

The HPPAE cohort of 2013:
Presents

**CAREGIVERS' GUIDE TO NUTRITION:
A COMPREHENSIVE GUIDE FOR INDIVIDUALS
CARING FOR OLDER ADULTS**

INTRODUCING:

CAITLIN BUTTERS

ERIN KULISHEK

COURTNEY ORTZ

LAUREN POLITO

ELIZABETH ZIMMERMAN-CLAYTON

Group Process

- Tasks based on personal strengths
- Split group to work on different parts of the whole

Why Nutrition and Care giving?

Choosing a Topic

- Common interest in food
- Question posed on personal, professional caregiving role.

Why is it
Important?

- Only 5% of elderly live in LTC facilities
- 95% live in community
- Most receive care by informal supports
- Perceived knowledge is greater than actual knowledge
- Malnutrition and Older Adults

- Research suggests malnutrition is twice as likely to occur with homebound older adults
- Associated with serious health consequences, including:
 - Mortality
 - Morbidity
 - Decline in physical and cognitive functioning
 - Decreased quality of life
 - Weakened immune response
 - Increased risk of developing osteoporosis
 - Increased risk of institutionalization

Literature Review

The background features a dark gray field with a light gray grid of small dots. At the bottom, there is a decorative graphic consisting of a bright green trapezoidal shape pointing downwards, which is partially overlaid by a yellow shape that also points downwards, creating a layered effect.

- Survey nutritional knowledge of family caregivers
- In this study, caregivers' average score on the nutritional knowledge scale was a 57.9% (SD +/- 12.1).
- Previous studies have found a gap between caregivers' perceptions and knowledge about the nutritional needs of older adults

Cass (1997)

- Conducted systematic review of feeding difficulties in older adults with dementia
- Caregiver strategies to help the older adults get food into the mouth and the ability of the older adult to chew and swallow food is often difficult

Chang and Roberts (2008)

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- Malnutrition can be a significant concern for older adults with dementia
 - Intake is influenced by
 - appetite,
 - food preferences,
 - sensory changes,
 - difficulty swallowing
 - self-feeding challenges.
 - food, refusal to eat, inability to perform coordinated movements, wandering away from table and eating nonedible objects

Keller et al. (2008)

- Interviewed formal care providers to discuss their experiences with the nutritional needs of family members
- Assessed the quality of nutrition resources for families
 - Nutritional topics covered
 - Correspondence to principles of adult learning
 - Organizational design

Keller et al. (2008)

- Common nutritional issues providers experienced included:
 - “decreasing appetite and stove safety issues,
 - food preferences,
 - refusal to eat,
 - food safety,
 - understanding their nutritional needs,
 - unfavorable eating behaviors (i.e., turning away from food, resisting assistance, agitation),
 - overeating,
 - swallowing problems,
 - eating nonedible objects,
 - difficulty self-feeding,
 - getting enough fluids”

Keller et al. (2008)

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- Researchers found a lot of the resources available for families are too detailed
 - Some resources did not provide enough examples or suggestions.
 - The content of resources was not in line with the previously listed concerns of families.
 - Most resources tend to focus on swallowing.

Keller et al. (2008)

Methods

Developing the Survey

- Our next step was to conduct a needs assessment on caregivers in the community to understand their needs in terms of their loved ones nutrition.
- In order to collect this information, we had several options:
 - *Focus groups
 - *One-on-one interviews
 - *Surveys

Developing the Survey

We decided on the survey for several reasons:

- It can be standardized; Everyone we sampled was asked the same questions.

Our response set would be consistent

- Length of time to complete

- Shortest amongst other options

- Cost efficient

- Easy to Distribute

We wanted our survey to include the following information:

- *Understanding of caregivers' help-seeking behaviors
- *What information caregivers felt it was important to know about nutrition?
 - *Caregiving activities:
 - *How long?
 - *What do they care for?
 - *Does the person have any chronic diseases?
 - * How often do they prepare meals or go grocery shopping?
 - *Caregivers' perception of nutrition:
 - *How well they feel they understand the nutritional needs of older adults?
 - *How well they feel their loved ones' nutritional needs are being met?

