

*“Listen to me”*  
*Non caregiving adult children’s needs from*  
*healthcare providers*

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# Background

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Extended lifespans, globalization and transnational migration will significantly reshape twenty-first century societies (Horn & Schweppe, 2015; The United Nations, 2015).

In the United States, more than half the population may live up to 80 years of age, with much of that time in a relative state of good health (Arias, 2015).

Adult children can expect to spend time as equal adults in this non-caregiving relationship with their aging parents.

Little known about pre-caregiving family experience

# Aim & Method

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Purpose: explore ways in which nurses can assist non caregiving adults to navigate a life-stage that involves independent but aging parents.

Hermeneutic phenomenology

Interviews

- *“What can Healthcare providers do to help you in this life stage? “*
- Purposive sampling
  - must have a parent(s) over 65 years of age
  - must not self-identify as a caregiver for parent/s
  - must speak English.

# Data Analysis

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Independent coding and categories

Joint review

Constant comparison to identify similarities and differences

Themes and meta theme created with mutual verification

Age		
30-49	9	56.25
50-69	7	43.75
Gender		
Female	12	75.00
Male	4	25.00
Education		
Pre - Baccalaureate Degree	1	6.25
Baccalaureate	4	25.00
Post-Baccalaureate	11	68.75
Race/ ethnicity		
White American	10	62.50
African American	2	12.50
Jewish	1	6.25
South Asian	1	6.25
Western European	2	12.50

# Participants (N=16)

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All had at least one child/step child

88.88% of the parents over the age of 70

N=11 (68.75%) had both parents alive

N=4 had one parent with cognitive/  
physical impairment

# Results

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## Caregiving anyway

### Worry

#### *Sources of concern*

1. Potential loss of parental good health
2. Lack of holistic approach by HCPs in care of aging parent
3. Fragmented and inadequate communication
4. Self-care challenges

#### *Strategies for care*

1. Pre-planning or anticipatory guidance
2. Care Navigator
3. Family centered holistic care

# Care-giving anyway

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*For the first time, I am useful to them*

*She's given up driving, and so, I'm doing a little bit more of that for her.*

*We were there two weekends ago and my Mom said would you mind, would you and [spouse] flip and rotate the mattress?*

*And then, obviously, my sisters around here will take her to doctor's appointments as required.*

# Worry: Potential loss of parental good health

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*Some point you're going to deteriorate health-wise, whatever that looks like. How do you prepare for that?*

*It's not going to be like this forever*

*It's like a matter of waiting for the other shoe to drop*

*He's not going to be there forever, at least not in this stage*

*Though you can imagine that in a few years, even that (cognition) is going to slip and she's not going to remember everything and that she'll misremember something and I'll be more in charge*

# Worry: Lack of holistic and individualistic approach

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## Knowing the individual

*They don't exactly ask the right questions*

*The (one thing the) doctors have really botched, is that they haven't really been tracking her cognition...I just wasn't satisfied with how that was happening*

*(No one) ...is keeping tabs on decline/ changes*

## Understanding family

*There's got to be an understanding of the family members... Just having a good relationship with your kids is not the same thing as sharing (information, resources, support)."*

# Worry: Lack of holistic and individualistic approach

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## Appreciating cultural context

*They tell you, recite something that you know very well by instinct like ABCs, or, you know, like Happy Birthday. So they tried to get him to say that. My dad is not really a happy birthday singer. But then like when my cousin came over, he said, can you say the Kalma\*? Because that is something that you just know. And he said it and it came so easily to him. So, it's just the cultural context is important."*

# Worry: Fragmented Communication

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*Her issues have been more around people listening to what she knows about the body that she's been in for 84 years...I would just like her HCP to stop and listen*

*With the health care community the way it is [you can't] contact a nurse or social worker. As a daughter I have no right to any information*

*I don't want to be BS'ed so to speak. Don't ask me to smell the roses, just tell me. Speak the language that I understand because I don't understand these large [terms]. Just tell me. Communicate with me*

*There are a lot of different players and it's complicated, and it's very broken down...it's not easy*

# Worry: Self care challenges

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*I've felt guilty about saying I just can't take care of another thing. My father called me for something...and I said, dad, I just can't do it.*

*I'm taking care of my wife and my daughter and I'm letting myself go.*

*I'm real conscientious about taking care of myself*

*If you don't take care of yourself you're not going to be able to take care of somebody else.*

# Strategies for care: Anticipatory guidance

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*I think we should have those pre-when-this-stage-of-life, the-before-medical-disaster-hits, or declining-health seminar. It could be something like what to do? How do you get to people to really prepare for “it’s not going to be like this forever”?*

*It would sort of ease the path if there was somebody who was clearly trained in those systemic issues so they could tell you that this is what you have to be doing and this is how you are doing it and so forth*

# Strategies for care: Care Navigator/ Helper

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*I think especially elderly folks need a representative, like someone who can navigate them through the process*

*At some point you just need someone who knows what to do and knows the legal issues and knows the finances*

*...to help him, to take him to his appointments and things like that, that would be really helpful..*

*I feel like if there's anything society would need especially with the aging epidemic it's that we need to figure out how to provide better care-management support in the home that's accessible to people*

# Strategies for care: Family centered holistic care

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*I think nurse practitioners are wonderful. Whenever I come across them, they're much different... they are much more helpful to the patient as a person, not just the illness or the disease*

*This nurse practitioner is a good example. My Dad was impressed with the fact that when he went she asked him like, Okay, so do you have a living will? Are you estranged from your children? Do you see them? ... I think it is important for healthcare professionals to, because not all parents and children are on a good level*

*I am glad you know, that they know my family already. The doctors and nurses that I've dealt with so far, they know my mom and what my mom has had medically, and my father. So they will turn around and they'll go, "OK, well, we know mom and dad. Now we want to take a look at you and make sure you're on the right track*

# Implications

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Assess intergenerational family unit

Assess adult children for sources of stress

- Anticipatory loss related to parents' health and functional status
- Self care needs
  - Sibling support

Communication strategies

- With aging adult
- With adult child/children

Future research that explores best practices

- Anticipatory loss
- Communication across international lines

# Conclusion

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Adult children spend time assessing their parents for possible needs and providing support

Adult children seek guidance as they anticipate a potentially stressful demand for care

Concern regarding HCPs' communications with adult children, especially those living internationally

Culturally safe care

Confirmation of findings with globally diverse researchers and participants