

Identifying The Oral Health Training Needs of Maine's Care Partners

MOTIVATE at Home Statewide Needs Assessment Survey



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I. INTRODUCTION

Nationally, the provision of unpaid caregiving, providing care to a family member or friend, is an increasingly common role with close to 42 million, or one in six, Americans providing care for an adult over the age of 50 (AARP & National Alliance for Caregiving, 2020). Like so many other states in the U.S., Maine is experiencing this growth in caregiving. As the oldest state in the nation, Maine's median age is currently 45.1 years (38.5 nationally) with 21.3% of its population aged 65 and older, compared to 15.6% nationally (U.S. Census Bureau, 2019). Maine is also the most rural state in the nation with 61% of residents residing in rural areas (U.S. Census Bureau, 2012). The majority of Maine's older adults reside in their own homes and communities and a significant portion receive care and support from a family member. Yet, there is little accessible education to help these informal caregivers provide proper oral health care to loved ones.

The rural nature of the state creates challenges for older adult access to preventive and treatment dentistry options due to factors such as poverty, lack of insurance coverage, and transportation. Compounding these issues, close to 1 in 4 Mainers reside in a HRSA-designated dental health professional shortage area (U.S. Health Resources and Services Administration, 2021). Considering these factors collectively, caregivers are critical frontline providers of the oral health care necessary to help maintain good oral health and overall health.

The MOTIVATE at Home program aims to address these oral health training and service gaps with evidence-based oral health education that emphasizes the connection between total health and oral health while giving caregivers the tools they need not only to provide daily oral health care but to also integrate oral health-related questions into care visits and consultations with a range of healthcare and allied health providers.

Leveraging community connections and access points, and with funding from the CareQuest Institute for Oral Health. The MOTIVATE at Home program was developed to give community-dwelling older adults and caregivers the tools and information needed to manage their oral health. The goal of MOTIVATE at Home is to improve the oral health care status of older adults by increasing caregiver knowledge of basic oral health hygiene, increasing confidence in having oral health conversations with healthcare providers and connecting caregivers with local oral health-related resources. This unique program is led by Lunder-Dineen Health Education Alliance of Maine of Massachusetts General Hospital in partnership with the University of Maine Center on Aging and Southern Maine Area Agency on Aging and with input from a committee of Maine caregivers currently caring for an older Mainer.

Curriculum Development

To begin to address long established oral health education gaps in long-term care, the Lunder-Dineen Health Education Alliance of Maine previously created the MOTIVATE program, which provides interprofessional teams in long-term care settings with cost-free education, to advance their knowledge, skills, and attitudes about oral health, while supporting best practices to promote an evidence-based oral health care model. The acronym MOTIVATE stands for

Maine's Oral Team-based Initiative: Vital Access to Education. The MOTIVATE program teaches not only oral health care basics, but also touches on strategies to translate this knowledge and skill into easily actionable steps.

Developed based on an initial needs assessment with frontline nursing home staff, MOTIVATE is an evidence-based and learner-informed innovative approach to education. All MOTIVATE curriculum is developed at a Certified Nursing Aid (CNA)-level of literacy for accessibility. Over the course of its pilot work across eight long term care facilities in Maine, evaluation data have consistently supported its efficacy in improving oral health knowledge and attitudes among paid caregivers (CNA and other frontline staff). With the addition of resident and family oral health satisfaction surveying at pilot sites, it has become clear that family members are a key constituency in maintaining good oral health for older adults with serious and chronic illness.

The MOTIVATE at Home program curriculum will be built using existing educational materials, approaches, and principles of practice tested in the original MOTIVATE program. Several notable oral health programs, like MOTIVATE, have been developed to support older adult oral health care including Mouthcare Without a Battle, Iowa's Mouth Care Matters, and the Improving Seniors Oral Health programs (The Cecil G. Sheps Center for Health Services, n.d.; Washington Dental Service Foundation, 2017). These programs focus primarily on frontline nursing home staff or paid caregivers as the target learner population. Very little oral health education programming exists to equip family caregivers, who provide a significant amount of care to community-dwelling older adults, with the tools and skills needed to maintain good oral health for their loved ones. In Maine, approximately 97% of adults aged 65 and over, reside in their own homes or in non-institutional settings (U.S. Census Bureau, 2018). There is a compelling need to bring a similar program to community dwelling adults and those that care for them.

II. SURVEY METHODS

Using the MOTIVATE curriculum as a base for the MOTIVATE at Home program, a needs assessment process was undertaken with caregivers of Maine's older adults to explore the following questions:

- 1) What are the primary oral health care gaps faced by caregivers of older adults in Maine?
- 2) What are the oral health training content needs of this population?
- 3) What are the preferred learning strategies for engaging this population of learners?

An initial literature review of oral health training needs assessments was conducted to identify existing tools to inform survey development. Several existing tools were identified and adopted for the purposes of this study including a survey conducted in 2020 by the Center for Health Equity of the Indiana Institute on Disability and Community at Indiana University Bloomington. This study explored the dental health access issues encountered by caregivers of individuals with

disabilities across the lifespan in Indiana (Lee et al., 2021). Additional survey questions were drawn from Mac Giolla Phadraig and colleagues' (2013) randomized controlled trial study of oral health education in a community-based residential setting for individuals with an intellectual disability. Questions regarding desired format and features of oral health training were drawn from Johansson and colleagues' (2014) study of public health placement education.

Once developed, the draft survey instrument was reviewed and piloted by Lunder-Dineen staff, MOTIVATE expert advisory team members along with members of the caregiver ad hoc advisory group and other caregivers from the community. The MOTIVATE expert advisory team consists of a national group of interprofessional oral health experts from dentistry, pharmacy, nursing, long-term care, aging, and social work. The caregiver ad hoc advisory group is facilitated by Southern Maine Agency on Aging and is a five-member group of care partners tasked with advising the MOTIVATE at Home program development. Edits and feedback from all stakeholders were incorporated into the final survey design prior to launch.

The final needs assessment survey consisted of 60 questions divided into the following sections: oral health knowledge and attitudes, oral health care access and beliefs about oral health care, education and training preferences, and caregiver and partner in care demographics. Surveys were distributed statewide in partnership with the five area agencies on aging in the state along with the two older adult research registries at the University of Maine and University of New England. Specialized outreach was also conducted by the Maine Community Health Worker Network and the Maine Chapter of the Maine Alzheimer's Association. Additional e-mail and Facebook distributions were delivered by the UMaine Center on Aging and the Maine Council on Aging. Surveys were distributed via both paper and online Qualtrics survey options based on distribution site preference and participants were offered a gift card incentive for returning a completed survey. The survey period was conducted from March through August 2022. A full copy of the survey instrument can be found in Appendix A.

Descriptive analyses and between groups t-testing was carried out on the resulting data using SPSS version 27. A sampling of report graphs and figures is highlighted in-text. All survey graphs can be found in Appendix B of this report.

A note about language: Based on feedback from the MOTIVATE at Home Caregiver Advisory Committee, this report will use the terms "caregiver" and "care partner" interchangeably to refer to the person who provides care to a family member, friend, or loved one. The term "partner in care" is used interchangeably with "care recipient" and refers to the person for whom the caregiver/care partner is providing care.

III. DEMOGRAPHICS AND ORAL HEALTH ACCESS

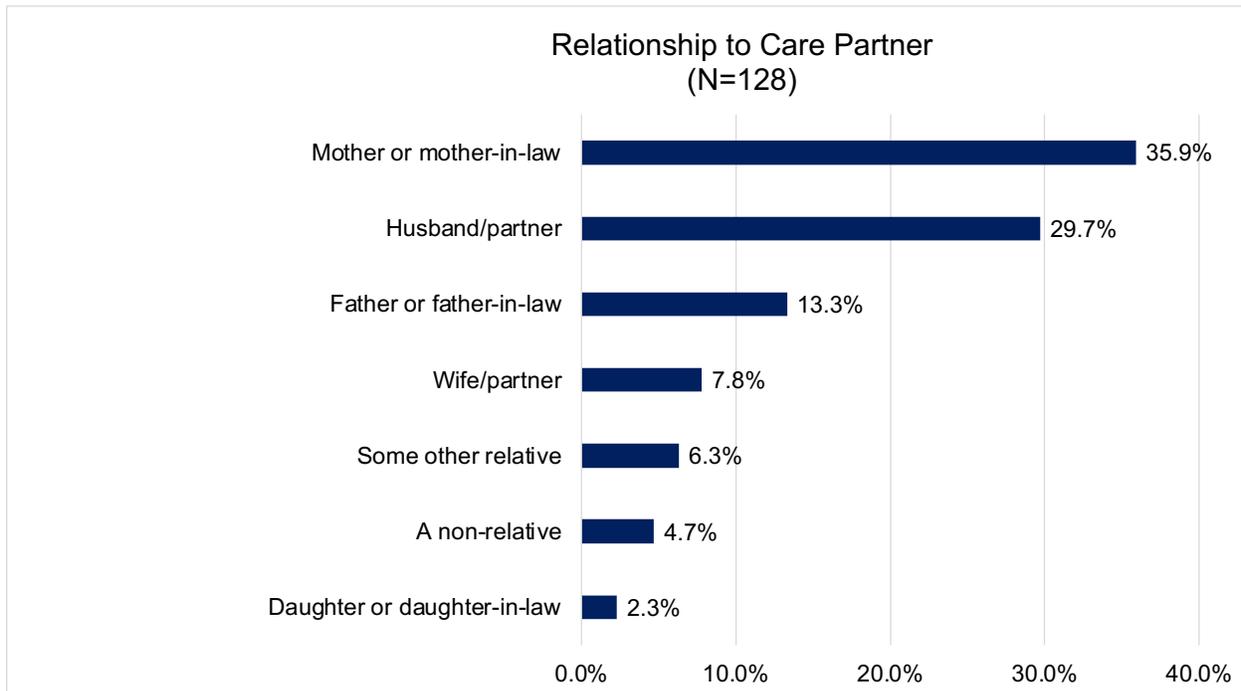
Care Partners

A total of 135 care partners were surveyed about oral health and dental caregiving for their respective partner in care, a person who depends on the care partner in some fashion to provide either local, hands-on care or care from a distance. Care partners were surveyed to provide

insight into both their own attitudes and practices in dental hygiene and care, as well as information about their partners in care.

First, survey results provide a backdrop for the demographics and background of care partners themselves. The average age of care partners who responded to the MOTIVATE At Home survey is 61 years, and the total age range of respondents is 28-85 years of age. Based on national statistics on caregiving, the Maine sample represents a slightly older group of caregivers as the national average age for a caregiver of an older adult is 50 years of age (AARP & National Alliance for Caregiving, 2020).

Regarding the relationship between the care partner respondent to the partner in care, most respondents identified partners in care as their mother or mother-in-law, their husband or partner, a father or father-in-law, or a wife or partner. Only 4.7% of those care partners surveyed identified their respective partner in care as a non-relative or friend. Of those surveyed, 85% of respondents identify as female, and 10.3% of respondents identify as Hispanic, Latino/a/x or Spanish. The vast majority (97.6%) of care partners identify as White, followed by equal distributions of Black or African American identities (0.8%), America Indian or Alaskan Native (0.8%), or Other (0.8%). There were no survey respondents in the group who identified as Asian or Native Hawaiian or Pacific Islander.



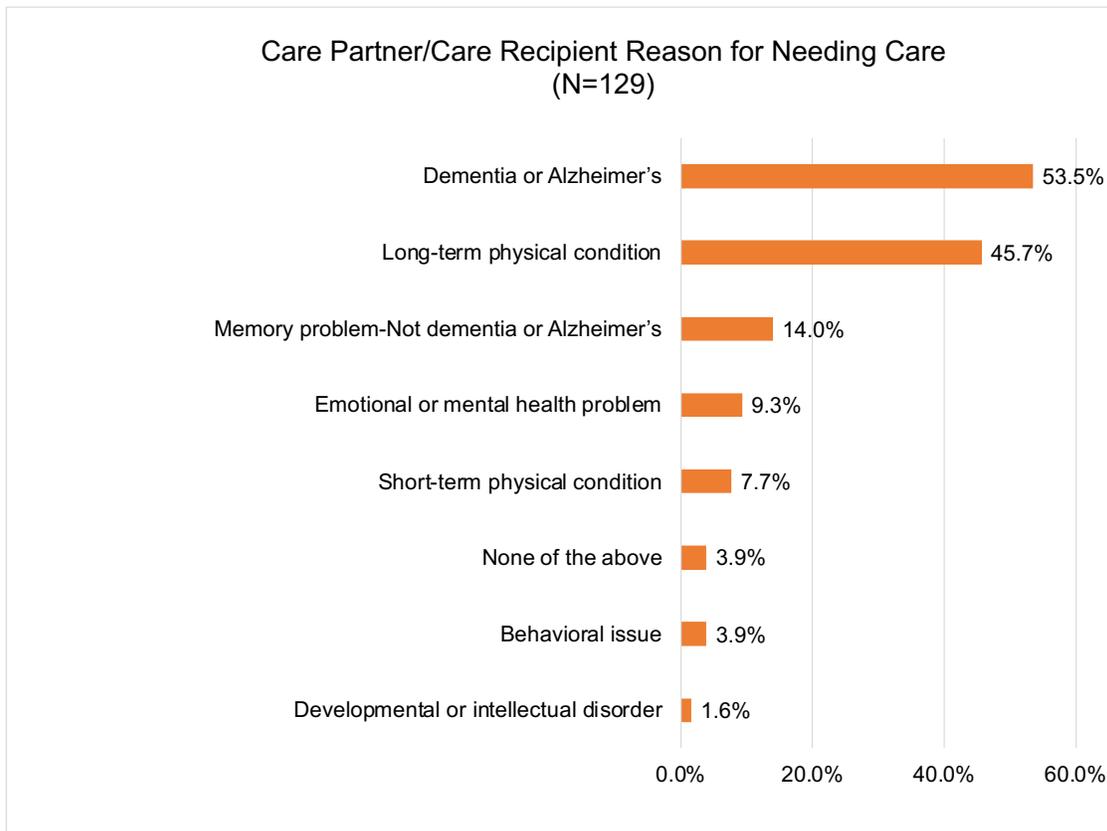
The care partner survey respondents have generally attained high levels of education, with 53.5% earning a bachelor’s degree or higher. However, roughly a third (33.1%) of respondents have some college or less. The care partner survey respondents live mainly in the following Maine

counties: Cumberland (18.9%), Aroostook (16.5%), York (11.0%), Kennebec (10.2%) and Penobscot (8.7%).

Partners in Care

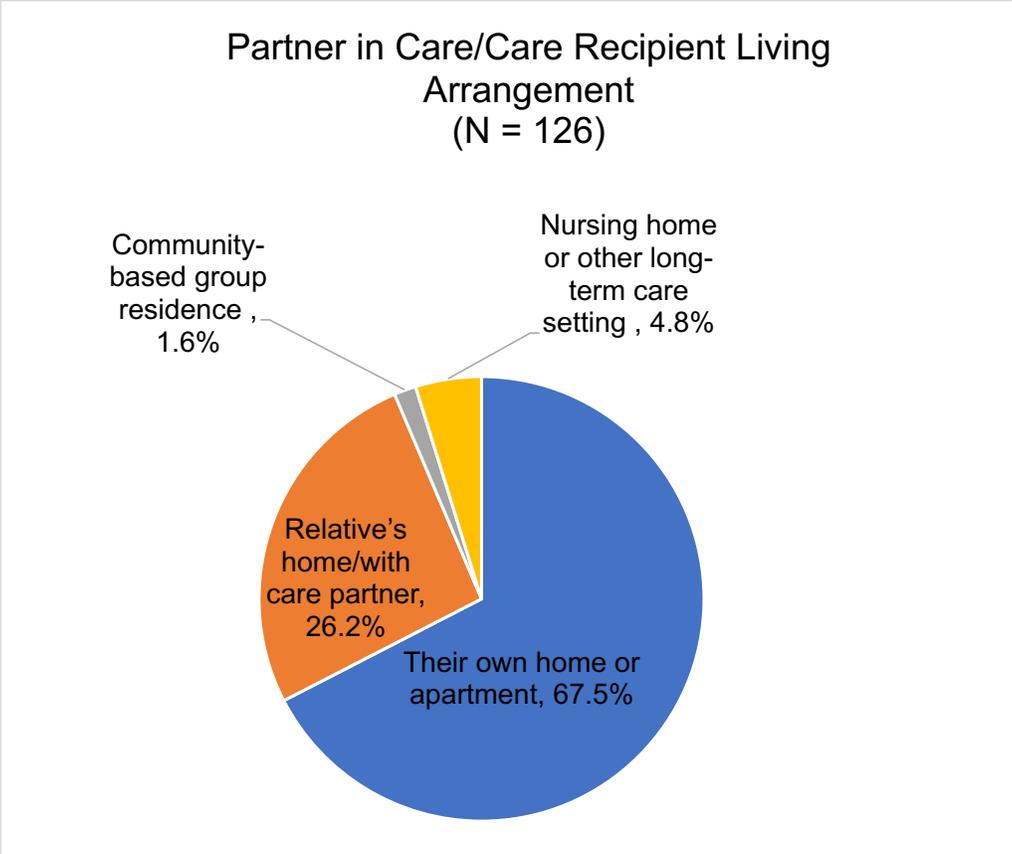
Care partners who completed the MOTIVATE At Home survey also provided demographic information about their partners in care (care recipients). A wide age range of partners in care is demonstrated in survey results (43-101 years of age), and the average age of care recipients is 80 years. While the MOTIVATE At Home survey was designed to target caregivers of individuals 65 years and older, however, caregivers were asked to respond for the person they provide the most care for if caring for multiple individuals. As a result, some of the partners in care were younger than 65 years old.