Developing the Survey

Our survey has a mixture of open- and close-ended questions:

- *Open-ended questions allow for participants to write their own responses in

- *Close-ended questions have participants select their answer from listed choices

- *Whether we used an open- or close-ended question, depended on the type of information we wanted from the caregivers

Developing the Survey

- After completing our first draft, we have several people outside of our group look at our survey:
 - *It was beneficial for us to have this feedback
 - *Given suggestions on our wording and ordering of questions
- Once our survey was completed, we needed to find our sample.

Developing the Survey

Applying to the IRB

- Exempt versus nonexempt
 - Filling Out the Application
 - Getting Approval from Support Groups
 - Writing Introductory Letter
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Distributing Survey

- First goal: How do we find people to fill out survey?
- Decided to reach out to caregiver support groups and adult day centers, as well as an online survey monkey
- Sent research proposal to Family Caregiver Alliance, that hosts student research for free
- Compiled a list of support groups by calling AAoA, researching Alzheimer's Association, Allegheny resource guide, Internet searches

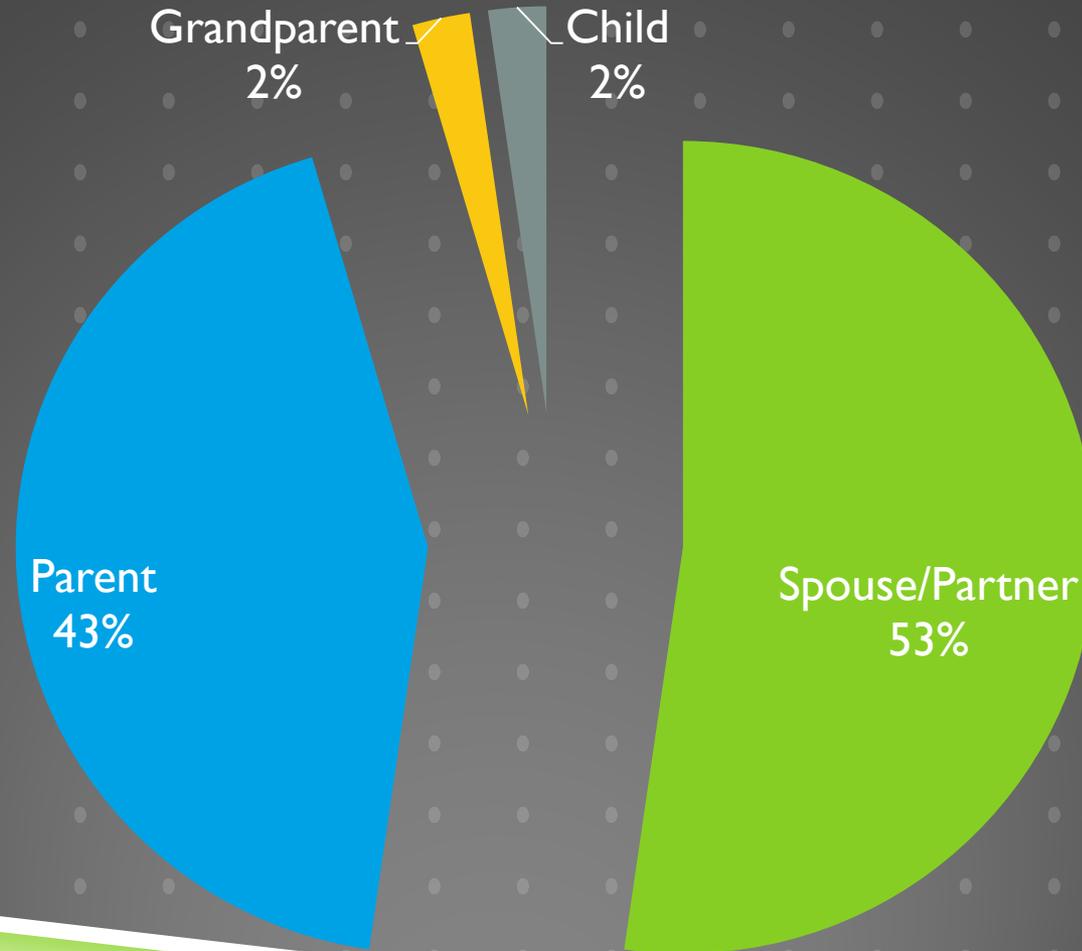
- Split the list down and call each agency to ask if they would be willing to participate
- We were able to attend 4 support groups, one adult day center and had online participation through Family Caregiver Alliance.
- Set a due date of March 1st for all surveys to be returned to us via email, in person pick up, or online

