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# Innovation in Developing Evidence-Based Programs that Identify and Address the Social and Emotional Needs of Cancer Caregivers: Distress Screening and Referral for Caregivers

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# Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

# Presentation Objectives

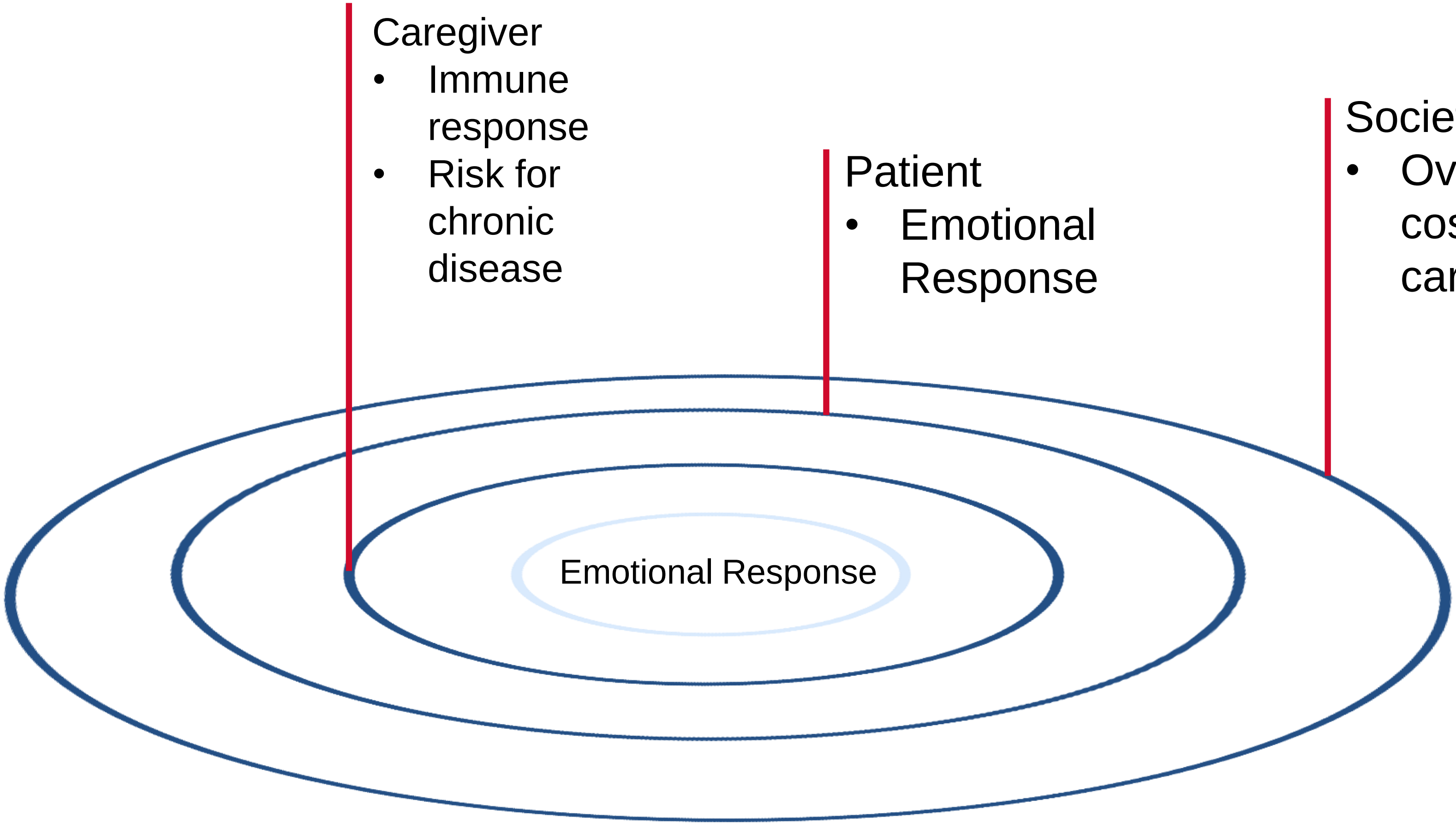
- Why distress screening and referral for caregivers matters
- Overview of the Cancer Support Community's (CSC) history on caregiving
- Describe the development of CSC's distress screening and referral program for caregivers
  - Planning phase
  - Research phases
  - Findings
- Challenges and opportunities in engaging diversity of caregivers
  - A call toward collaboration

# Why distress screening and referral for caregivers….

- Family caregivers are an indispensable component of our national health care resources.
  - The economic value of informal care was estimated at $470 billion in 2013.
- Caring for cancer patients is accompanied by emotional distress.
- Psychosocial distress is associated with poorer outcomes for caregivers and patients.
- While caregiver burden measures exist, there is a lack of validated distress screening and referral programs for cancer caregivers.

**References: Sherwood et al., 2008; Northouse et al., 2012; Litzelman & Yabroff, 2015; Mittleman et al., 1996; Reinhard et al., 2015.**

# Potential implications of caregiver well-being?



Caregiver
- Immune response
- Risk for chronic disease

Patient
- Emotional Response

Society
- Overall cost of care

Emotional Response

References: Sherwood et al., 2008; Northouse et al., 2012; Litzelman & Yabroff, 2015; Mittleman et al., 1996.