More than half (52.8%) of care recipients are male, and 8.1% identify as Hispanic, Latino/a/x or Spanish. The vast majority of recipients of care were White (97.6%), followed by Black or African American recipients (1.6%) and American Indian or Alaskan Native (0.8%). Care recipients were more likely to identify as veterans (22.8%) compared to their care partner counterparts (5.5%). The main reasons for care recipients needing care as indicated by their care partners included diagnoses of dementia or Alzheimer’s disease, a long-term physical condition, memory problems distinct from dementia or Alzheimer’s disease, or emotional or mental health problems. Only 7.7% of care partners indicated that they provide care for their partner in care for short-term physical conditions.



The majority of partners in care reside in their own home or apartment (67.5%), though more than a quarter of partners in care (26.2%) reside at a relative's home or with their care partner. A very small number of the partners in care reside in a community-based group residence nursing home or other long-term care setting. Consistent with geographic data from their respective care partners, the majority of partners in care reside in the following Maine counties: Aroostook (18.1%), Cumberland (15.0%), York (11.0%), Kennebec (10.2%) and Penobscot (8.7%).

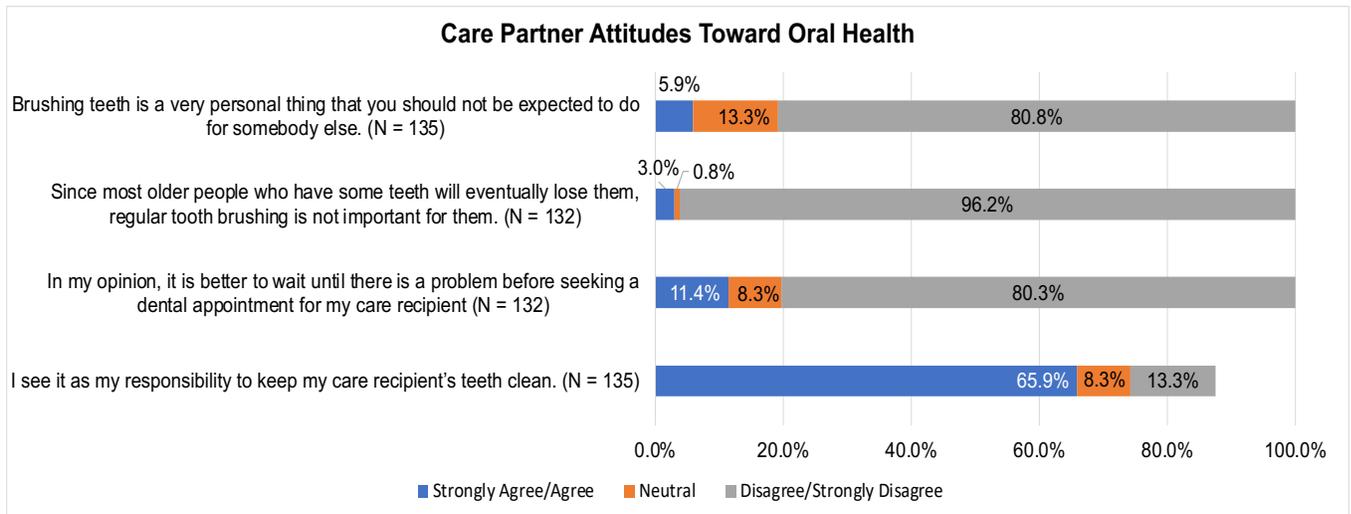
Most care recipients live in their own homes or apartments and receive daily oral care in these dwellings.



As with data obtained from care partners themselves, the MOTIVATE At Home survey also captured information about insurance coverage and access of those partners in care. The vast majority of partners in care were covered for medical insurance by Medicare Advantage plans (42.3%), Medicare (36.6%), or Medicaid/MaineCare (30.2%). Given the target age of 65 and older for partners in care, it is assumed that the majority are also covered by traditional Medicare coverage in addition to these insurance programs. Smaller shares of partners in care received medical insurance coverage from insurance plans purchased directly from an insurance company (13.0%), TRICARE or other military coverage (9.8%), or a medical plan provided by a current or former employer (4.9%).

IV. CARE PARTNER BELIEFS TOWARDS ORAL HEALTH

The MOTIVATE At Home Survey begins by addressing care partner attitudes toward oral health to set a foundation for understanding other trends in care recipient health and access. In addressing the hands-on task of brushing the teeth of the care recipient, the vast majority of care partners (80.8%) felt that brushing teeth was not too personal to complete for their care recipient. Similarly, the overwhelming majority of care partners (96.2%) indicated that regular tooth brushing for care recipients is important and disagreed with the myth that older people will eventually lose some teeth and therefore don't need proper tooth brushing. Only 11.4% of care partners felt that it was better to wait for an oral health problem to appear before seeking a dental appointment for their care recipient. Care partners saw the task of teeth cleaning for their care recipient as a responsibility of care (65.9%), though a number of respondents (21.6%) indicated that they did not see keeping their care recipient's teeth clean as part of their responsibility or felt neutral about that responsibility.



V. ACCESSING ORAL HEALTH CARE

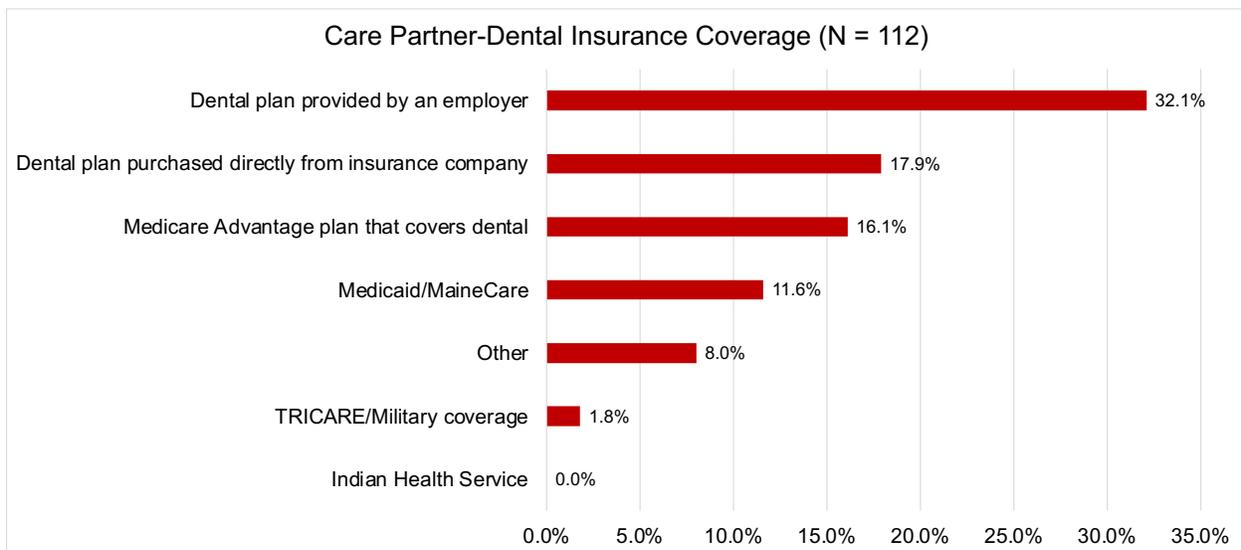
In addition to capturing information about foundational understanding of oral health and attitudes towards incorporating oral health into caregiving, the MOTIVATE At Home survey also sought to investigate care partners' and care recipients' access to oral health care. Areas of interest related to access to oral health care include frequent oral health problems and utilization of care if a dental provider has been established.

Care Partner Access

The vast majority (90.6%) of caregiver respondents indicated that they have their own dentist that they visit for their own dental care. Of those respondents who indicated that they do not currently have a dentist whom they see for regular dental care (9.4%), most respondents indicated that they do not visit a dentist because they cannot afford care (38.5%), indicated "other," including the expense, having dentures or false teeth, or the dentist not taking on new patients (30.8%), or experience feelings of nervousness, fear, or dislike of visiting the dentist

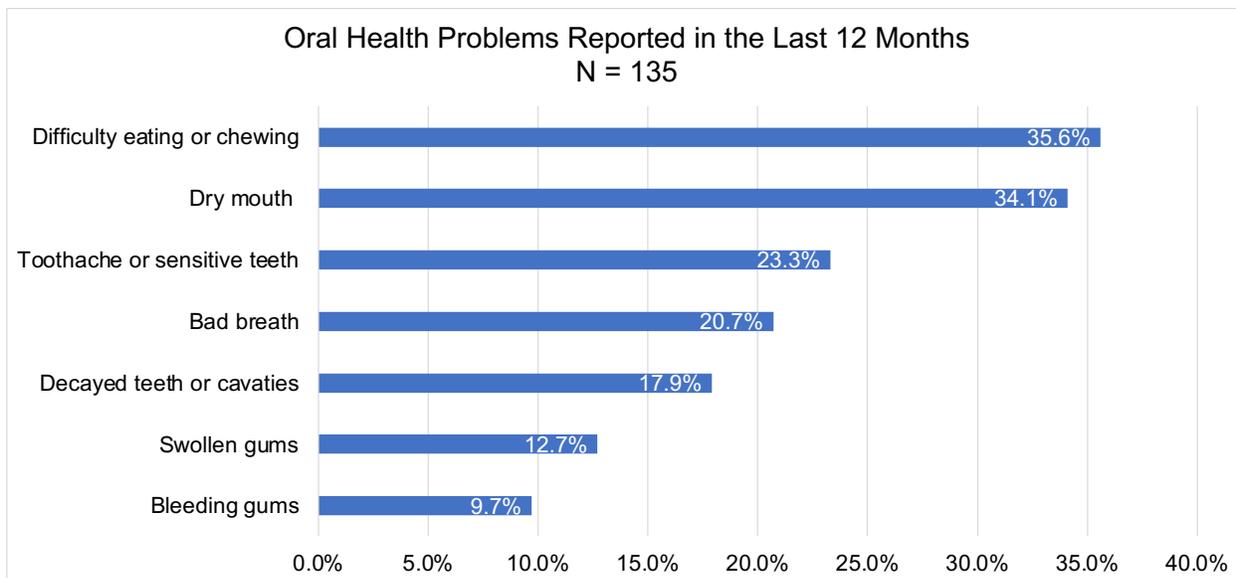
(30.8%). The vast majority of care partners (83.5%) indicated that they had visited a dentist (including visits to a general dentist or specialist like an orthodontist, oral surgeon, or a dental hygienist) in the last year from taking the survey.

The survey results also illuminate access to oral health coverage and complexity of the healthcare system by exploring insurance coverage. Of the nearly 83% of care partner respondents who were covered by dental insurance during the past year, the majority (32.1%) of respondents received coverage through a dental plan provided by their employer. Following employer-based coverage were respondents who purchased a dental plan directly from an insurance company or a Medicare Advantage plan which covers dental care. A small share of care partner respondents were covered by Medicaid/MaineCare, and a much smaller portion were covered by military coverage (TRICARE). An even smaller slice of those care partner respondents identified themselves as a veteran (5.5%).



Care Recipient Access

Care partners indicated that the main oral health problems reported for their care recipients in the past 12 months include difficulty eating or chewing, dry mouth, toothaches or sensitive teeth, and bad breath. Other problems that were reported less frequently were decayed teeth or cavities, swollen gums, and bleeding gums.



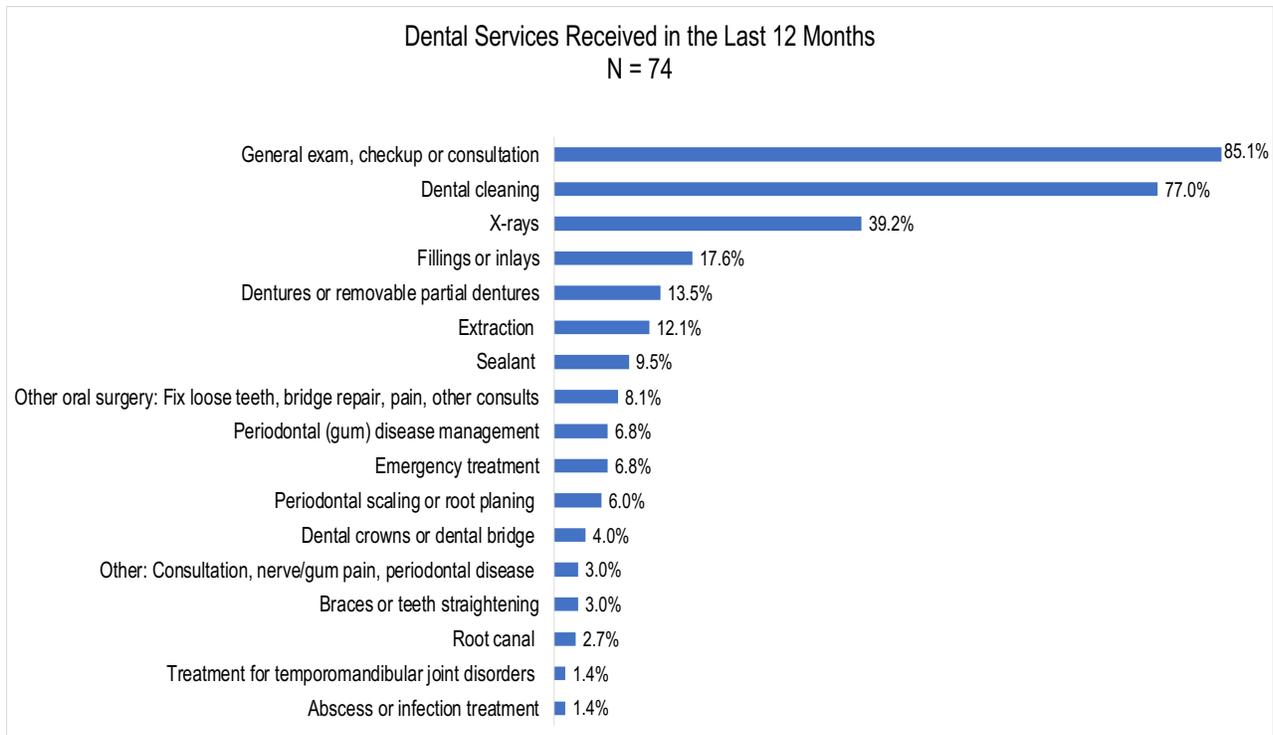
To address these oral health problems, care partners were also asked about their partner in care's established dentist and the frequency at which they may visit this provider. One in four care recipients (25.9%) do not have a dentist that they see for dental care. Of the 36 partners in care

Over a quarter of care recipients are not followed by a dentist due to a number of barriers to care.

who did not have a dentist for whom they visited for oral problems, the main impediments or reasons care recipients go without a dentist were seldom or never needing dental care (10 care recipients), being unable to afford care (10 care recipients), or fear, apprehension nervousness or dislike of visiting the dentist (7 care recipients). Additional themes noted in write-in responses included having dentures (6 care recipients)

with smaller numbers of write-ins around lack of insurance coverage, not knowing who their provider is, being in hospice, COVID-19, and anxiety.

In addition to determining access to dental providers for care, the MOTIVATE At Home survey also gathered data related to utilization of care for care recipients. Nearly half (45.2%) of all care partners indicated that they had not visited a dental clinic for any reason for their care recipient's dental care in the past 12 months. For those who had dental clinic visits, services received care included a general exam, checkup, or consultation (85.1%), dental cleaning (77.0%), X-rays (39.2%) or fillings and inlays (17.6%). A small proportion of partners in care received emergency treatment (6.8%) at a dental clinic, and even smaller numbers reported receiving more intensive dental care such as a root canal (2.7%), treatment for temporomandibular joint (TMJ) disorders (1.4%) or abscess or infection treatment (1.4%). A statistically significant relationship was noted between care recipients who had a dentist and visiting a dentist in the last 12 months such that those with a dentist were more likely to report care access in the last year ($M = .71$, $SD = .456$; $t(96.15) = 9.43$, $p < .001$).



Overall, care partners whose care recipients had accessed care were satisfied with the care received with 64.9% of respondents indicating they were very satisfied with such services. Only 4.1% of all respondents indicated that they were somewhat dissatisfied or very dissatisfied with the dental care that their partner in care received. Write-in responses provided the following reasons for being dissatisfied with oral health care services: difficulty reaching their provider for a follow-up appointment for the care recipient, or the dentist retiring and feeling unhappy with a new dentist’s approach.

Dental insurance coverage for care recipients reflected the same trends as medical insurance coverage, with 27.9% of care recipients covered by a Medicare Advantage plan, 26.0% covered by Medicaid/MaineCare, and 12.5% covered by a dental plan purchased directly from an insurance company. Only 4.8% of care recipients were covered by TRICARE or other military coverage.

Most care recipients who have dental insurance are covered by Medicare Advantage, Medicaid, or a private plan.

