; 4 hrs/day</b>	<b>5-8 hrs/day</b>	<b>9-16 hrs/day</b>	<b>&gt; 16 hrs/day</b>
	52%	29%	16%	3%

# Caregiver Religiosity



Caregiver Religiosity						
<b>Religion</b>	<b>Christian</b>	<b>None</b>				
	95%	5%				
<b>Importance of faith in life</b>	<b>Very</b>	<b>Somewhat</b>	<b>Not at all</b>			
	84%	7%	8%			
<b>Time in private religious/spiritual activities</b>	<b>&gt; once a day</b>	<b>Daily</b>	<b>&gt; 2 times/week</b>	<b>Rarely or never</b>		
	39%	32%	16%	7%		
<b>Attend church or other religious meetings</b>	<b>&gt; once/week</b>	<b>Once a week</b>	<b>A few times a month</b>	<b>A few times a year</b>	<b>Once a year or less</b>	<b>Never</b>
	23%	23%	17%	20%	3%	13%
<b>Do you consider yourself...</b>	<b>Not at all religious</b>	<b>Only slightly religious</b>	<b>Fairly religious</b>	<b>Deeply religious</b>		
	10%	13%	30%	47%		

# Outcomes over Time



# Caregiver Discussion Themes



- **Motivation for Caregiving**
  - Love, duty, faithfulness, calling, compassion, gratitude, reciprocity, growth
- **Caregiving Challenges**
  - Information seeking, wrestling with mortality, reflecting on self and without loved one, difficult daily tasks, caregiver stress, role changes.
- **Learning from Caregiving**
  - Patience, prioritizing, self-realization, previous caregiving as foundation, personal and relational growth
- **Narrative Life Themes**
  - Quest, chaos, on-script, off-script

# Caregiver Themes (cont.)



- **Grief and Loss**
  - Anticipation of future death, current disability, and loss of former functioning, broken relationships, expectations, questioning legacy, unresolved guilt or shame, failure, dissonance between hopes and dreams and current state, regret.
- **Spiritual strengths and Journey**
  - Walking the path of God's will, religious support, rituals, faith as coping, right faith, transformation, peace, forgiveness, steadfastness, resilience
- **Spiritual/religious Struggle**
  - Religious history or "negative coping"

# Caregiver Motivation: Love



“Well, people tell me all the time, ‘You’re such a good man.’ [I] ain’t a good man; I serve a great God and I have a wonderful wife...And, this is what I’m having to do. She feels like I’m having to do it, but it’s a joy that I’m able to do it. So, the caregiver part is love.”

# Caregiver Motivation: Duty



“My husband and I have not always had an easy relationship - we are very different. We have a shared value system that has kept us together and it has also kept me in the marriage at times where I felt that I was not that happy...Our biggest problem is his drinking...last night he drank a whole bottle of wine and slipped and fell in the kitchen... Since he's two hundred pounds, it's very hard for me to get him up. So, ... I valued my marriage vows, and I was determined to make it work. And sometimes I don't think I was very wise in doing that for myself.”

# Learning from Caregiving



“I’m stronger than I thought and weaker than I thought. I depend on God a whole lot more than I thought I did. I learned that just because I think it’s impossible, do it anyways, ‘cause it’s not.... And, when you get it all done and you’ve accomplished - you’ve done the chore. And then I say, what have I learned about? - I’m still learning, still learning.”

# Grief and Loss



“I feel at peace, somewhat but I can’t say that I feel 100% at peace, ‘cause I still, part of me thinks I can do something, or we can do something to stop the disease. I still get that obsession kind of thing, I just wanna fight it. I don’t wanna go quietly into the night. I think that disturbs some of my peace, thinkin’ of what can we do, to fight it? What can we do to slow the progression down? But as far as peace where, do I know where his soul will go - I am at peace with that. I’m just not at peace with him dyin’, to be honest.”

# Spiritual Struggle



“To take care of somebody and you know that they’re possibly dyin’ ...you have to try to get in their head and almost understand their fears. It’s not just the fact that she’s sick and not able to do some things for herself and in pain, but it her spiritual self, you have to try and get in and understand that. ‘Cause she seems to be afraid. I don’t think she’s afraid of passin’ on. I think she’s afraid of how we’re gonna be without her. I think she think that somewhere deep down in the back of her mind and deep in her heart that she might be leaving us... abandoning us.”

# Spiritual Journey



“We never questioned God, what He’s doin’ or why He’s doin’ it, you know. It’s in His hands. And I believe that He’s got everybody’s life laid out in a plan that they should walk in or live in and go with it and do the best they can with what they got. Sometimes things don’t always go our way, according to our schedule or plan, you know. We just got to roll with the punches, with what God sends down the pike and that’s just the way it is.”