# A History of Serving Caregivers at CSC

- 1983: Recognized the vital role of caregivers
- Caregiver survey with NCCS
  - Key findings: 1) Patients thought their caregivers were doing fine, while caregivers reported being under distress; 2) caregivers expressed random acts of kindness
- The CSC Affiliate voice to screen caregivers
  - Currently, 44% of CSC Affiliate care is to caregivers
- A united strategy for screening patients/survivors and their caregivers
  - CancerSupportSource® (CSS) program assesses patients' levels of distress and need, and then helps refer them for help and follow-up care.

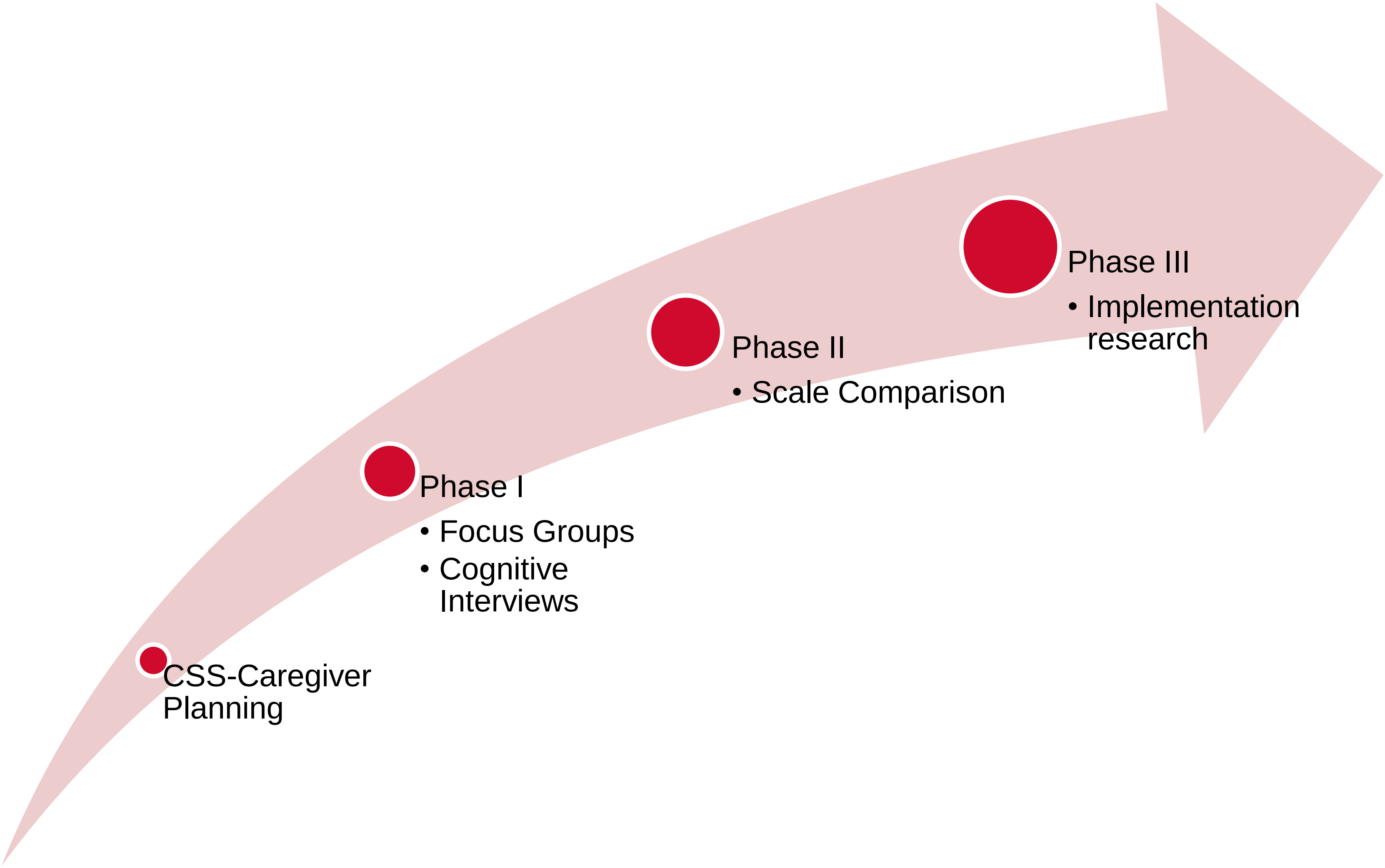
# Proof of Concept: CancerSupportSource-Caregiver

- Can we assess concerns and distress among caregivers, refer them for services or information and follow up?
- Is CancerSupportSource® a feasible foundation?
- What are appropriate comparison scales?
  - Based on advisor input, the selected measures captured the range of the caregiver experience
    - The Center for Epidemiologic Studies Depression Scale (CES-D)
    - SF-12
    - Distress Thermometer (DT)
    - Zarit Caregiver Burden measure (short form)
    - Caregiver Reaction Assessment