Factors Influencing Oral Health Care Access

Survey findings underscore the linkage between care partner oral health attitudes and access to care for their care recipient. Care partners who felt they have a role in preventing tooth decay (see chart in section 6) were more likely to report an oral health visit in the last 12 months for their care recipient, ($M = .75$, $SD = .438$; $t(84) = -2.66$, $p = .009$).

The majority of care partners surveyed (82%) did not delay getting dental care that was perceived as necessary by the care partner or a dental professional. However, close to one in five (18%) did report delaying oral health care. Main reasons cited for that delay included the care recipient’s fear or nervousness (45.8%), inability to afford care (41.7%), “other” which included COVID or waiting for appointments (37.5%), or the dentist’s office being too far away (25.0%).

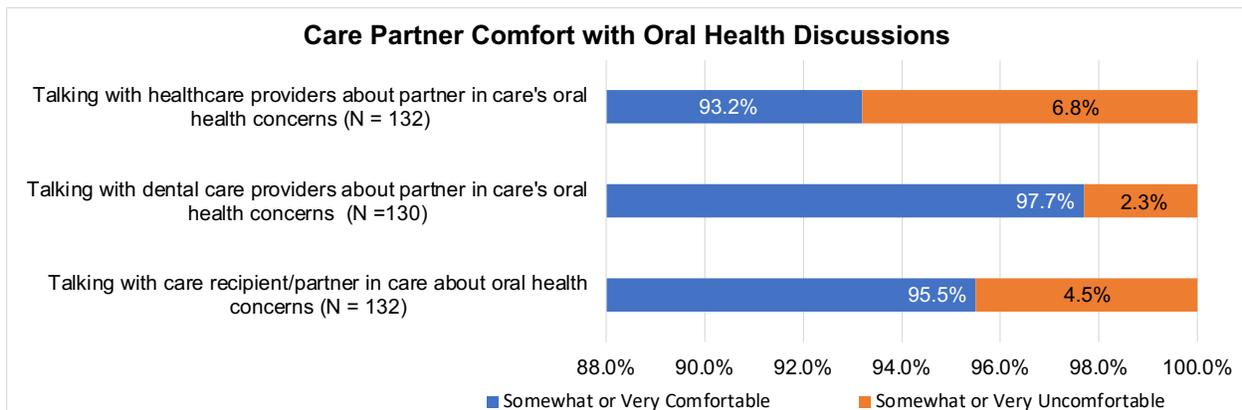
Factors Influencing Oral Health Conversations

A key goal of the MOTIVATE at Home program is to encourage conversations between care partners, care recipients, and the healthcare team. In addition to indicating if there was any delay in care, care partners were also asked about their comfort in participating in oral health discussions with members of the healthcare team including dental health providers and healthcare providers. Statistical testing was used to identify the relationship between oral health access and comfort in having oral health conversations.

While partners in care are comfortable speaking with healthcare providers, over a third report not discussing oral health concerns with a provider in the last year.

The vast majority of care partners feel very comfortable speaking about their partner in care’s oral health concerns with healthcare and dental care providers (93.2% and 97.7%, respectively). Care partners also indicated they were mostly comfortable talking about oral health with their partner in care (95.5%). Despite comfort in discussing oral health concerns with healthcare providers, only 34.3% of care partners indicated that they had

discussed their care recipient’s oral health concerns with such a provider (like a primary care provider or nurse practitioner) in the last year.



In considering ease and comfort with which care partners collaborate with medical professionals, the data suggest a statistically significant relationship between having a regular dentist and care partner comfort in talking with their care recipients about oral health problems ($M = 1.58$, $SD = .751$; $t(42.13) = -2.23$, $p = .031$). When a care recipient lacks a regular dentist, their care partner reports feeling less comfortable having oral health conversations with them, suggesting either a perceived lack of importance about oral health issues or reluctance to raise oral health topics.

A significant relationship was observed between a lack of dental care in the last year and care partner comfort with speaking with members of the healthcare team. Caregivers whose care recipient had not had dental care in the last year reported feeling less comfortable speaking with dental health care providers ($M = 1.50, SD = .632; t(92.84) = -3.01, p = .003$), or medical health care providers ($M = 1.53, SD = .754; t(94.06) = -2.42, p = .017$). Caregivers whose care recipients did not have dental care in the last 12 months were also less likely to report having an oral health conversation with a healthcare provider compared to those whose care recipients had such coverage ($M = .22, SD = .415; t(131.92) = 2.90; p = .004$). Lastly, for those care recipients who do not have a regular dentist, a significant relationship is seen in the care partner being less comfortable in speaking with the care recipient about oral health care, ($M = 1.58, SD = .751; t(42.13) = -2.23; p = .031$).

Statistical analysis of the data revealed significant relationships between those care recipients without dental coverage feeling more comfortable talking with a healthcare provider about dental issues, ($M = 1.23, SD = .426; t(96.62) = -1.99, p = .049$), yet being less likely to have had conversations with healthcare providers about dental problems in the last year, ($M = .23, SD = .426; t(78.77) = -2.20, p = .031$).

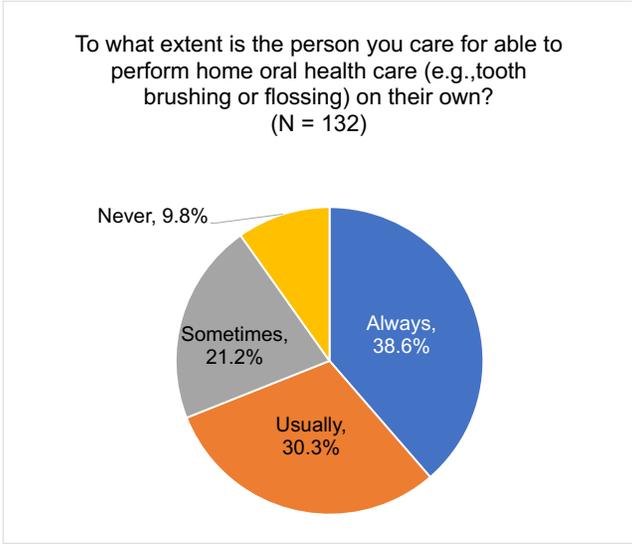
VI. INFORMATION ABOUT ORAL HEALTH CARE IN PRACTICE

According to care partners surveyed, 38.6% of their partners in care completely perform their own oral health care (such as tooth brushing or flossing) always, while 30.3% perform this care

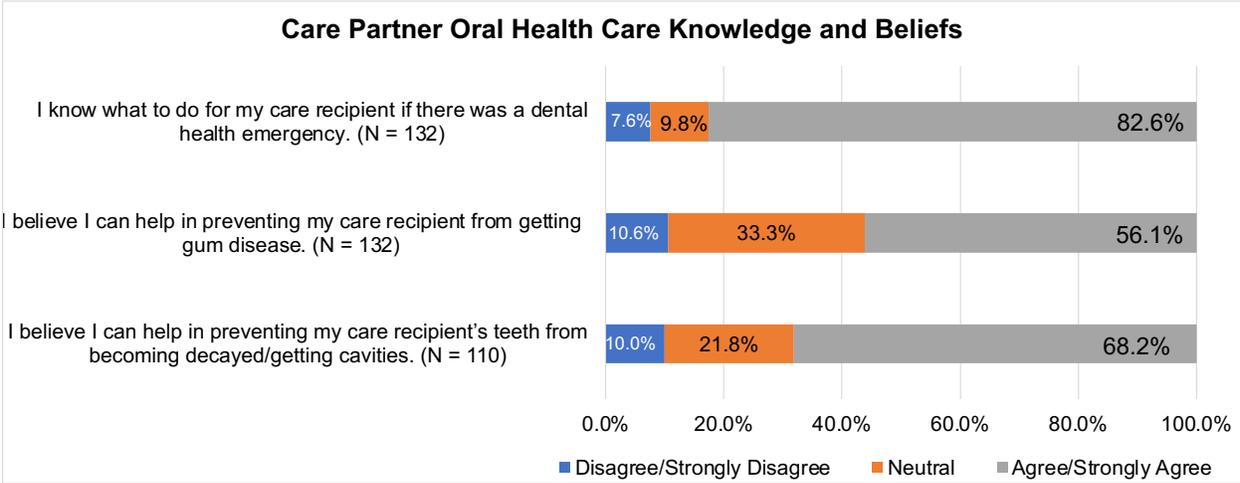
Close to one in three care partners find it very challenging to provide oral care to their care recipient.

usually. Close to one in ten (9.8%) partners in care do not do their own independent oral health care. Close to a third of caregivers (30.6%) reported providing hands-on oral care for their care recipient. Of those care partners who indicated that they do provide that oral care assistance to their partner in care, over 30% felt that the oral care they provided to be difficult. In contrast, about 34% of care partners found that providing oral

care to their care recipient was easy, while 26.8% were neutral on whether the care they provided was easy or difficult.



When examining oral health care beliefs espoused by care partners, a number of respondents (7.6%) indicated that they would not know what to do for their care recipient in a dental emergency, with 9.8% remaining neutral on this question. Additionally, some care partners do not believe they can help prevent their care recipient from developing gum disease (10.6%) and experiencing tooth decay and the development of cavities (10.0%).

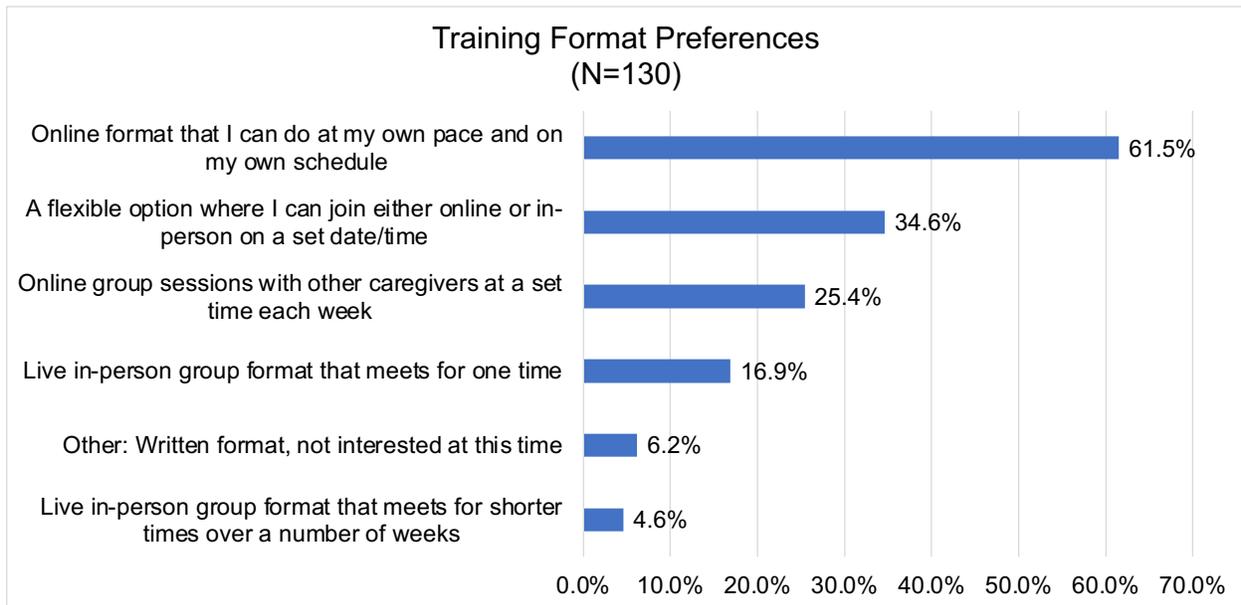


More than half of care partners (56.4%) reported that they spent as much time brushing their care recipient's teeth or caring for dentures as they would like, though 23% of respondents indicated that they were neutral on feeling like they did a very good job of brushing their care recipient's teeth, and a very small percentage (0.3%) acknowledged that they did not do a very good job with this task. In providing care or observing their care recipient performing their own oral health care, care partners describe the main oral health tools used for care as regular toothpaste (69.2%), a regular toothbrush (65.4%), antibacterial mouthwash (29.3%), dental floss (25.6%) or a flosser (22.6%), and denture soak (21.8%). Very few care partners or recipients of care utilized electric toothbrushes (12.0%), whitening toothpaste (7.5%) or a water flosser (6.0%).

VII: EDUCATION PREFERENCES

Care partners were asked to indicate their preferences and attitudes toward educational programs and initiatives about oral health care for their care recipients. The majority of care partners (61.5%) prefer to receive training and educational programs on oral health care in an online format that is self-paced and asynchronous, so that they may access the program on their own schedule. Over a third of those surveyed preferred to participate in a flexible training option which included both an online or in-person session at a set date and time. A set time was also preferred by over a quarter of care partner respondents for an online group session with other caregivers. Other respondents preferred a live, in-person group format in a one-time meeting or a live, in-person group format that met over a number of weeks. Only a small number of respondents preferred the “other” option on the survey, which could include a written format or could indicate that the respondent was not interested in a training program at this time.

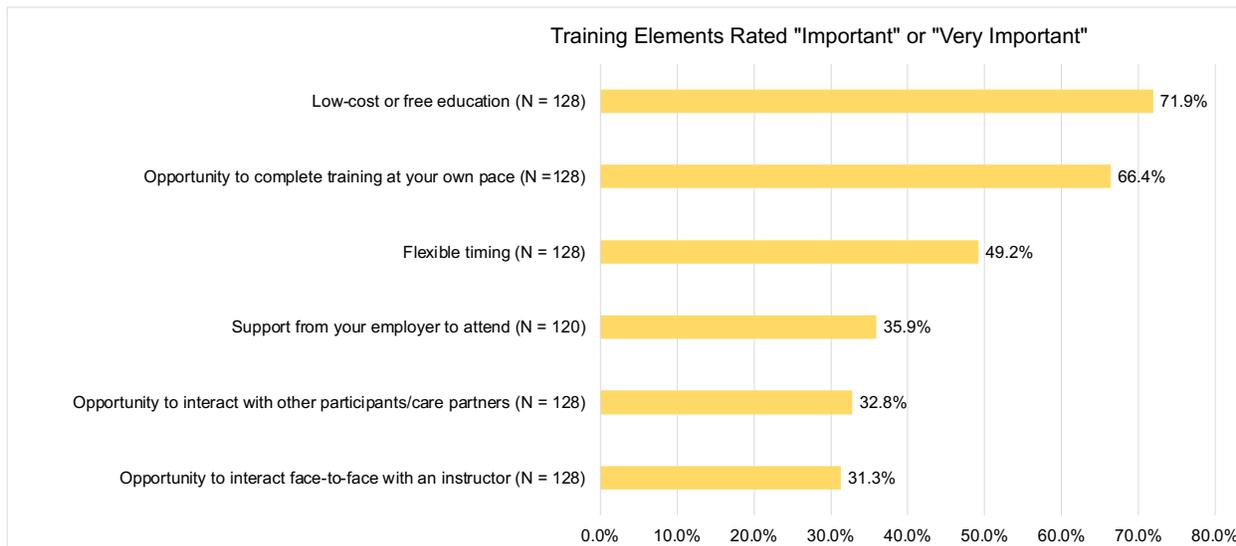
Online, self-paced, asynchronous courses about oral health care are preferred by care partners.



Relatedly, almost all care partners (95.3%) indicated that they have access to the internet and use the internet on personal laptops or computers (86.0%), smartphones (63.9%), other products like a tablet (9.8%) or at the local library or community center (2.5%). More than half of care partner respondents (57.8%) indicated that it is very easy for them to use a device to access the internet, while only 0.9% found accessing the internet to be very difficult.

Survey respondents overwhelmingly prefer to participate in workshops that occur during the week as opposed to weekends and prefer a mid-to-late morning session between 9am-11am (47.0%). In participating in educational programs, respondents prefer to receive education on oral health care in the form of paper handouts or printed materials (57.4%), interactive online websites (51.2%), online recordings (47.3%) or web-based documents or PDFs (40.3%). Care partner respondents indicated that it is most important that educational programming be low-cost or free, self-paced, have flexible timing, and provide the opportunity to interact with other care

partners and the instructor. Care respondents also felt it was important that they had support from their employer to participate in these programs.



Most care partner survey respondents described being somewhat interested (58.2%) or very interested (16.4%) in learning more about oral health care for their care recipient. The top five training topics of interest include:

- How drugs affect oral health (47%)
- Quick fixes for oral health problems (44.4%)
- How to uncover problems that the care recipient may not share with the care partner (44.4%)
- When to wait and when to worry about oral health problems (40.2%)
- How to address challenging behavior when providing oral care (35%)

VIII: OPEN-RESPONSE FEEDBACK

Survey respondents were invited to offer their own comments and reflections on oral health issues. The following is a summary of the key themes from these write-in responses. A full list of comments received is included in Appendix B.

Caring for Someone with Alzheimer's and Dementia

A significant number of write-in responses touched on the challenges of helping their care recipient with oral health care in the face of progressive memory loss. Of note are the challenges of getting their loved one out into the community for a dental appointment or the burden of adding to an already complex care and appointment schedule:

Sample quotes:

“...as a caregiver- adding a dental appointment to a slew of doctor appointments/lab tests/PT feels daunting. It’s hard to get her and I ready and out the door.”

“I know other caregivers who really struggle with helping a person living with dementia or intellectual disabilities manage oral care, especially going to the dentist. Dentists aren’t all comfortable in these situations either.”