Distributing Survey

- Compiled all survey answers into the Survey Monkey account to make it easier to calculate specific needs
- We sat in pairs when putting the surveys in to the survey monkey to ensure no errors occurred

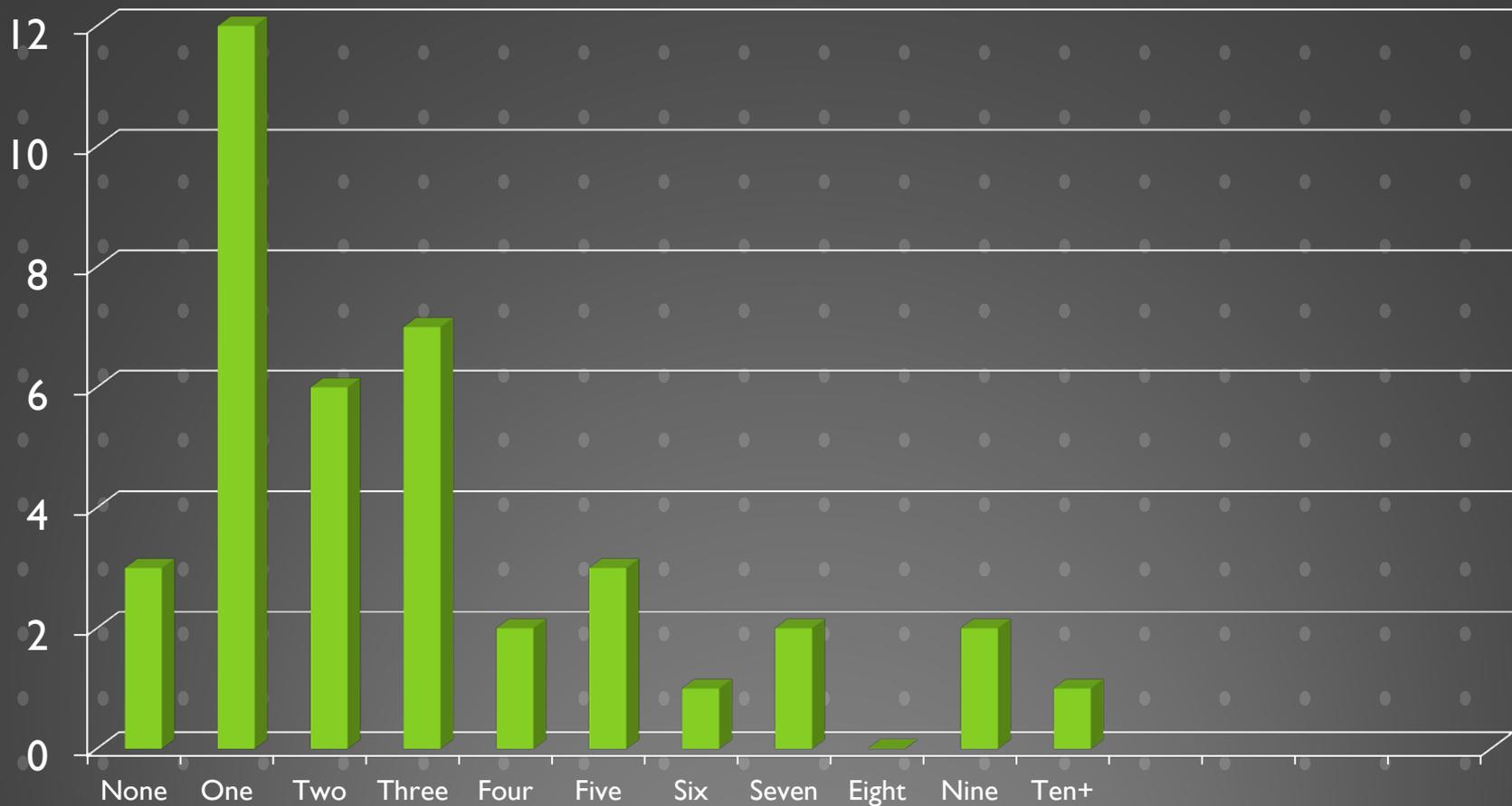
Data Analysis

Who do you provide care for?