# CSS-Caregiver Study Objectives

- To identify problems primary cancer caregivers report, and which are most distressing
- To learn which problems relate to cancer caregivers by age, SES, race, gender, and cancer type
- To validate CancerSupportSource® for caregivers using “gold standard” instruments

# Study Trajectory



CSS-Caregiver Planning

Phase I

- Focus Groups
- Cognitive Interviews

Phase II

- Scale Comparison

Phase III

- Implementation research

# Phase I: Focus Groups Objectives

- To evaluate how well CancerSupportSource® (i.e., patient version) addresses the needs of cancer caregivers and make changes based on their recommendations.
- To receive caregiver input on what changes need to be made to the screening tool so that it is appropriate for the caregiver population.
- Conducted 3 focus groups at CSC Affiliates with 24 total caregivers
  - Cancer Support Community Delaware: 8 Caregivers
  - Gilda’s Club Louisville: 11 caregivers
  - Gilda’s Club Chicago : 5 caregivers

# 25-Item CSS-Patient Version Used to Guide Focus Groups (Based upon IOM, 2007)

- Information about cancer and its treatment and services
  - e.g., Communicating with your doctor
- Help in coping with emotions
  - e.g., Feeling sad or depressed
- Help in managing the illness
  - e.g., Eating and nutrition
- Assistance in changing behaviors to minimize the impact of the disease
  - e.g., Recent weight change
- Material and/or logistical support
  - e.g., Transportation to treatment and appointments
- Help in managing disruptions in work, school, family
  - e.g., Changes or disruptions in work and/or school
- Financial advice and/or assistance
  - e.g., Health insurance or money worries

# Focus Group: Primary Learnings…

- Led to clarifying language in directions
- Led to clarifying language in items
    - “Managing and/or keeping up with **my** health care needs”
    - “Communicating with **the patient’s** health care team “
- Separated out items
    - Changes or disruptions in my home life, work or school (now 2 items)
- New caregiver specific items, such as:
    - “feeling guilty”
    - “Feeling unappreciated”
    - “Maintaining appearances or keeping it all together in front of others”
    - “Feeling that I’m always *on*”

# CSS-Patient Repurposed for Caregiving

- Care for self
  - e.g., Today how CONCERNED are you about the following for YOURSELF?...eating and nutrition
- Management of caregiving roles and responsibilities
  - e.g., Today, how CONCERNED are YOU about the following caregiving roles or tasks (i.e., ways you help)?... Talking with the patient’s doctors and health care team
- Experience of witnessing change or decline of loved one
  - e.g., Today, how CONCERNED are YOU about the following for THE PERSON YOU ARE CARING FOR?... The patient’s pain and/or physical discomfort

# Phase I: Cognitive Interviews Objectives

- A “think aloud” process for caregivers to provide thoughts or opinions about each question.
- 10 phone interviews of caregivers identified via CSC affiliates.
- 3 interviewers with audio-recording and transcription
  - Based upon a cognitive interviewing guide developing based on “Using Cognitive Interviews to Refine a Questionnaire” Garcia (2007)

# Cognitive Interview: Examples of Learning

- Caregivers validated the items
  - Most caregivers understood and supported items
  - At times, caregivers reported a disconnect with a phrase or word:
    - Feeling sad or depressed: “Felt ‘bad’ ‘bummed out’ ‘worried’ but ‘depressed’ is like being on meds”
  - If there was critical mass, then we made changes:
    - Communicating with my healthcare team: “If I get sick what happens - a little redundant.”

# Table 1. Focus Group and Cognitive Interview Participant Demographics (n=34)

| | Frequency (n) | % |
|---|---|---|
| **Female** | 22 | 65% |
| **Non-Hispanic white** | 31 | 91% |
| **Spouse** | 25 | 73% |
| **Age (n=33)** | | |
| 26-38 | 6 | 18% |
| 42-55 | 12 | 36% |
| 48-64 | 6 | 18% |
| 65 or older | 9 | 27% |
| **Household Income* (n=24)** | | |
| < $40,000 | 5 | 21% |
| $40,000-$79,999 | 7 | 29% |
| $80,000 or above | 8 | 33% |
| Prefer not to share | 4 | 17% |
| **Residence* (n=24)** | | |
| Urban | 10 | 41% |
| Suburban | 11 | 46% |
| Rural | 3 | 12% |