Denture Care

Numerous write-in responses regarding denture care for the care recipient reflected some of the challenges in maintaining the dentures themselves and focusing on comfort and ease of wearing. Respondents shared that there is a general lack of awareness and training on denture upkeep for care providers, and the consequences of poor fit such as discomfort or sores in the mouth.

Sample quotes:

“As people live longer, I think my mother stopped worrying about her teeth around 75 thinking she wouldn’t live longer than 5 years or so. She will be 99 in July and her teeth (she has partial denture[s]) are now loose from gums and make it hard to have a good variety of diet.”

“My mother has had dentures for 50 years and has never gone to the dentist (that I am aware). Now she has Alzheimer’s and does not regularly clean her dentures (or even regularly take them out...like when going to bed). I am wondering, given all the other challenges and challenging behavior, how much I should worry about dental care – which battles to choose if you will.”

Additional Access Challenges and Barriers

Common themes that emerged in the write-in responses were issues of cost of care for older adults, challenges in physically getting to a dentist’s office, anxiety, and apprehension in visiting a provider, and feelings of pain or discomfort which are also tied to anxiety and apprehension.

Sample quotes:

“Appointments are too long but need a dentist to call upon when needed...He [the care recipient] stopped going for regular cleaning because of the costs. Now it’s fear-based and anxieties.”

“It would be wonderful if dental practitioners came to the home. Difficult to get some elderly (due to mobility issues) to the dentist.”

“...it can be expensive. Finding a dentist or endodontist who will take Medicaid is almost impossible. A budget for an older adult does not necessarily allow for private dental insurance. When I first started caring for my mother, she had multiple dental problems.

She had not seen a dentist in years. The issues were fixed, but the cost was out-of-pocket. Something needs to be done to help older adults to have dental coverage through insurance.”

IX: RECOMMENDATIONS

Based on a review of the survey data outlined above about oral health training needs, the following are key recommendations to inform the development of the MOTIVATE at Home curriculum:

- **MOTIVATE at Home should emphasize the importance of having a regular dentist and regular oral health visits and echo MOTIVATE’s core theme of the connection between oral health and overall health.** This focus is important given the proportion of care recipients and even care partners who lack a regular dental provider and have gone without oral health care in the last 12 months. Coupled with that emphasis is **a need to increase access to oral health resources.** As such educational content should emphasize affordable and accessible dental care options for care recipients including the newly implemented Medicaid dental coverage expansion in Maine.
- Based on the statistical connections between caregiver beliefs and oral health access for their partner in care, oral health education should focus on **strengthen caregiver understanding of their role in oral health.**
- As a significant portion of caregivers have not had recent conversations with healthcare providers, **MOTIVATE at Home should aim to give care partners the tools needed to have conversations with a range of health and oral health providers.**
- **Provide resources and education to make oral healthcare affordable.** This includes increasing awareness of Medicaid dental coverage among care partners, as Maine’s newly expanded dental coverage took affect during this survey process.
- In order to address access gaps for older adult partners in care, education should address the following key issues noted within the findings:
 - **Easing anxiety about going to the dentist**
 - **Address the myth that those with dentures don’t need to go to the dentist**
- Format considerations for training include the following based on stated learning format preferences and demographic considerations:
 - Offer **content at a high school or lower level of comprehension** as a third of the sample did not have significant levels of schooling past high school.
 - Offer a **variety of formats for learning:** handouts, podcasts, short videos, etc.
 - Utilize a **flexible online self-paced modality** to serve caregiver learner needs.
 - Consider **in-person meeting/discussion option** for those who want to connect with other care partners.
 - Integrate **accessible design and delivery principles** such as closed captioning for recordings and audio materials for those caregivers who have hearing impairments.
- **Oral health education should also be constructed with regard to the caregiving context** including the fact that a significant portion of the target audience is caring for an

individual who lives independently, who takes care of their daily oral health care independently, and who has memory loss. For example, curriculum should emphasize how caregivers can offer prompting and support for oral health care, managing appointments, and other care tasks that are not hands-on in nature. In addition, illustrate strategies to assist with behavioral issues and tips on proper care for those with memory loss.

- Focus education on **common oral health issues encountered by partners in care including difficulty eating and chewing, dry mouth, toothaches or sensitive teeth, and bad breath**. Additional focal points based on caregiver learning preferences include **tips for prompting/encouraging daily care along with dental visits, denture care, and care tips for those with memory loss**.

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APPENDICES: SURVEY INSTRUMENT AND GRAPHS BY QUESTION

**MOTIVATE at Home
Caregiver Oral Health Education Needs Assessment Survey**



An Invitation to all caregivers!

If you are caring for an older friend or family member (someone who is 65 or older) and help manage their day-to-day personal care needs, then you are a caregiver. Please take a moment to share your thoughts with us! We would like to hear from caregivers who provide daily care and those who help with care from a distance.

The Lunder-Dineen Health Education Alliance of Maine, Southern Maine Area Agency on Aging, and the University of Maine Center on Aging are developing an education program for caregivers of older adults. This education program will provide caregivers with education to improve the oral health care provided to homebound and dependent older adults.

We are inviting caregivers who care for an older adult (65 and older) to take part in this needs assessment survey. Your survey answers will help us to build the MOTIVATE at Home program to help Maine's caregivers and older adults.

This survey will take approximately 20-25 minutes to complete. **Each caregiver who takes this survey will receive a \$20 Hannaford gift card.**

We ask that only one caregiver per care recipient respond to this survey. For example, if you and your spouse provide care for a loved one, only one of you should take this survey.

The survey is confidential. We will only use your personal information to send your gift card. Any personal information you provide (name, address, contact information) will be destroyed once the gift cards are mailed out.

You may skip any questions you do not wish to answer or end your participation in the survey at any time.

If you have any questions about this survey, please contact Dr. Jennifer Crittenden, Associate Director, UMaine Center on Aging at 207-262-7923 or jennifer.crittenden@maine.edu.

Please mail your survey back in the envelope provided, no postage needed

Instructions

For this survey, we are inviting those who provide unpaid care to an older adult who is a loved one, relative, neighbor or friend to complete this survey. You may be caring for this person locally or from a distance.

Daily care includes providing hands-on care or supporting an individual while they do their own personal care. Personal care includes activities like bathing, brushing teeth, dressing, assisting with medication and other medical care activities.

If you care for more than one person, please select the person for whom you provide the most care and answer these survey questions with that person in mind.

This survey is about oral health care. Oral health care is any care that supports the health of the whole mouth including lips, teeth, gums, and tongue.

This survey uses the term “care recipient” to refer to the person you are caring for (friend, family, neighbor, etc.).

Section 1: Knowledge about Oral Health

This first section will tell us more about what caregivers already know about oral health care.

Please review and rate each statement below and check the answer that reflects how much you agree or disagree with the statement.

1. I see it as my responsibility to keep my care recipient’s teeth clean.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

2. In my opinion, it is better to wait until there is a problem before seeking a dental appointment for my care recipient

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

Turn over----->

3. Since most older people who have some teeth will eventually lose them, regular tooth brushing is not important for them.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

4. Brushing teeth is a very personal thing that you should not be expected to do for somebody else.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

Section 2: Getting Oral Health Care

5. During the past 12 months, has the person you care for had FREQUENT difficulty with any of the following? [Please circle one answer per each difficulty.]

a. ***A tooth ache or sensitive teeth***

Yes No Don't know

b. ***Bleeding gums***

Yes No Don't know

c. ***Swollen gums***

Yes No Don't know

d. ***Decayed teeth or cavities***

Yes No Don't know

e. Difficulty eating or chewing

Yes No Don't know

f. Bad breath

Yes No Don't know

g. Dry mouth

Yes No Don't know

6. Does the person for whom you provide care have a dentist they go to for dental care?

- Yes-Skip to question 8
- No

7. What are the main reasons your care recipient does NOT have a dentist they go to for dental care? [Choose up to THREE answers]

- The person I care for seldom or never needs dental care
- Cannot afford care
- Cannot find a dentist who accepts insurance plan
- Do not know where to go for dental care
- Communication difficulties with dentist or oral health professionals
- Dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible
- Cannot find a dentist who knows how to work with individuals with disabilities or the types of needs my care recipient has
- Care recipient's (the person you care for) fear, apprehension, nervousness, or dislike of going to a dentist
- Concern that the person I care for will have difficulty controlling his/her behavior
- Other (please specify): _____

8. Did you visit a dentist or a dental clinic for any reason, for your care recipient's dental care, within the past 12 months? Include visits to dentists and dental specialists, such as orthodontists and oral surgeons, as well as dental hygienists.

- Yes
- No-Skip to question 11

Turn over----->

9. What services did your care recipient receive at his/her last dental visit within the past 12 months? (Check ALL that apply.)

- General exam, checkup or consultation
- X-rays
- Dental cleaning
- Sealant (thin layer of plastic coating painted onto teeth to prevent tooth decay)
- Fillings or inlays
- Dental crowns (cap that covers tooth), or dental bridge (device that bridges the gap created by one or more missing teeth)
- Dentures (false teeth which can replace missing teeth and that you can take out and clean daily) or removable partial dentures
- Root canal (removal of the nerve from inside the root of a permanent tooth)
- Periodontal scaling or root planing (deep tooth cleaning and removal of hard and soft deposits from teeth above and below gums)
- Follow-up visit for periodontal (gum) disease management
- Extraction (tooth pulled)
- Abscess or infection treatment
- Other oral surgery (mouth surgery)
- Braces or teeth straightening
- Treatment for temporomandibular joint disorders (pain in jaw joint and jaw muscles)
- Emergency treatment (for example, broken tooth, pain, etc.)
- Other (please specify): _____

10. In general, how satisfied are you with the dental care the person you care for has received in the past 12 months? Would you say...?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied

10a. If you said somewhat dissatisfied or very dissatisfied, please tell us why:

11. During the past 12 months, did the person you care for delay getting dental care, tests, or treatments that you or a dentist believed to be necessary?

- Yes
- No-Skip to question 13

12. What were the main reasons the person you care for was delayed in getting dental care, tests, or treatments you or a dentist believed to be necessary? [Choose up to THREE answers.]

- Could not afford care
- Could not find a dentist who accepts insurance plan
- Dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible
- Dentist too far away
- No transportation
- No appointments available
- Communication difficulties with dentists or oral health professionals
- I could not get time off work
- Did not know where to go to get care
- Care recipient's (the person you care for) fear, nervousness, or dislike of going to a dentist
- Concern that the person I care for will have difficulty controlling his/her behavior
- Need for anesthesia
- Other (please specify): _____

13. In general, how comfortable are you talking with your care recipient about oral health concerns?

- Very comfortable
- Somewhat comfortable
- Somewhat uncomfortable
- Very uncomfortable

Turn over----->

14. In general, how comfortable are you talking with dental care providers (dentist, hygienists, etc.) about your care recipient's oral health concerns?

- Very comfortable
- Somewhat comfortable
- Somewhat uncomfortable
- Very uncomfortable

15. In general, how comfortable are you talking with healthcare providers (doctor, nurse practitioner, primary care provider, etc.) about your care recipient's oral health concerns?

- Very comfortable
- Somewhat comfortable
- Somewhat uncomfortable
- Very uncomfortable

16. In the past year have you discussed your care recipient's oral health concerns with a healthcare provider (doctor, nurse practitioner, primary care provider, etc.)? Examples include: swelling or pain in the mouth, trouble eating, bleeding in the mouth, bad breath, or medications that affect the mouth, etc.

- Yes
- No

17. To what extent is the person you care for able to perform home oral health care (e.g., tooth brushing or flossing) on their own?

- Always
- Usually
- Sometimes
- Never
- Don't know

18. Do you provide hands-on oral care for the person you care for?

- Yes
- No-Skip to question 22

18a. If yes, how difficult is it to provide oral care your care recipient?

- Very difficult
- Difficult
- Neither difficult nor easy
- Easy
- Very easy

19. When I brush my care recipient's teeth (or clean their dentures) I do a very good job.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

20. When I brush my care recipient's teeth I am unsure if I am doing it right.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

21. I spend as much time brushing my care recipient's teeth (or caring for their dentures) as I would like.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

Turn over----->

Please rate your agreement with the following statements:

22. I believe I can help in preventing my care recipient's teeth from becoming decayed/getting cavities.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree
- N/A-my care recipient does not have any natural teeth/they have dentures

23. I believe I can help in preventing my care recipient from getting gum disease.

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

24. I know what to do for my care recipient if there was a dental health emergency (for example, extreme tooth pain, swelling, ulcers in the mouth, bleeding, etc.).

- Strongly disagree
- Disagree
- Neutral (not sure)
- Agree
- Strongly agree

25. Which of the following oral health care methods does the person you care for use for their care. Please check all that apply. Check if the person you care for uses the tool or if you help them to use it. Please check all that apply.

Toothpastes

- Regular toothpaste (such as Crest, Aim, Aquafresh, etc.)
- Enamel toothpaste(Colgate Phos- Flur)
- Sensitivity toothpaste (Sensodyne)
- Whitening toothpaste

Brushes

- Battery powered toothbrushes
- Electric toothbrushes (plug-in/charging style)
- Manual or regular toothbrush

Rinses and washes

- Fluoride rinses (such as ACT or Crest Pro-Health)
- Dry mouth rinse (Biotene)
- Antibacterial mouthwash (Listerine, Cepacol, CLoSYS, Thera breath, Colgate Peroxy)
- Denture soak (Efferdent, Polident)

Floss aids

- Water flosser (Water Pik)
- Interdental Cleaners (Stim-U-Dent) clean between teeth
- Flosser/or pick
- Dental floss

Other

- Other (please explain): _____
- None of the above

Turn over----->

Section 3: Education and Training Preferences

This next set of questions will ask about training or education you may need in oral health care.

26. We are developing an educational program for caregivers on oral health care. If you were to take part in oral health education (workshops/classes) what would you prefer? Check your TOP TWO.

- Online group sessions with other caregivers at a set time each week
- Online format that I can do at my own pace and on my own schedule
- A flexible option where I can join either online or in-person on a set date/time
- Live in-person group format that meets for one time
- Live in-person group format that meets for shorter times over a number of weeks
- Other (please specify):

27. For workshops, generally what days of the week would work best? (Check all that apply)

- Mondays
- Tuesdays
- Wednesdays
- Thursdays
- Fridays
- Saturdays
- Sundays

28. For workshops, generally what times of day would work best? (Check all that apply)

- Early morning (7am-9am)
- Mid to Late morning (9am-11am)
- Late morning to Early afternoon (11am-1pm)
- Mid-afternoon (1pm-3pm)
- Late afternoon (3pm-5pm)
- Early evening (5pm - 7pm)

29. What types of learning materials are most helpful to you? Select your TOP THREE

- Online recordings
- Interactive online websites
- Audio/podcast recordings
- DVD recordings that can be played at home
- PDF/web-based documents
- Paper handouts/printed materials
- Other (please specify): _____

30. How important are the following to you when it comes to learning?

a. The opportunity to interact face-to-face with an instructor/teacher

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

b. Flexible timing (learning in the evenings or weekends)

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

c. Low-cost or free education

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

Turn over----->

d. Support from your employer/superiors to attend training

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

e. Opportunity to complete training at your own pace

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

f. Opportunity to interact with other participants/caregivers

- Not Important
- Slightly Important
- Fairly Important
- Important
- Very Important

31. Do you currently have internet access?

- Yes
- No-Skip to question 34

32. If you currently access the internet how do you get online? Please check all that apply.

- Personal laptop or computer
- Computer at a local library or some other place in the community
- Smart phone (iPhone, Android phone, etc.)
- Other (please specify):

33. How difficult is it for you to use a device to access the internet?

- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

34. How interested would you be in learning more about oral health care for the person you care for?

- Not at all interested
- Not very interested
- Somewhat interested
- Very Interested

**35. Please check the oral health issues that you would want to learn about:
(Please check all that apply)**

- Why is oral health care important?
- What causes mouth pain?
- What is a cavity?
- What is gum disease?
- What causes mouth and gum infections?
- What does bad breath mean?
- What causes dry mouth and decay?
- What are some quick fixes for oral health problems?
- How do drugs affect oral health?
- How do food choices and diet affect oral health?
- How to clean teeth/dentures
- How to address challenging behavior when I give oral care
- How to teach the person I care for about their oral health
- How to fit oral health care into the daily routine
- How to uncover problems the person I care for doesn't tell me about
- When to wait and when to worry (when to call a dentist or a specialist)
- Other (please explain):

Turn over----->

Section 4: About You and Your Care Recipient

About you, the Caregiver

36. What is your age? _____ years

37. What is your gender:

- Male
- Female
- Other (specify):

38. Are you of Hispanic, Latino/a/x, or Spanish origin?

- Yes
- No
- Don't know

39. What is your race? (Check ALL that apply.)

- White
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Pacific Islander
- Other (please specify): _____

40. What is the highest grade or level of school you have completed?

- Some high school or less (No high school diploma)
- High school graduate or GED completed
- Some college or technical school
- Associate's degree
- Bachelor's degree or higher

**41. What is your relationship to the person you are caring for?
They are my:**

- My mother or mother-in-law
- My father or father-in-law
- My wife/partner
- My husband/partner
- My daughter or daughter-in-law
- My son or son-in-law
- Some other relative
- A non-relative

42. In which Maine county do you live? Check one.

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> Androscoggin | <input type="checkbox"/> Piscataquis |
| <input type="checkbox"/> Aroostook | <input type="checkbox"/> Sagadahoc |
| <input type="checkbox"/> Cumberland | <input type="checkbox"/> Somerset |
| <input type="checkbox"/> Franklin | <input type="checkbox"/> Waldo |
| <input type="checkbox"/> Hancock | <input type="checkbox"/> Washington |
| <input type="checkbox"/> Kennebec | <input type="checkbox"/> York |
| <input type="checkbox"/> Knox | <input type="checkbox"/> N/A-I do not live in Maine |
| <input type="checkbox"/> Lincoln | |
| <input type="checkbox"/> Oxford | |
| <input type="checkbox"/> Penobscot | |

43. Do you have a dentist you go to for your own dental care?

- Yes-Skip to question 45
- No

Turn over----->

44. What are the main reasons you do NOT have a dentist you usually go to for dental care? [Choose up to THREE answers]

- I seldom or never need dental care
- Cannot afford care
- Cannot find a dentist who accepts insurance plan
- Do not know where to go for dental care
- Communication difficulties with dentist
- Dentist's office/clinic or dental equipment (for example, dental chair) not physically accessible
- Cannot find a dentist who knows how to work with individuals with disabilities or the types of needs I have
- Fear, nervousness, or dislike of going to a dentist
- Other (please specify): _____

45. Did you visit a dentist or a dental clinic for any reason within the past 12 months? Include visits to dentists and dental specialists, such as orthodontists and oral surgeons, as well as dental hygienists.