How long have you been an elder caregiver?

- Mean: 6 years
- Median: 5 years
- Range: 24 $\frac{3}{4}$ years
 - Longest: 25 years
 - Shortest: 3 months

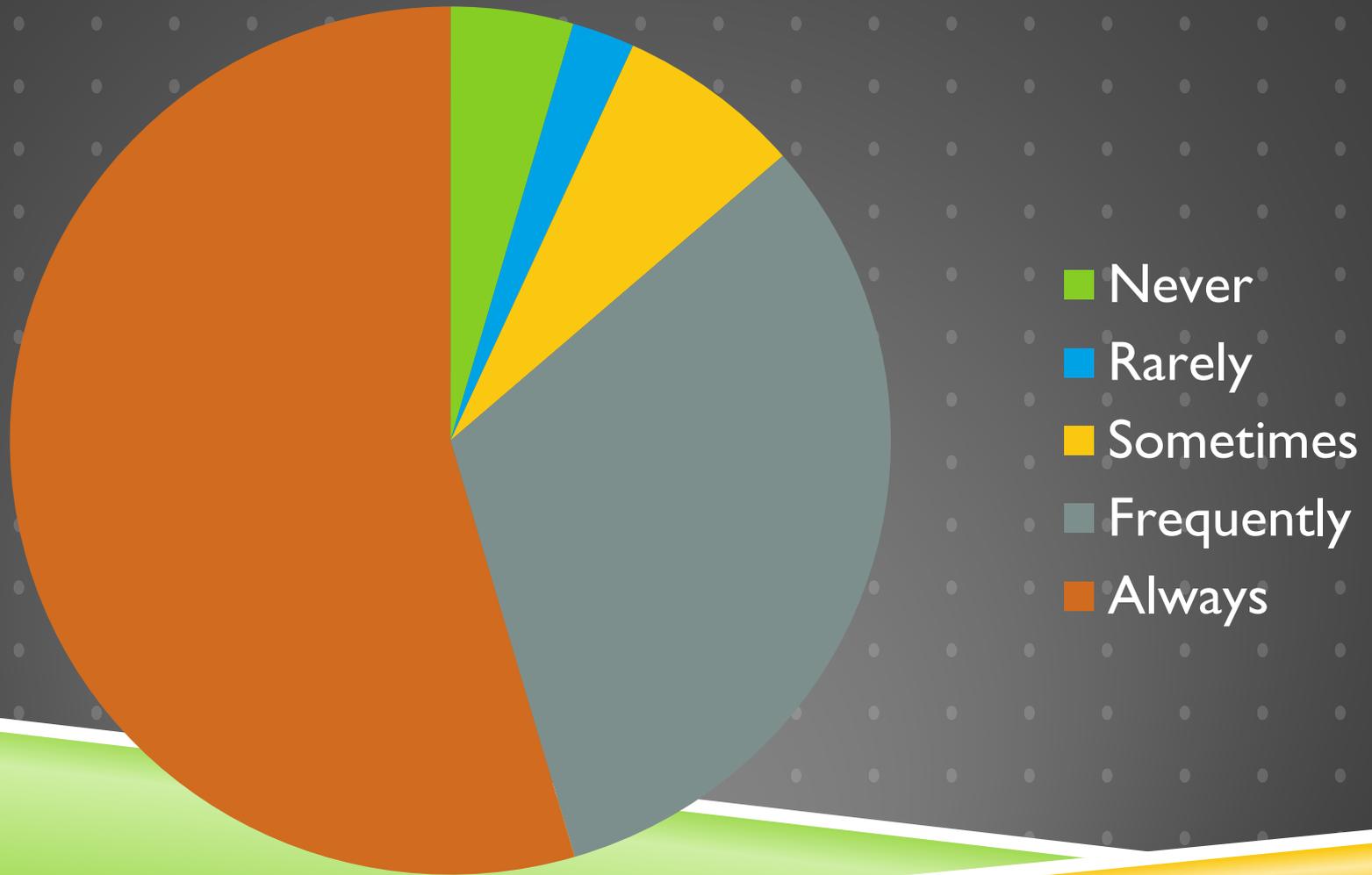


How many chronic conditions does this person have?