*Focus group only

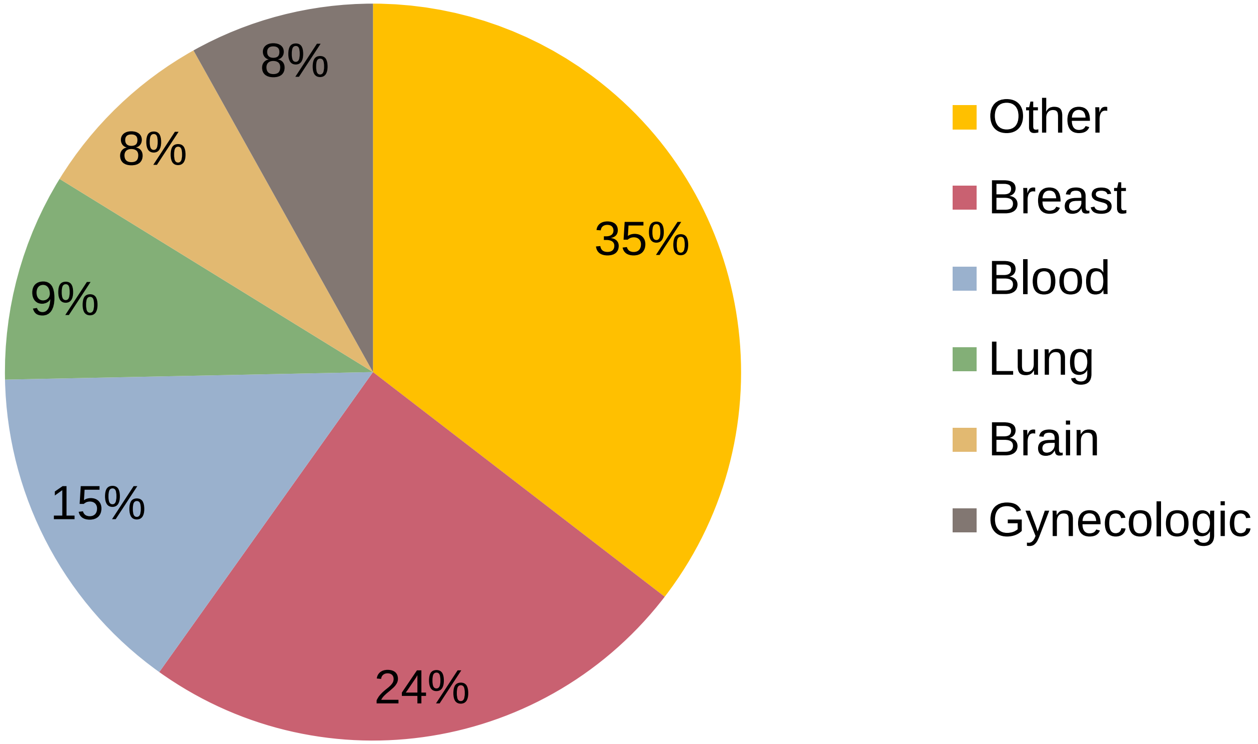
# Phase II: CSS-Caregivers Validation

- 10 Affiliate Recruitment Sites for Validation Study
  - GC Chicago
  - GC Quad Cities
  - CSC Greater St. Louis
  - GC Kansas City
  - CSC Central Ohio
  - GC Madison
  - GC Louisville
  - CSC Delaware
  - CSC San Francisco Bay Area
  - CSC Greater Philadelphia
- Outreach and registration via affiliates
- Web-based platform delivery (link via email following registration)
  - Paper version option
- Enrollment goal of 250-300 caregivers
  - Current enrollment = 221

# Table 2. Phase II Sample Characteristics

| | Frequency (n) | % |
|---|---|---|
| **Gender (n=211)** | | |
| Male | 68 | 32.2% |
| Female | 143 | 67.8% |
| **Race/Ethnicity (n=197)** | | |
| Asian | 6 | 3% |
| Black | 5 | 2.5% |
| Hispanic | 10 | 5.1% |
| Non-Hispanic White | 171 | 86.8% |
| Prefer not to share | 5 | 2.5% |
| **Household Income (n=209)** | | |
| < $40,000 | 34 | 16% |
| $40,000-$79,999 | 47 | 22.2% |
| $80,000 or above | 80 | 37.7% |
| Prefer not to share | 48 | 22.6% |
| **Region (n=210)** | | |
| Urban | 46 | 21.7% |
| Suburban | 135 | 63.7% |
| Rural | 29 | 13.7% |
| **Age (n=206)** | Mean = 53.62 (SD: 113.86; range: 22-83) | |
| **Age Categorical** | | |
| 22-39 | 44 | 21.6% |
| 40-54 | 58 | 28.2% |
| 55-64 | 56 | 27.1% |
| ≥65 | 48 | 23.1% |