- Yes
- No

46. Are you currently covered by Medicare for medical insurance?

- Yes
- No

47. Do you currently have access to dental insurance coverage?

- Yes
- No
- Don't know

48. During the past 12 months, if were you covered by dental insurance coverage, which insurance(s) did you have? (check all that apply)

- Medicaid/MaineCare
- Medicare Advantage plan that covers dental
- Dental plan provided by an employer
- Dental plan bought directly from an insurance company
- TRICARE or other military coverage
- Indian Health Service coverage
- I did not have dental insurance coverage in the last 12 months
- Other (please specify): _____

49. Are you a veteran?

- Yes
- No

NOTE: If yes, the Maine Veterans Dental Health Network may be a free resource for you. For more information or to access the Maine Veterans' Dental Network, please contact Sherman at 207-430-5816 or email Sarah.Sherman@Maine.gov

About the Person You Care for, Your Care Recipient

50. What is the age of the person you care for? Fill in: _____ years

51. What is the gender of the person you care for?

- Male
- Female
- Other (specify): _____

52. Is the person you care for of Hispanic, Latino/a/x, or Spanish origin?

- Yes
- No
- Don't know

Turn over----->

53. Which one or more of the following would you say is the race of the person you care for? (Check ALL that apply.)

- White
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Pacific Islander
- Other (please specify): _____

54. Why does this person need care? Please check all that apply:

- Short-term physical condition
- Long-term physical condition
- Emotional or mental health problem
- Developmental or intellectual disorder
- Behavioral issue
- Memory problem-Not dementia or Alzheimer's
- Dementia or Alzheimer's
- None of the above

55. Where does this individual live?

- Their own home or apartment
- Relative's home/my home
- Community-based group residence (group home, agency-operated apartment)
- Nursing home or other long-term care setting (including assisted living)

56. In which Maine county does the person you care for live? Check one.

- | | | |
|---------------------------------------|--------------------------------------|---|
| <input type="checkbox"/> Androscoggin | <input type="checkbox"/> Lincoln | <input type="checkbox"/> Washington |
| <input type="checkbox"/> Aroostook | <input type="checkbox"/> Oxford | <input type="checkbox"/> York |
| <input type="checkbox"/> Cumberland | <input type="checkbox"/> Penobscot | <input type="checkbox"/> N/A-my care recipient does not live in Maine |
| <input type="checkbox"/> Franklin | <input type="checkbox"/> Piscataquis | |
| <input type="checkbox"/> Hancock | <input type="checkbox"/> Sagadahoc | |
| <input type="checkbox"/> Kennebec | <input type="checkbox"/> Somerset | |
| <input type="checkbox"/> Knox | <input type="checkbox"/> Waldo | |

57. In the past 12 months, what medical insurance coverage did the person you care for have? (check all that apply)

- Medicaid/MaineCare
- Medicare
- Medicare Advantage plan
- Medical plan provided by their current or former employer
- Medical plan provided by my (caregiver's) current or former employer
- Insurance plan bought directly from an insurance company
- TRICARE or other military coverage
- Indian Health Service coverage
- They did not have health insurance coverage in the last 12 months
- Other (please specify): _____

58. During the past 12 months, if your care recipient was covered by dental insurance, which insurance(s) were they covered by? (check all that apply)

- Medicaid/MaineCare
- Medicare Advantage plan that covers dental
- Dental plan provided by their current or former employer
- Dental plan provided by my current or former employer
- Dental plan bought directly from an insurance company
- TRICARE or other military coverage
- Indian Health Service coverage
- They did not have dental insurance coverage in the last 12 months
- Other (please specify): _____

59. Is the person you care for a veteran?

- Yes
- No

NOTE: If you answered yes, the Maine Veterans Dental Health Network may be a free resource for your care recipient. For more information or to access the Maine Veterans' Dental Network, please contact Sherman at 207-430-5816 or email Sarah.Sherman@Maine.Gov.

Turn over----->

60. Use the space below to give us any other thoughts you have on older adult oral health that you would like to share:

**MOTIVATE at Home
Caregiver Oral Health Education Needs Assessment Survey
Graphs by Question**



Total surveys received: 135

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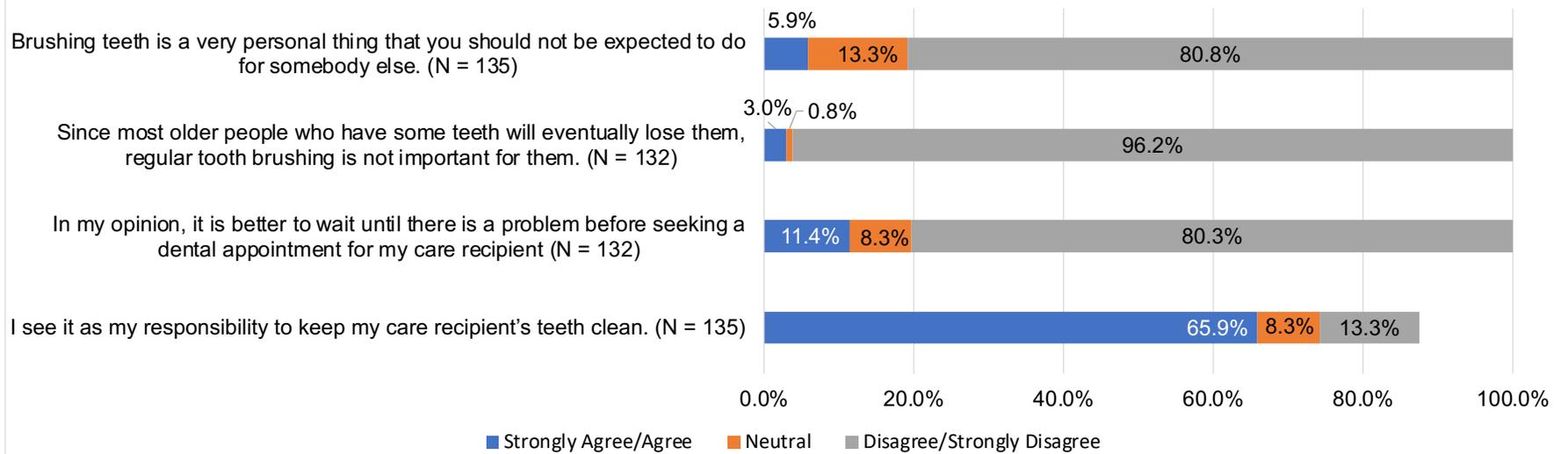
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Language note: Based on feedback from the MOTIVATE at Home Caregiver Advisory Committee, this report will use the terms “caregiver” and “care partner” interchangeably to refer to the person who provides care to a family member, friend, or loved one. The term “partner in care” is used interchangeably with “care recipient” and refers to the person for whom the caregiver/care partner is providing care.

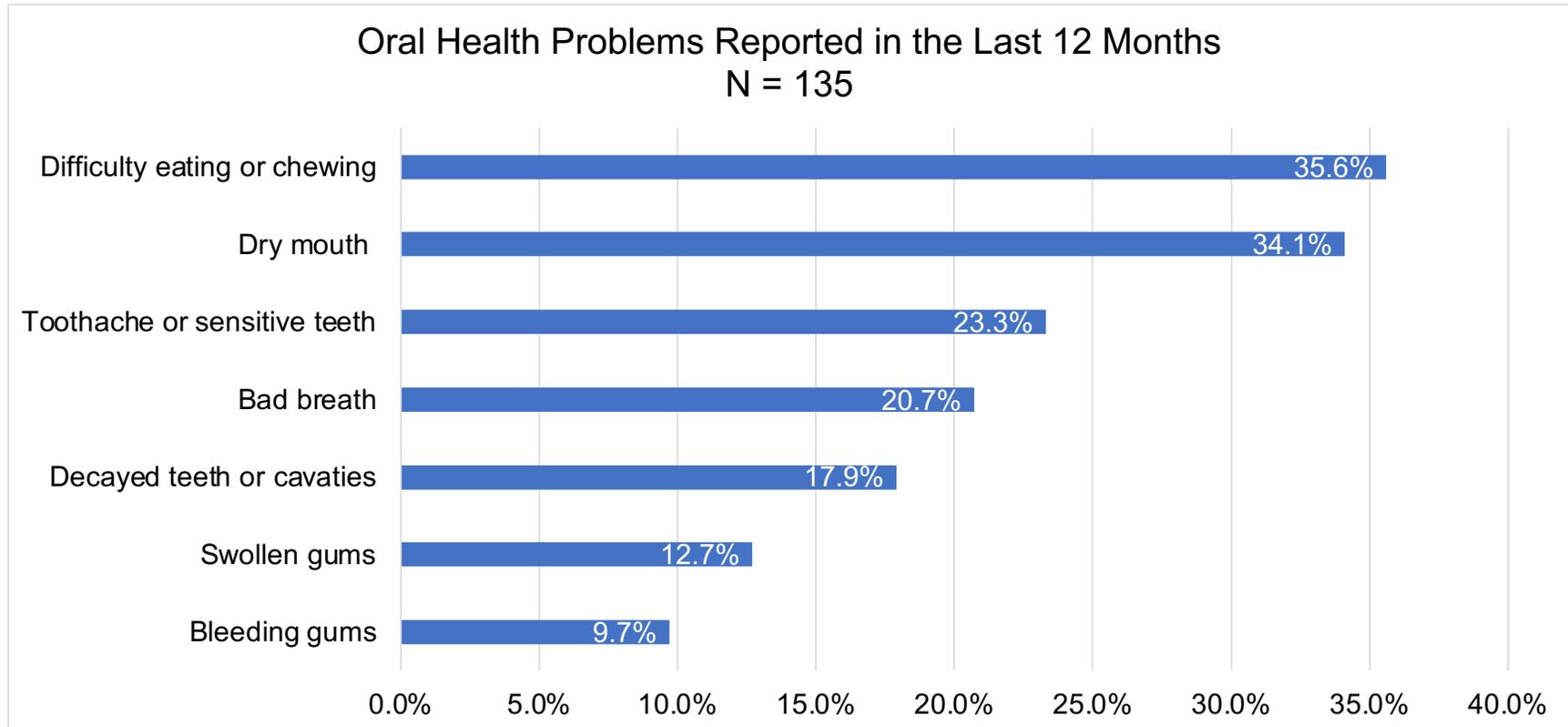
Section 1: Knowledge about Oral Health

Care Partner Attitudes Toward Oral Health



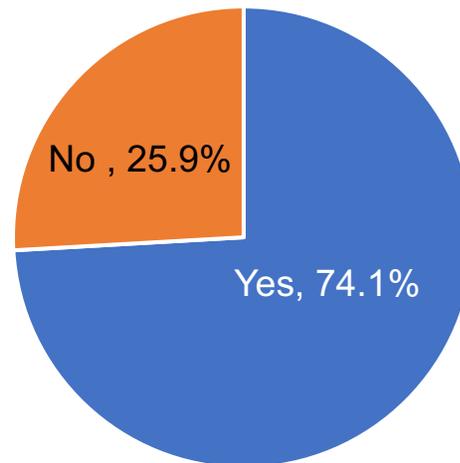
Section 2: Accessing Oral Health Care

5. During the past 12 months, has the person you care for had **FREQUENT** difficulty with any of the following?
[Please circle one answer per each difficulty.]

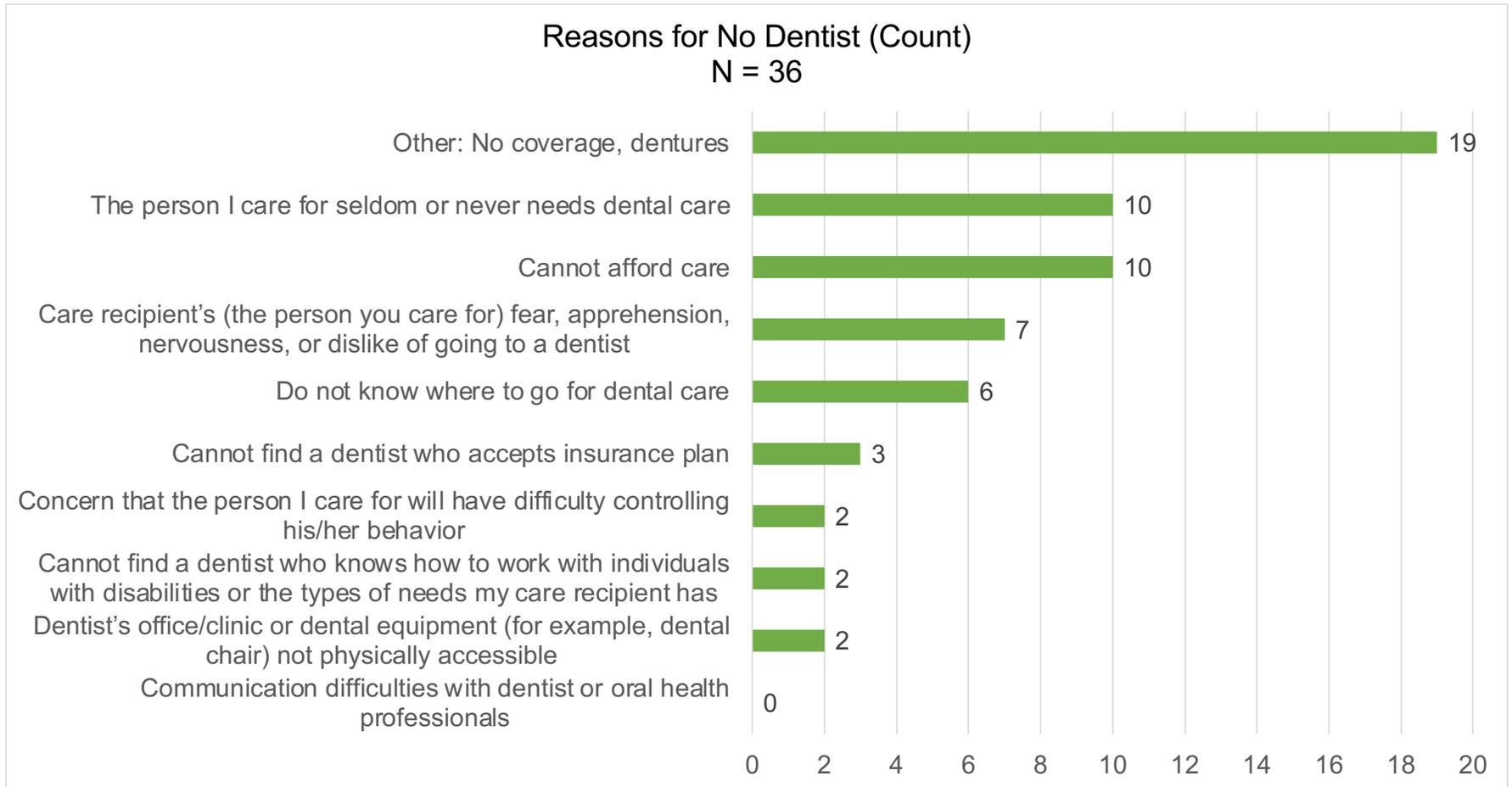


6. Does the person for whom you provide care have a dentist they go to for dental care?

Does the person for whom you provide care
have a dentist they go to for dental care?
N = 135

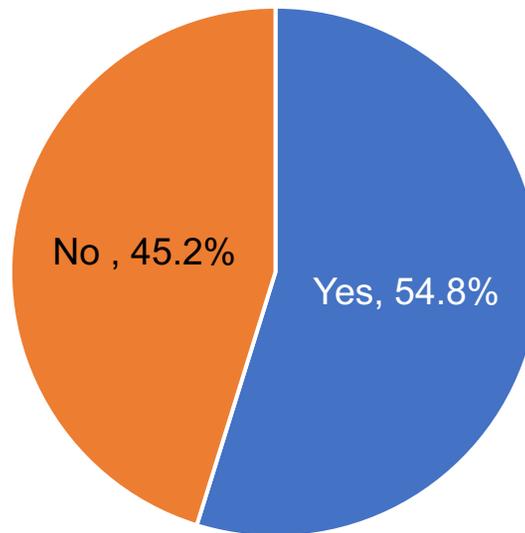


**7. What are the main reasons your care recipient does NOT have a dentist they go to for dental care?
[Choose up to THREE answers]**