Top chronic conditions listed in response to Question 3

- Alzheimer's Disease /Dementia (24)
- Cardiovascular issues (13)
- Diabetes (8)
- Depression and Anxiety (7)
- Arthritis (4)

How often do you prepare meals for the individual you care for?





Rate how well you feel this individual's nutritional needs are being met.



Rate your knowledge on the nutritional needs of older adults.

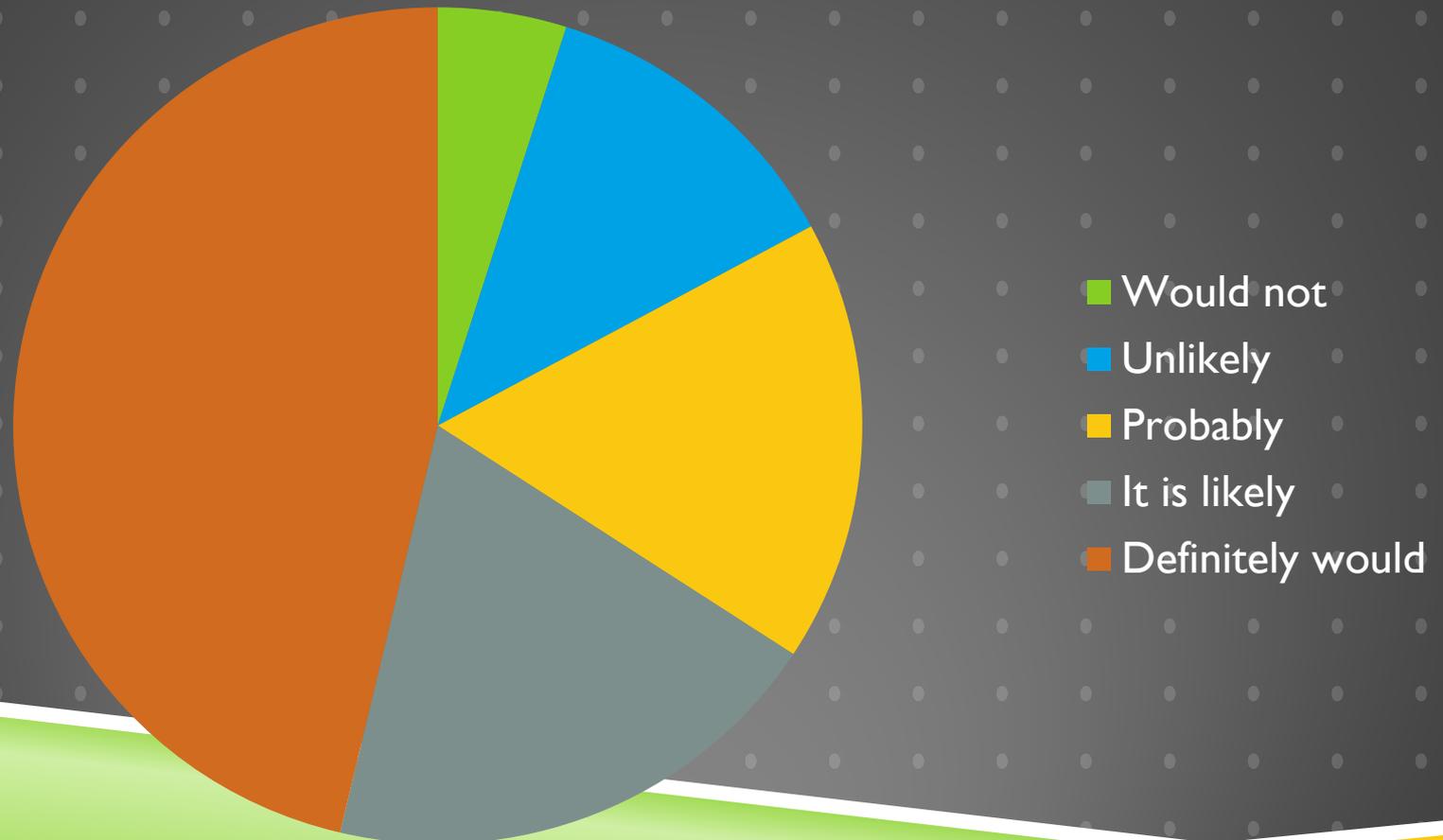
- Responses fell into one or more of the following categories:
 - Meal planning (n=10)
 - Creating interest in eating (n=6)
 - Community resources (n=4)
 - Healthy/organic eating (n=4)
 - Foods for memory (n=2)
 - Nutrition for older adults (n=2)
 - Food/medicine interaction (n=1)
 - Specific nutritional concerns (n=1)
 - Swallowing