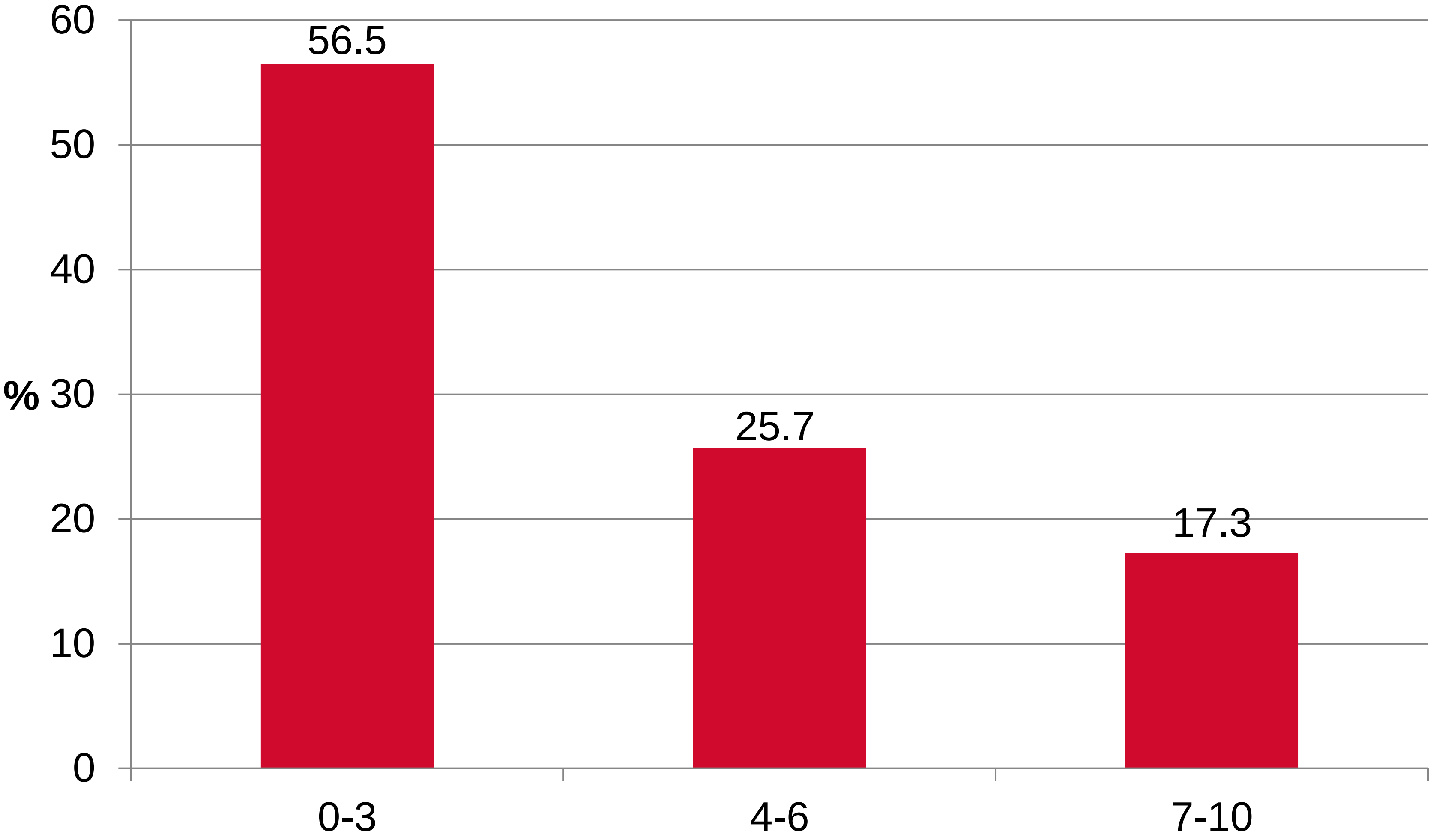
# Patient's Cancer Type (n=209)