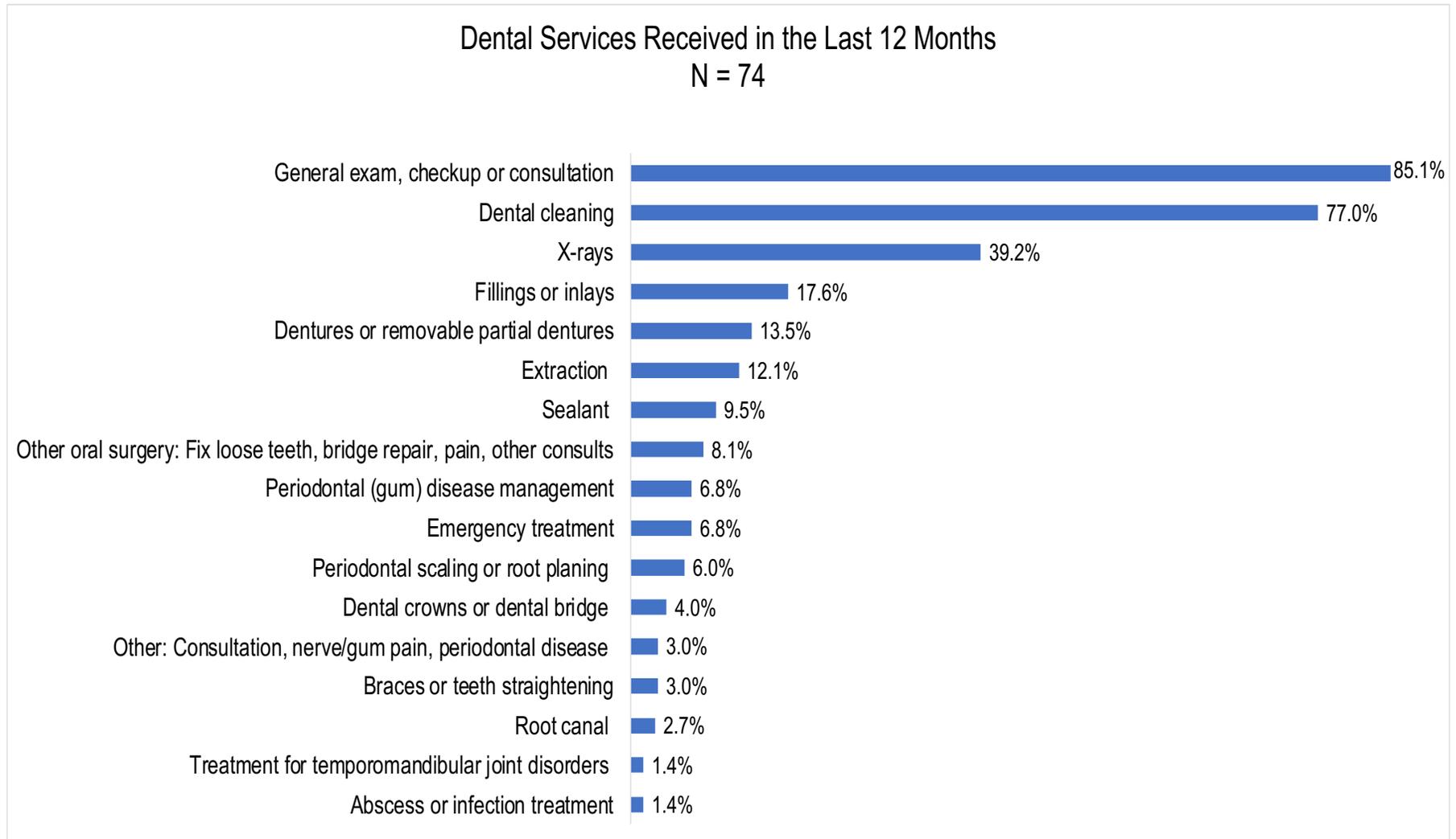


8. Did you visit a dentist or a dental clinic for any reason, for your care recipient's dental care, within the past 12 months? Include visits to dentists and dental specialists, such as orthodontists and oral surgeons, as well as dental hygienists.

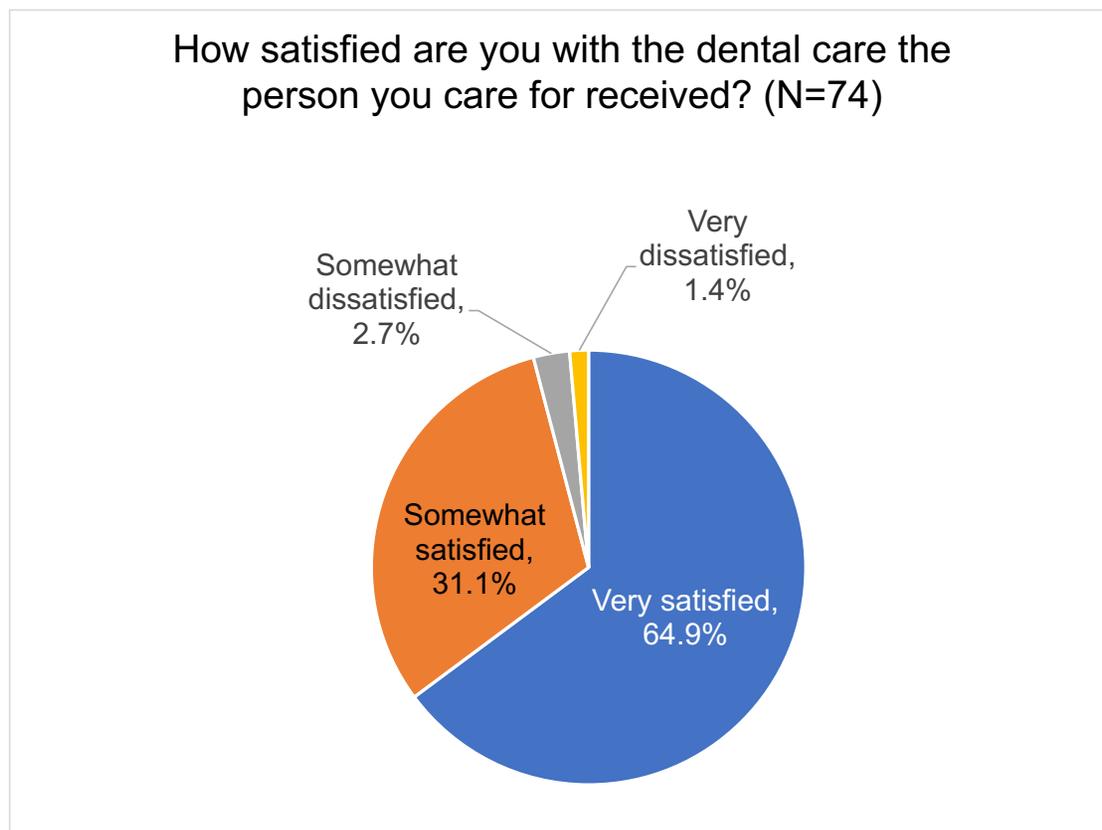
Did you visit a dentist or a dental clinic for any reason, for your care recipient's dental care, within the past 12 months? (N = 135)



9. What services did your care recipient receive at his/her last dental visit within the past 12 months? (Check ALL that apply.)



10. In general, how satisfied are you with the dental care the person you care for has received in the past 12 months? Would you say...?

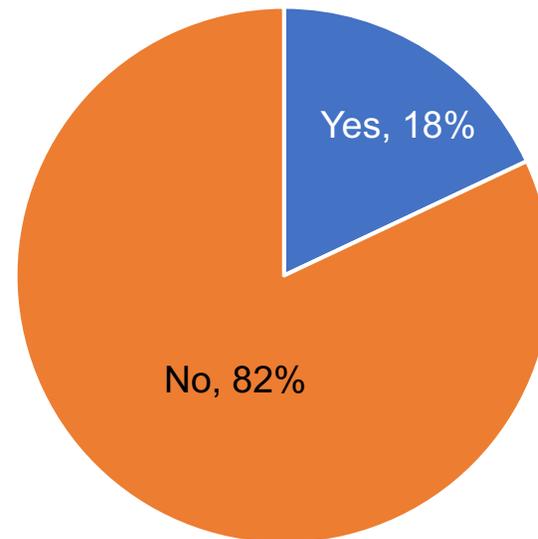


10a. If you said somewhat dissatisfied or very dissatisfied, please tell us why:

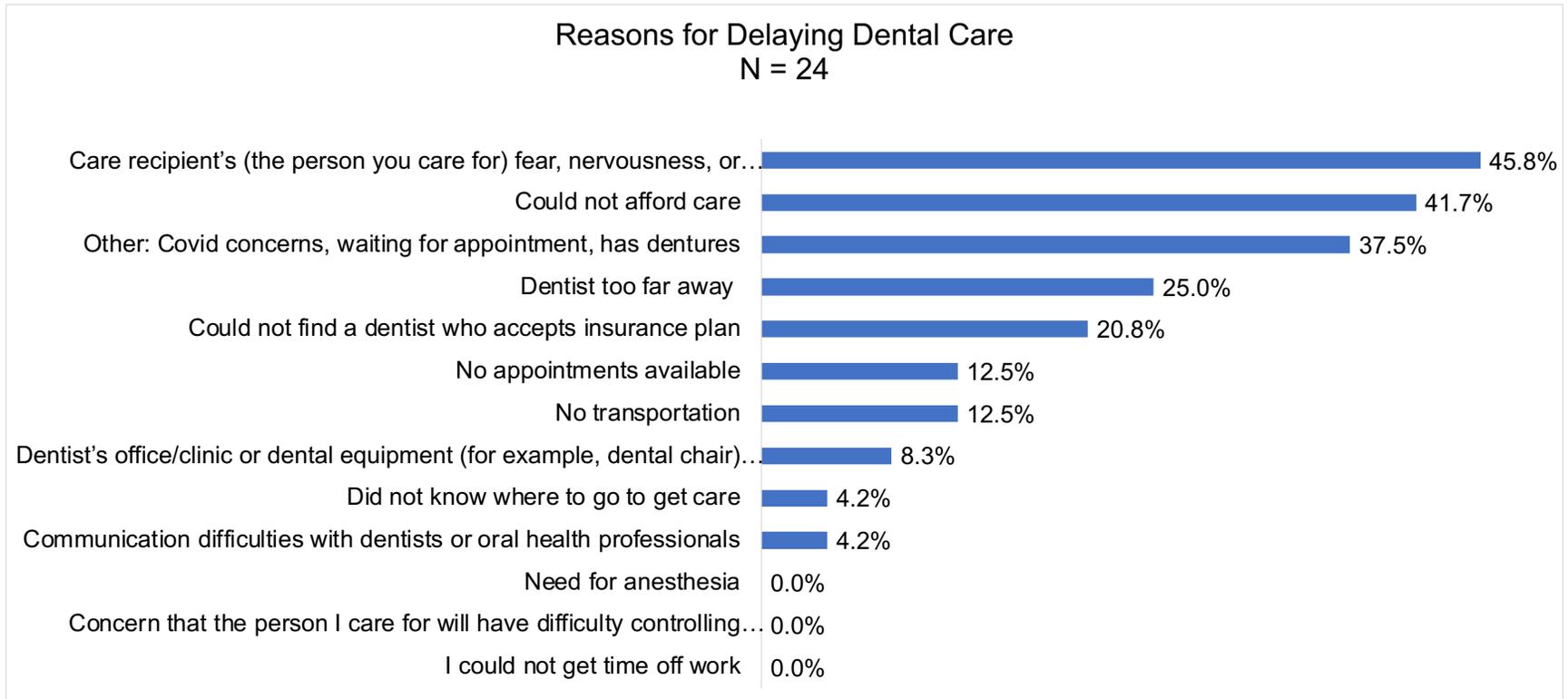
- Dental provider retired and not happy with new dentist's approach
- Difficulty reaching provider for follow-up appointment

11. During the past 12 months, did the person you care for delay getting dental care, tests, or treatments that you or a dentist believed to be necessary?

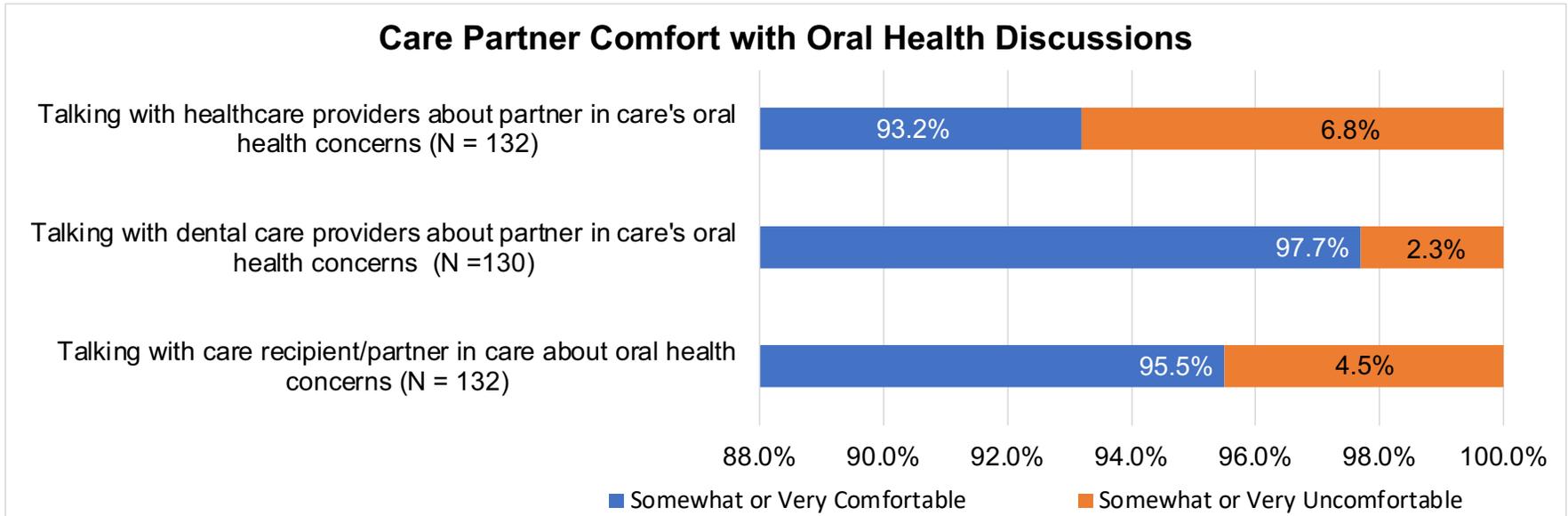
During the past 12 months, did the person you care for delay getting dental care? (N=133)



12. What were the main reasons the person you care for was delayed in getting dental care, tests, or treatments you or a dentist believed to be necessary? [Choose up to THREE answers.]