What do caregivers need to know more about in regards to older adult nutrition?

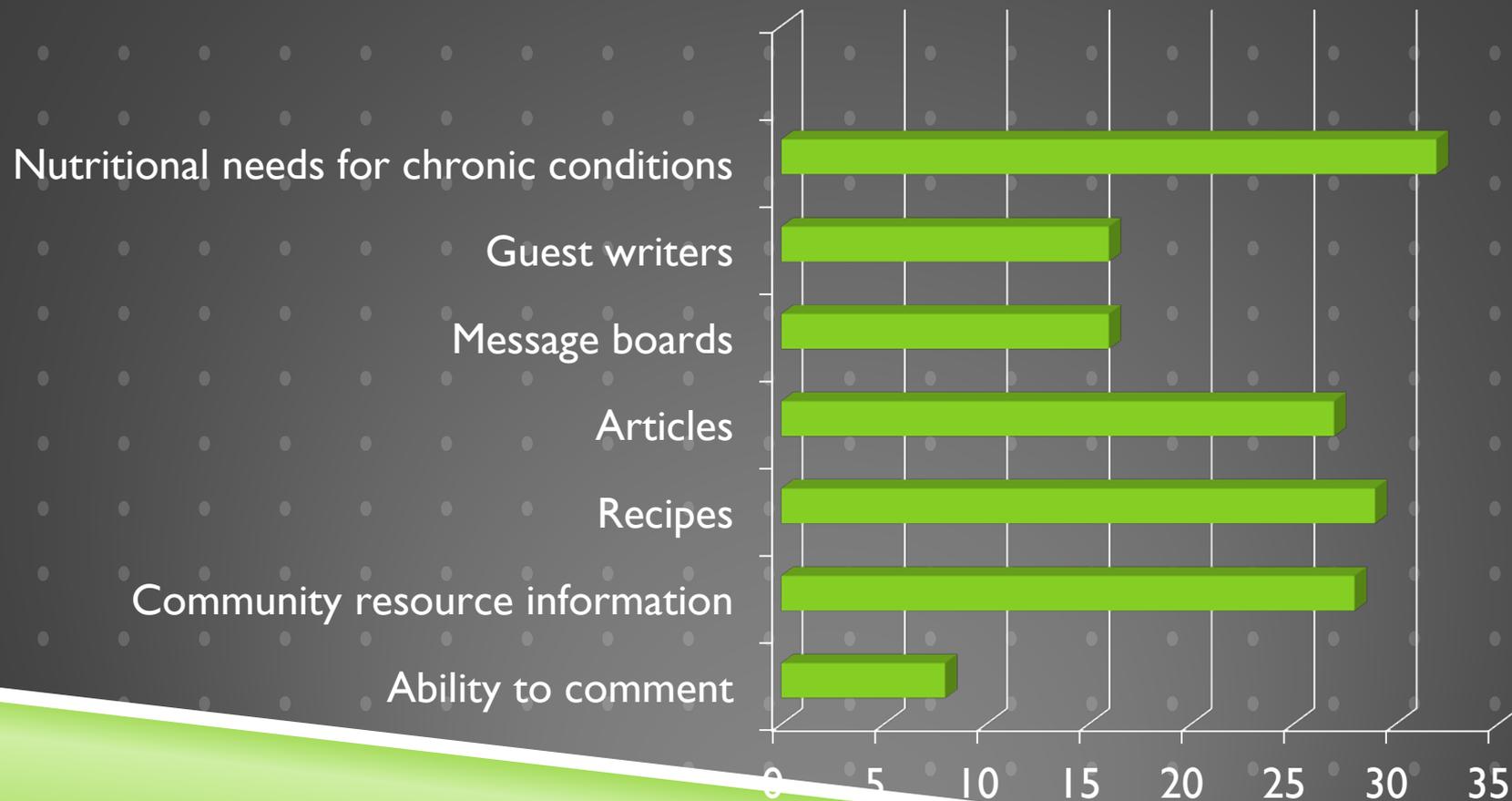
- Responses fell into one or more of the following categories:
 - Internet (n=14)
 - Reading (n=13)
 - Professional/professional organization (n=10)
 - Self-knowledge (did not site a specific information source, common sense) (n=6)
 - Formal education (n=4)
 - Have not previously searched for information (n=3)
 - Support group (n=3)
 - Work (n=3)
 - Television (n=2)