# Table 3. Caregiving Characteristics

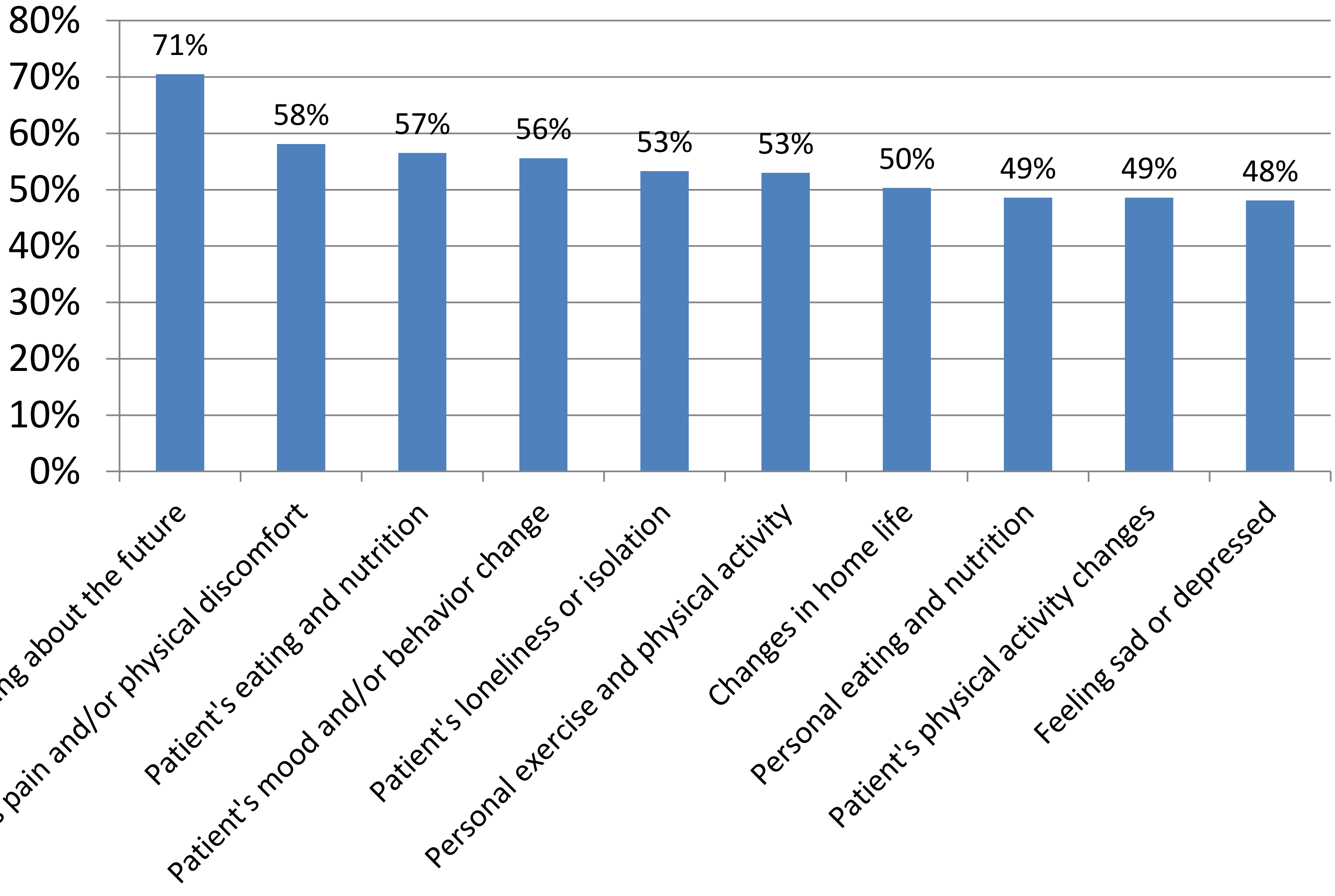
| | Frequency (n) | % |
|---|---|---|
| **Care recipient is: (n=214)** | | |
| Spouse | 126 | 58.9% |
| Parent/In-law | 41 | 19.2% |
| **Active Treatment in Past 2 Years: (n=212)** | | |
| Yes | 173 | 81.6% |
| No | 27 | 12.7% |
| Not applicable | 12 | 5.7% |
| **Hours of care provided/week: (n=210)** | | |
| ≤20 hours | 137 | 65.2% |
| 21-80 hours | 46 | 21.8% |
| >80 hours | 27 | 12.8% |

# Graph 1. Caregiver Self-Reported Distress (n=214)



(Distress Thermometer: 0; not at all -10; extreme distress)