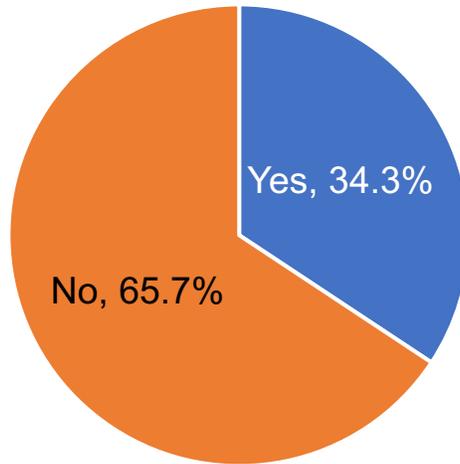


Questions 13-15: Comfort talking with providers

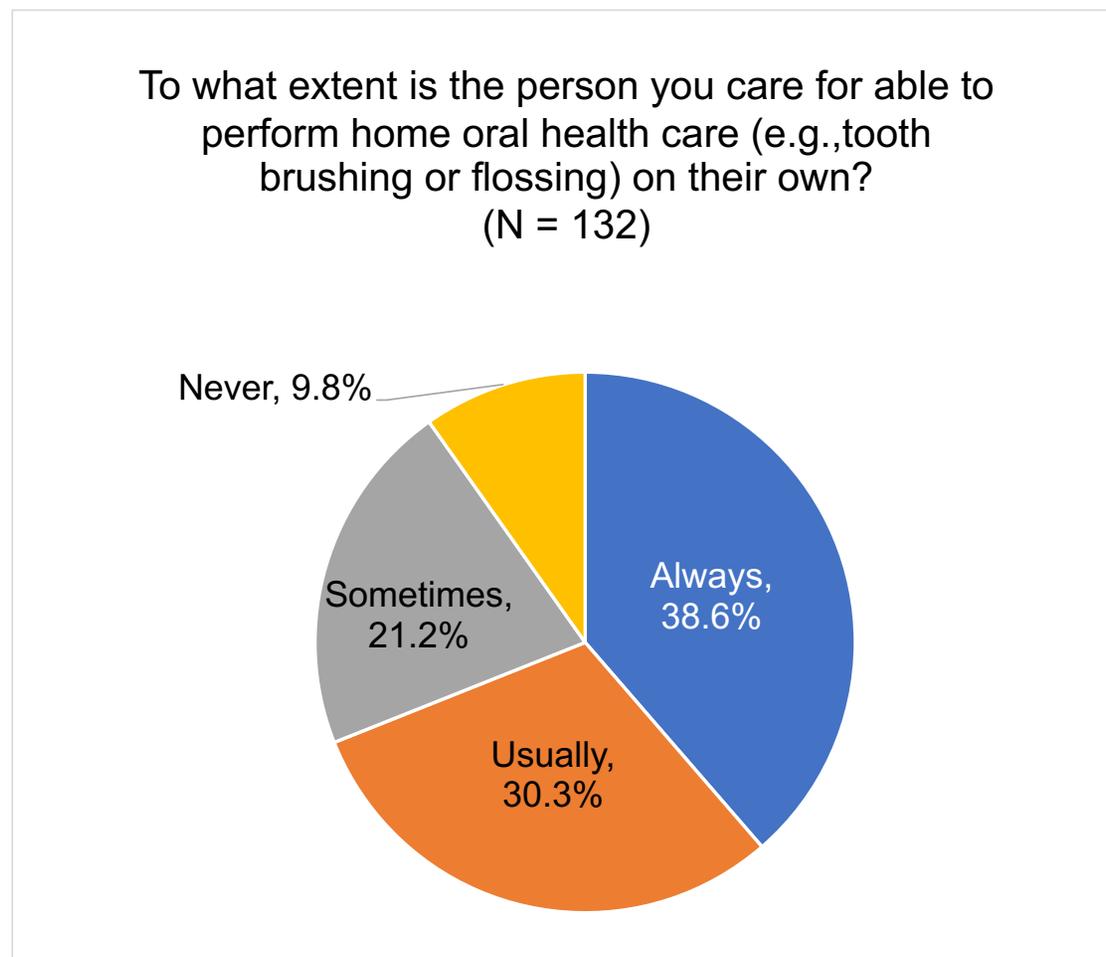


16. In the past year have you discussed your care recipient's oral health concerns with a healthcare provider (doctor, nurse practitioner, primary care provider, etc.)? Examples include: swelling or pain in the mouth, trouble eating, bleeding in the mouth, bad breath, or medications that affect the mouth, etc.

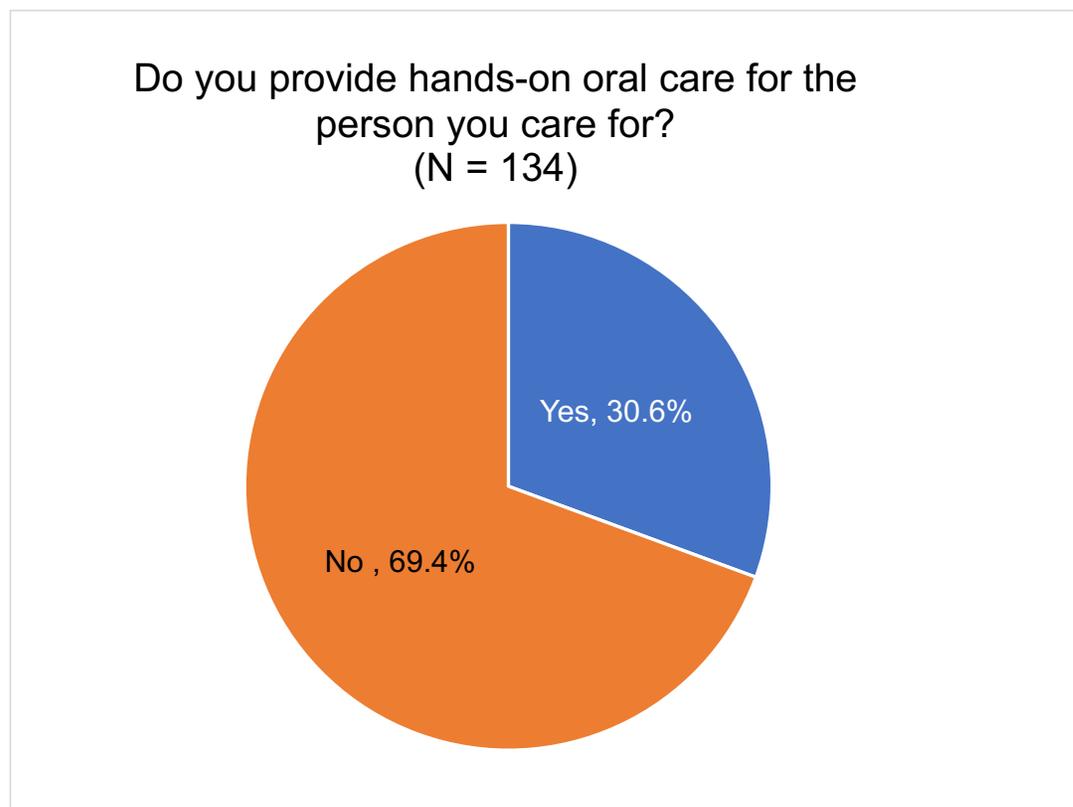
In the past year have you discussed your care recipient's oral health concerns with a healthcare provider?
(N = 134)



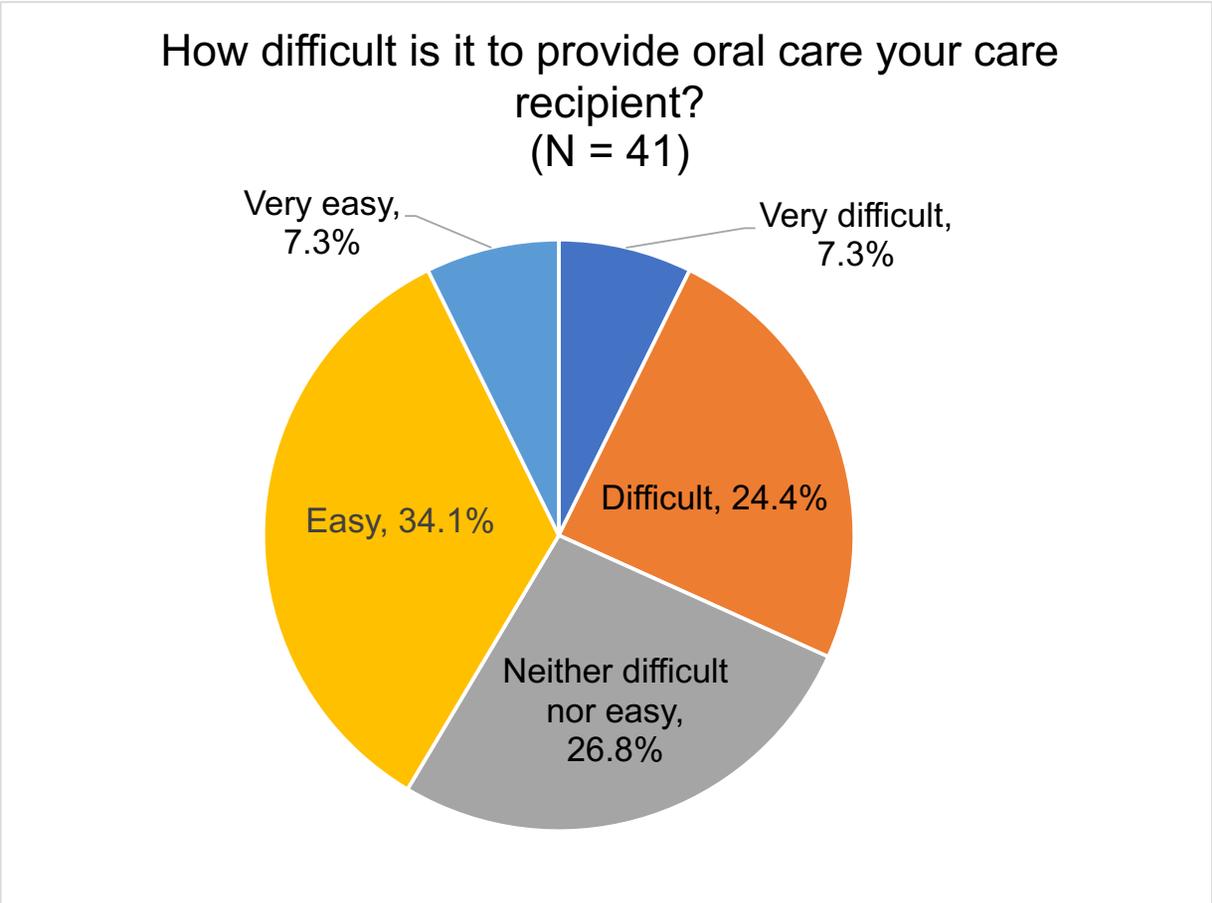
17. To what extent is the person you care for able to perform home oral health care (e.g., tooth brushing or flossing) on their own?



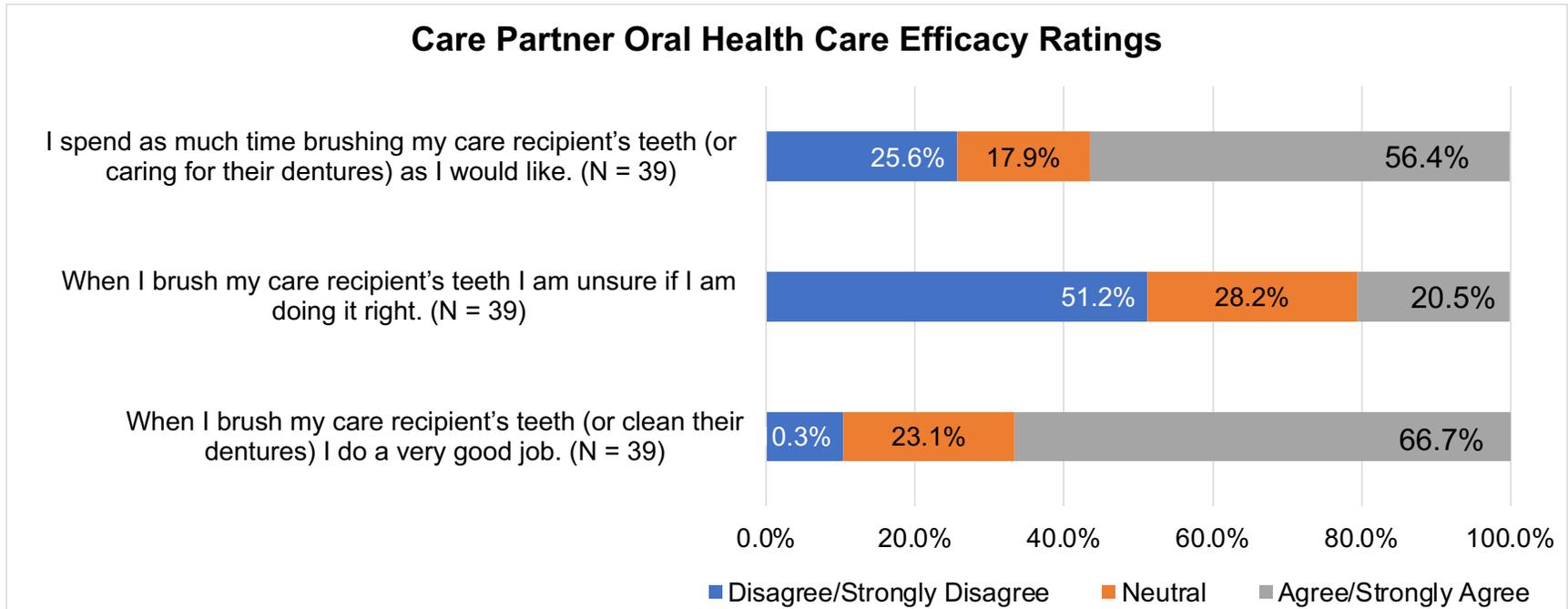
18. Do you provide hands-on oral care for the person you care for?



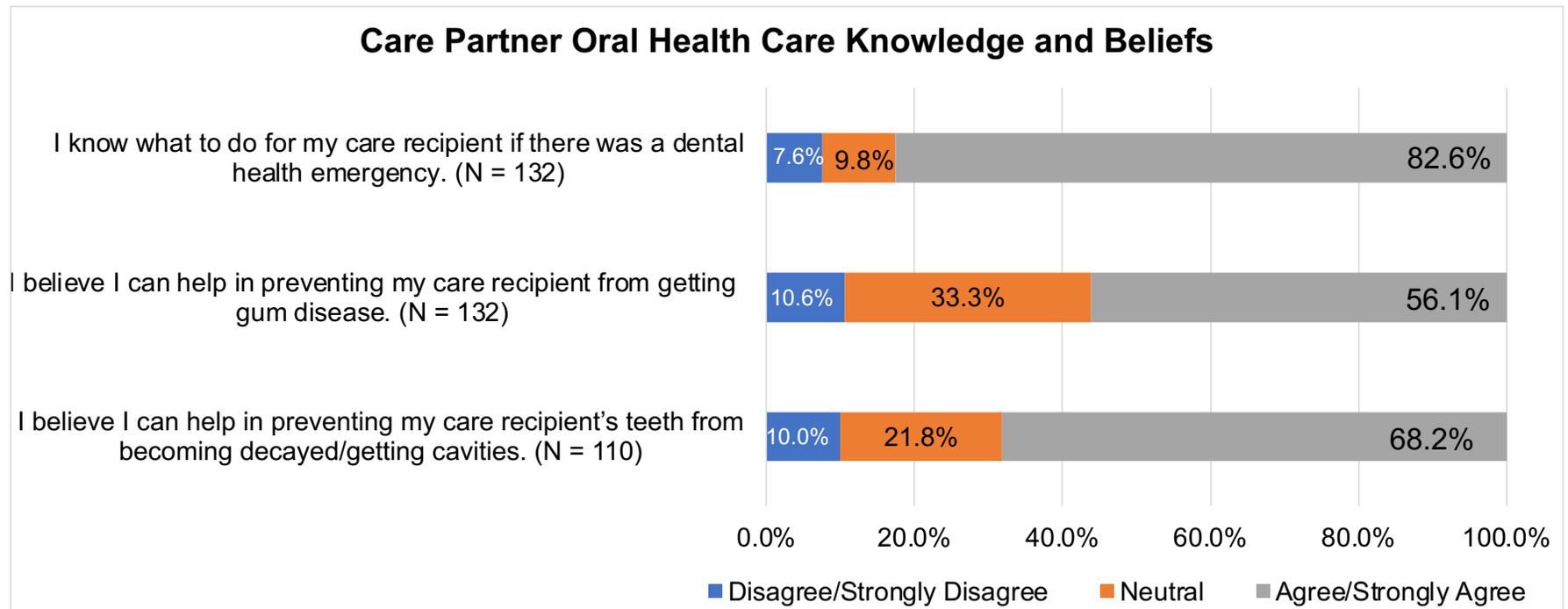
18a. If yes, how difficult is it to provide oral care your care recipient?