How have you obtained information regarding the nutritional needs for the person you provide care for in the past?

Rate the likelihood that you would utilize a website that provides information on nutrition as it relates to caregiving.



Which of the following would you like to see on the website?



Question 10 Continued

- Caregivers could also write in a response to Question 10:
 - Holistic approaches to nutrition
 - Links to videos
 - Information on nursing homes
 - Meetings through the site
 - Community and connection on the site

Discussion

Exploratory

- We were curious to find out what the specific needs would be for caregivers if we were to create an online community resource for nutrition
- We hoped to find out what kinds of topics they would be interested in and what sorts of formats they would like to see

Our respondents...

- Six reported a desire for additional information on how to create better interest in eating for care recipient. One person reported a need for more resources for 'issues with swallowing.'
- 24 reported that they care for someone with Alzheimer's Disease or Dementia

- Past research from Chang and Roberts (2008) suggests that caregivers of persons with dementia may need better resources on strategies to get care recipient to chew/swallow
- Keller et al. (2008) echoes the importance of maintaining interest in food. Findings suggest that refusal to eat, appetite, and difficulty swallowing are factors that influence malnutrition for older adults with dementia.

Compared with past findings...

Strengths

- Cost effective/time efficient method.
- We went to people that are a good source of information for our topic by going to caregiver support groups that were willing to participate. Our respondents are the most experienced since they have cared/care for an older adult

Strengths

- Past research suggests that most nutritional resources for caregivers do not have enough specific suggestions/examples
- We listed common elements of online community resources so that respondents could select ones which they thought they would utilize.

Limitations

- We did not assess demographic information of participants.
- Our sample only reflects a small portion of caregivers. We surveyed caregivers located predominantly in Allegheny county, with some online submissions for which we do not know the location
- Our sample was purposive, so not very generalizable to the greater population of caregivers.

Limitations continued

- Similar to findings presented by Cass, 1997, there could be a disconnect between caregivers' perception of nutrition knowledge and what they actually know.
- Social desirability– Since we surveyed people who are caring for older adults, they may have been more likely to report in a way that reflects favorably on the quality of care
- We found a minor formatting error in the survey. Participants could not easily see one of the answer options, we had to discard the answer entirely.

- Responses allowed us to have a concrete focus for blog discussions/topics
- Allowed us to provide specific requests that caregivers have expressed a need for
- Overall, major request was for better resource for meal planning. Our website has been geared toward not only providing quick resources for specific nutritional needs, but for examples of how to maintain these needs.

Implications for the website

Implications for site continued..

- Findings from Keller et al. (2008) also suggest that caregivers found many resources to be “too detailed” which means they might benefit from more simple and concise advice
- We have taken this into consideration and made every attempt to create site that is user friendly and easy to navigate

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- It would be best to take an assessment that reflects senior nutrition knowledge for participants to take so that their self-reported knowledge could be compared with their *actual* knowledge of the topic. This may also help to control for social desirability.
 - Does the caregiver relationship make a difference? For example, do partners/spouses have better knowledge than children/younger relative caregivers?
 - Past research has mostly focused on physical health and nutrition for older adults. It would be beneficial to look at mental health and nutrition.

Implications for future studies