# Table 1. CSS-Caregiver top concerns, moderate, serious or very serious concern (n=214)



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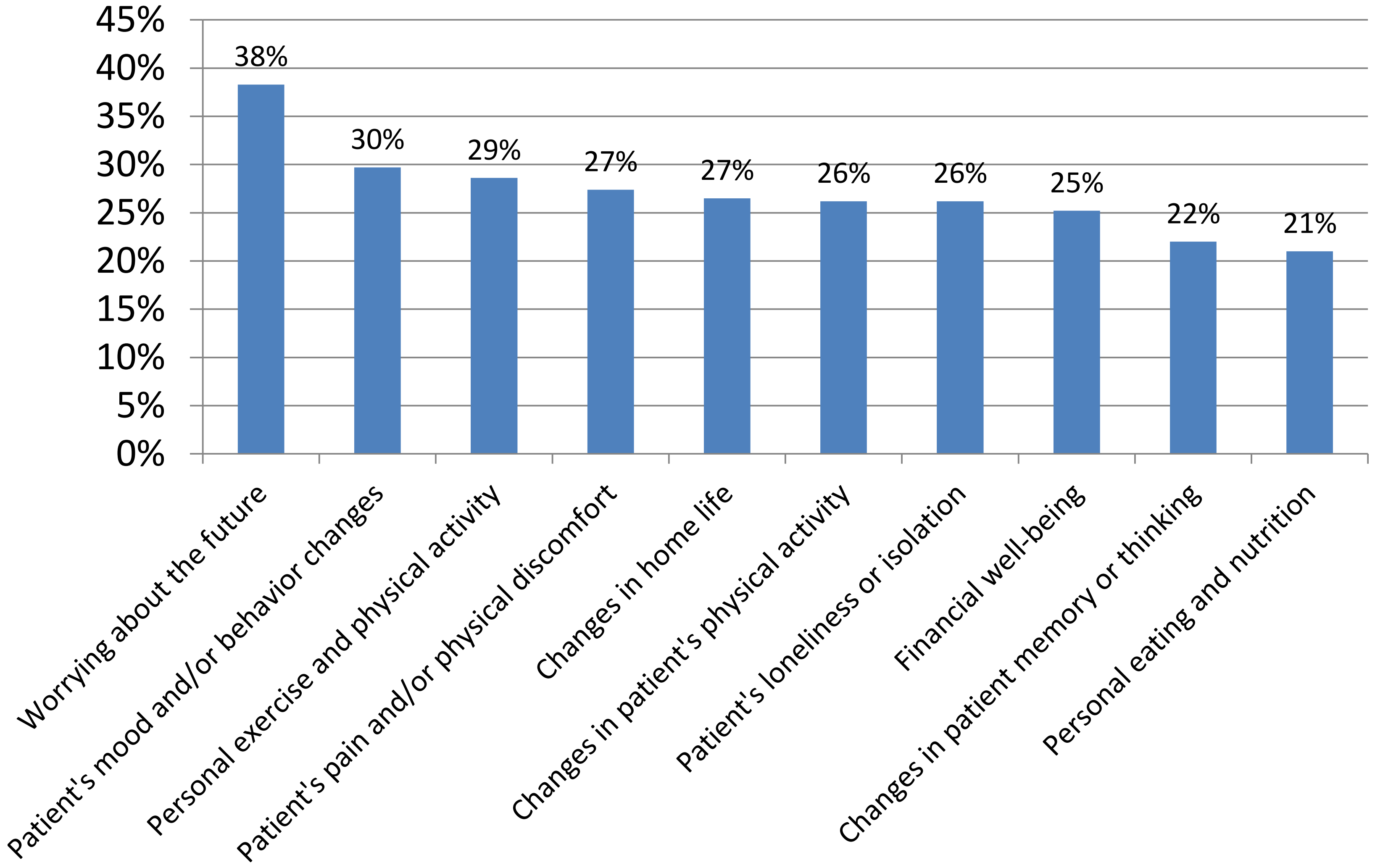
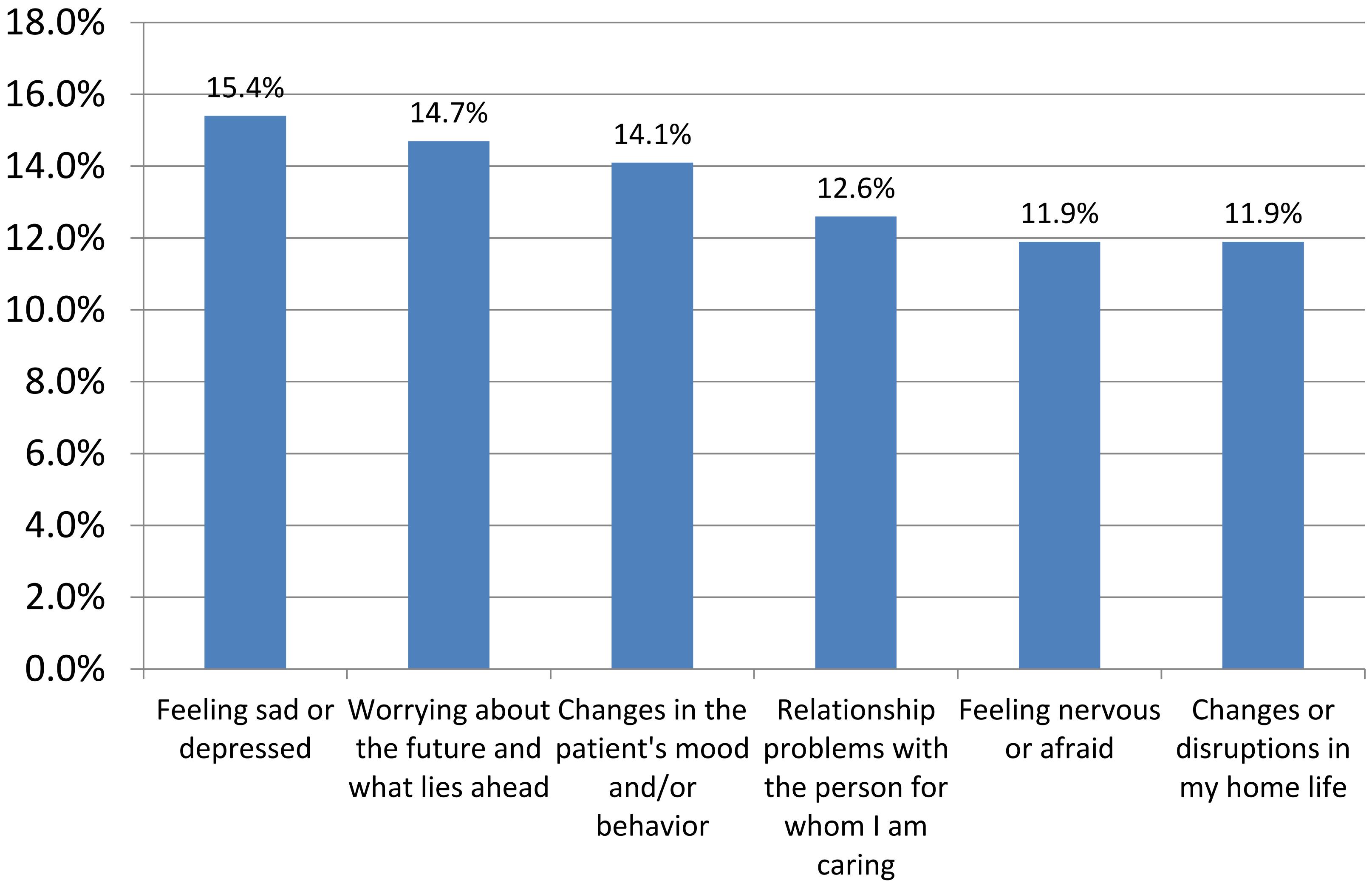
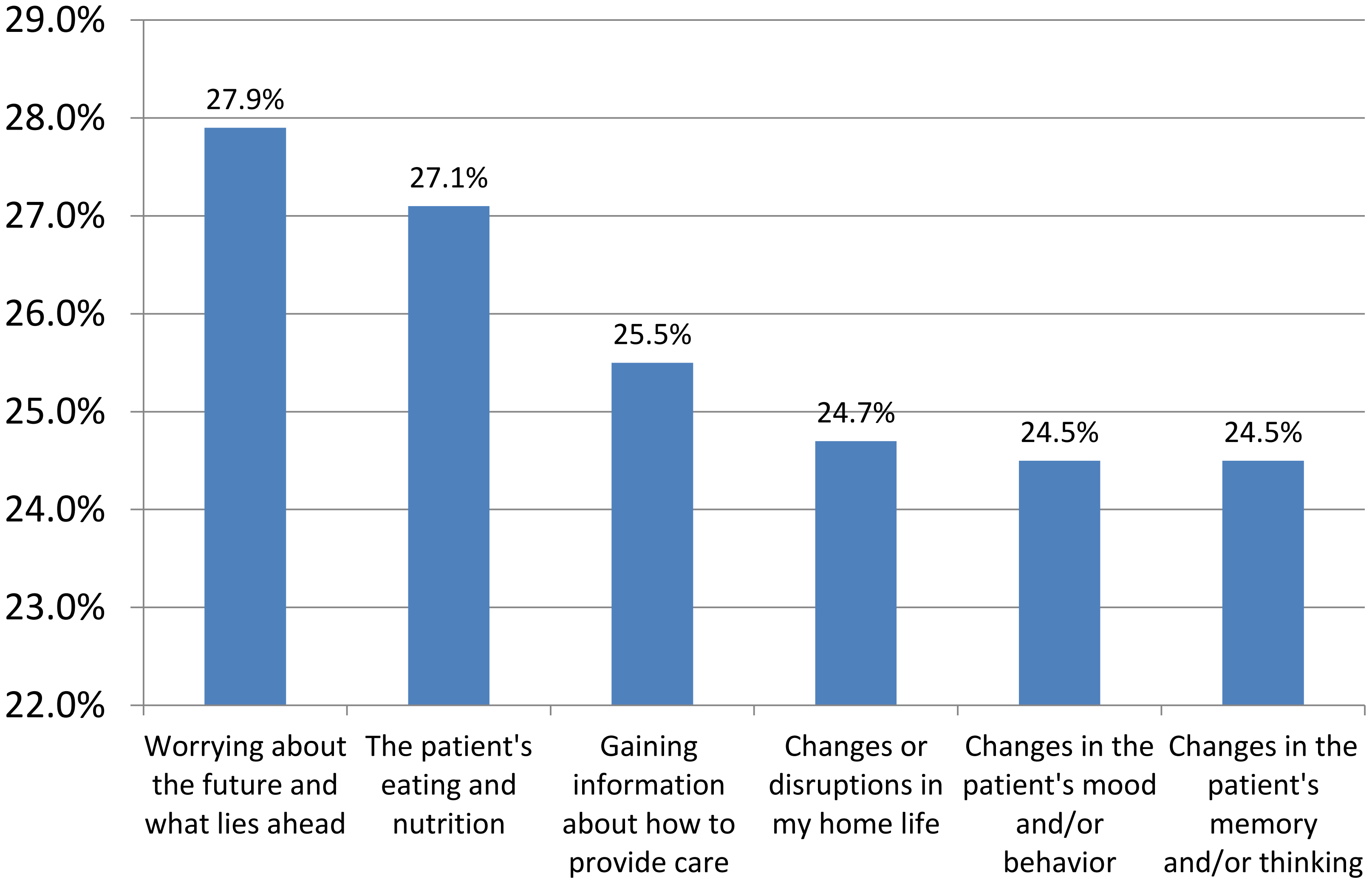
# Table 2. CSS-Caregiver top concerns, serious or very serious concern (n=214)



# Table 2. CSS-Caregiver top items for which caregivers requested talking to staff (n=214)



# Table 2. CSS-Caregiver top items for which additional information was requested (n=214)



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# Next Steps…Challenges and opportunities in engaging diversity of caregivers

- Explore Differences
  - Race/ethnicity
  - Age (young adult caregivers)
  - Region (rural caregivers)
- Strategies
  - Paper version
  - Engaging community sites with greater diversity
    - CSC Greater Philadelphia at Temple University
    - CSC Whitman-Walker Health Clinic, Washington DC
  - Making web-based platforms accessible via phones

# Thank you…

- To the many patients, survivors and caregivers who have contributed to the vision of improving cancer care for all those impacted by cancer
- To the many colleagues and advisors who contributed their time and expertise to advance care
- This research was funded by Amgen Oncology