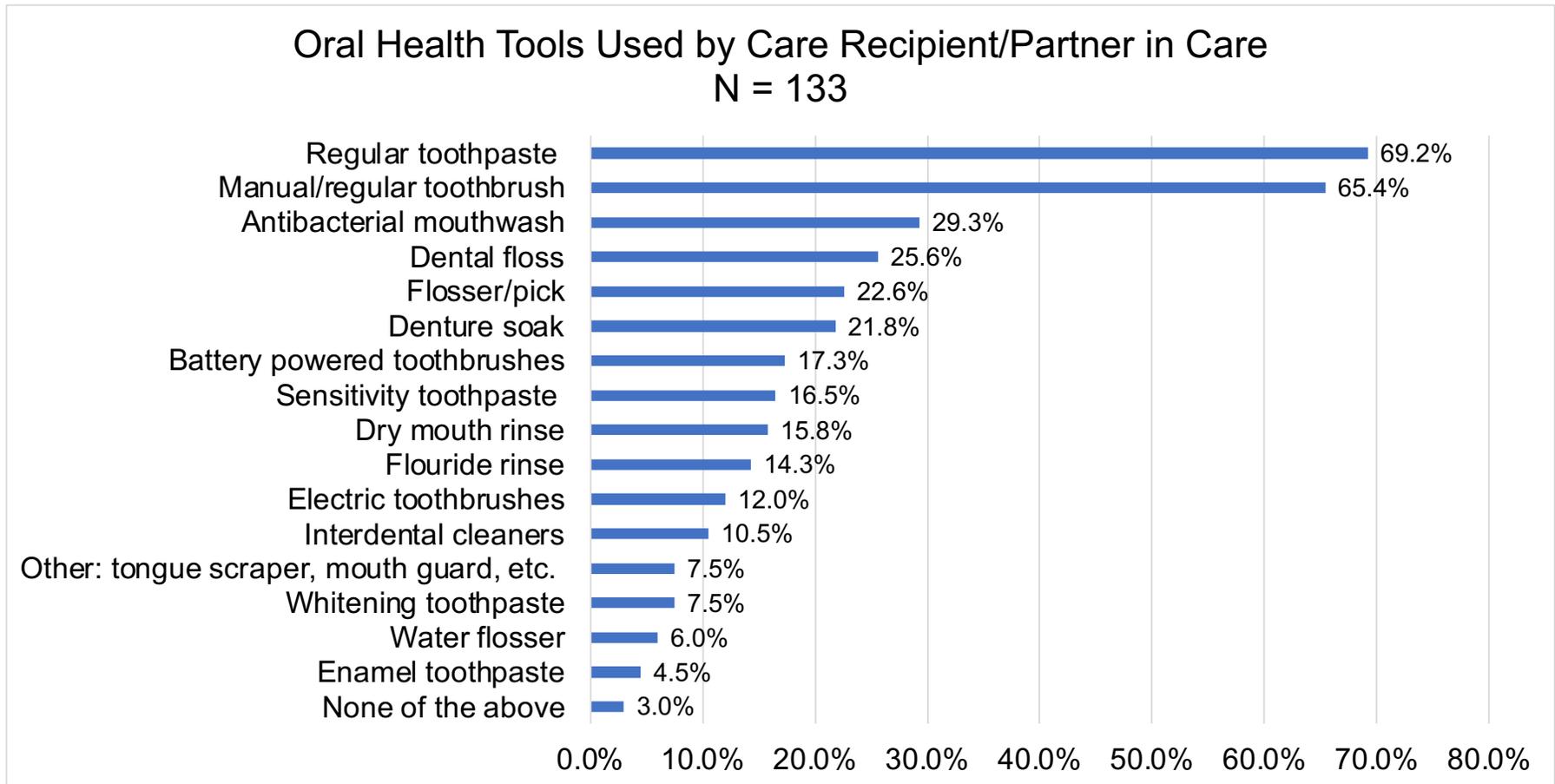
Questions 19-21: Care Efficacy



Questions 22-24: Oral Health Knowledge and Beliefs

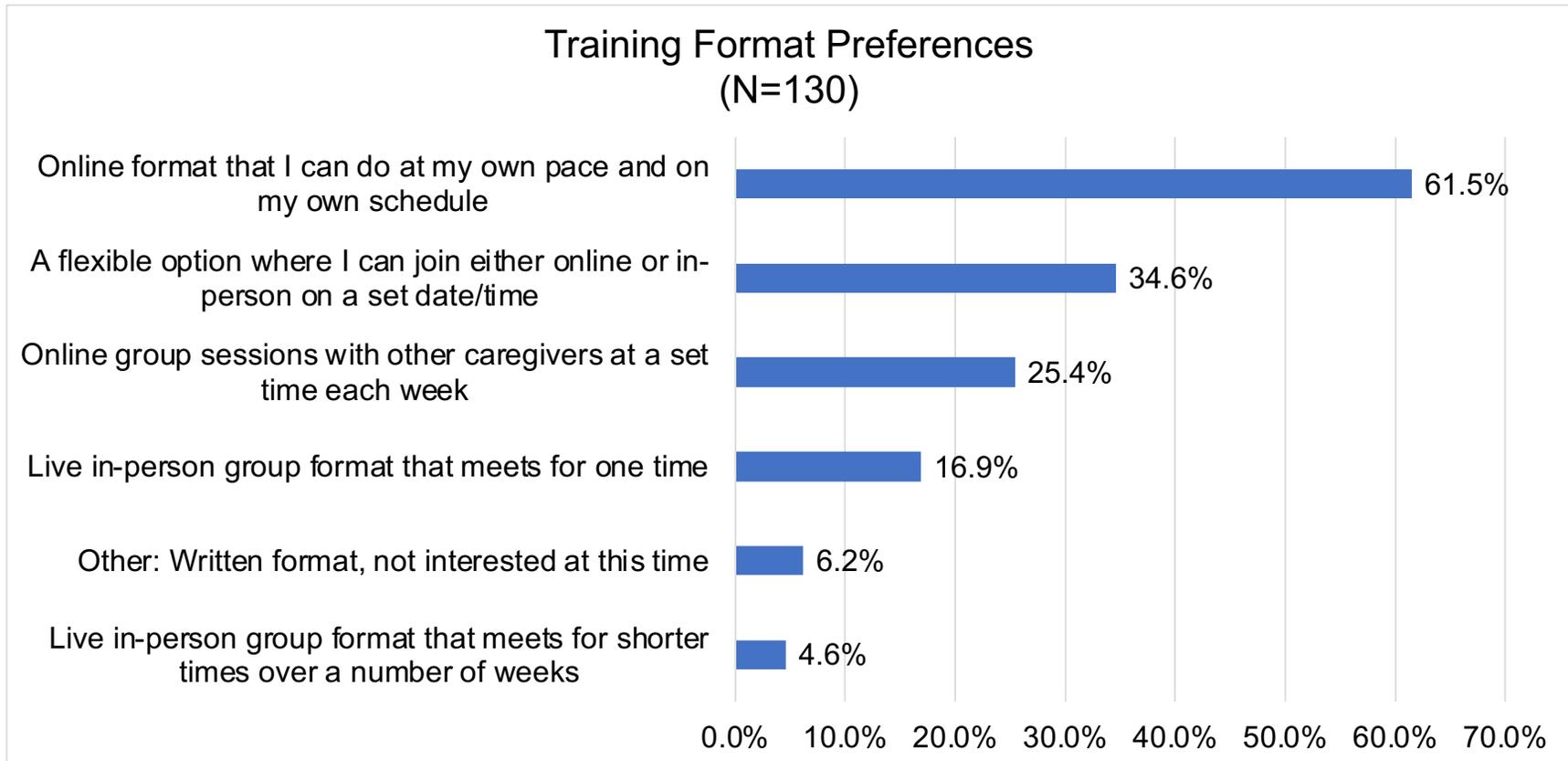


25. Which of the following oral health care methods does the person you care for use for their care. Please check all that apply. Check if the person you care for uses the tool or if you help them to use it. Please check all that apply.

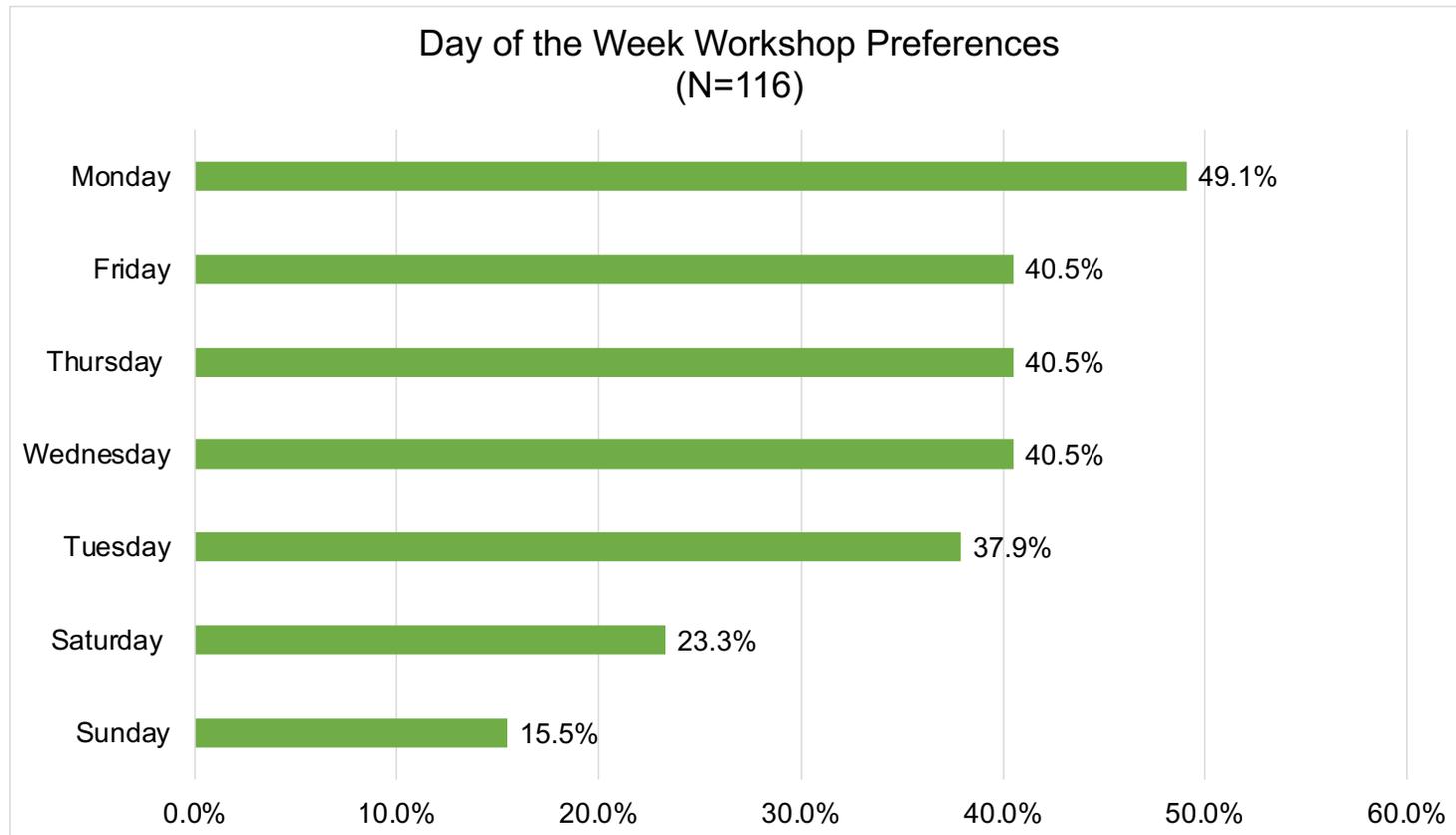


Section 3: Education and Training Preferences

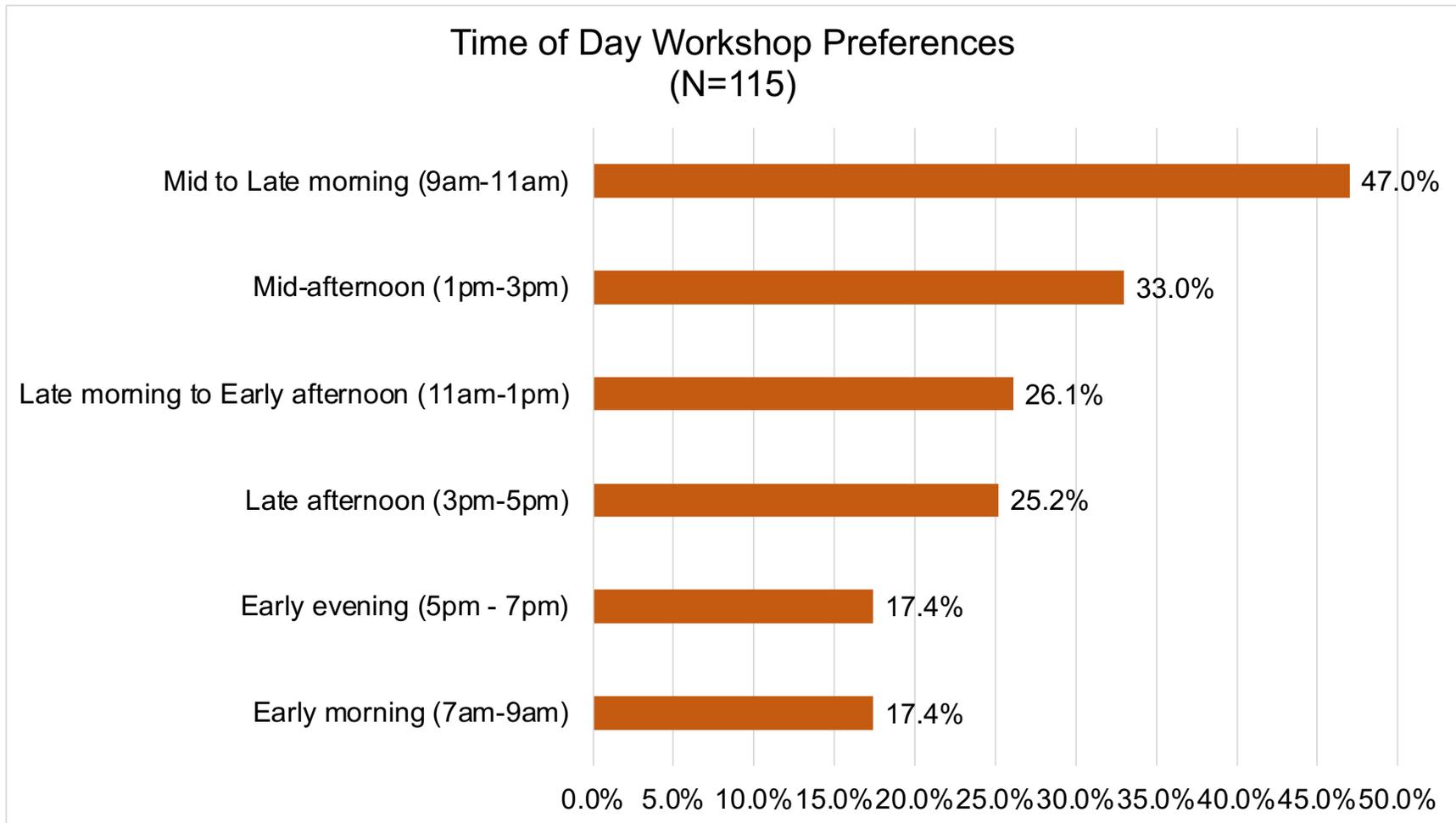
26. We are developing an educational program for caregivers on oral health care. If you were to take part in oral health education (workshops/classes) what would you prefer? Check your TOP TWO.



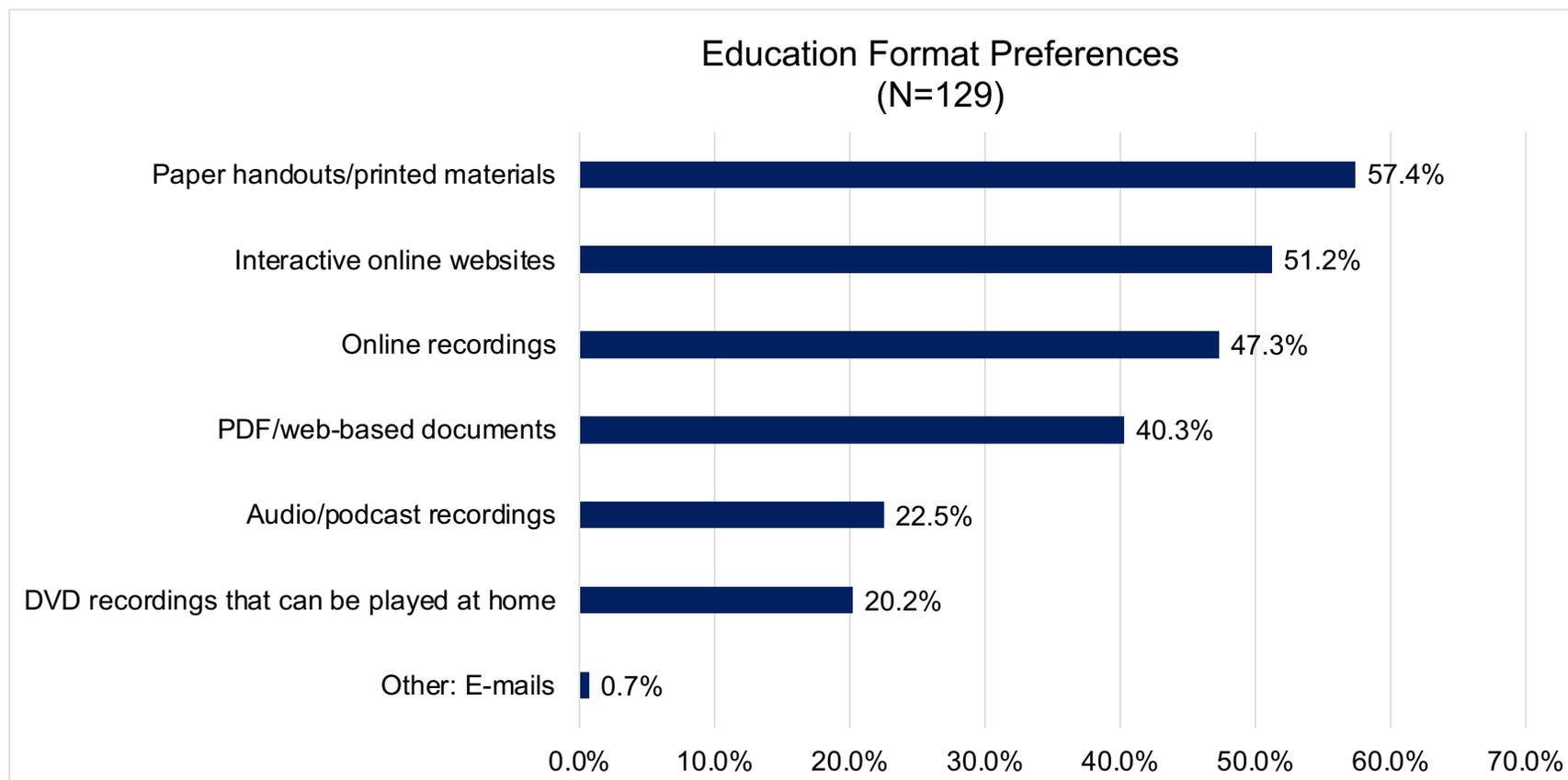
27. For workshops, generally what days of the week would work best? (Check all that apply)



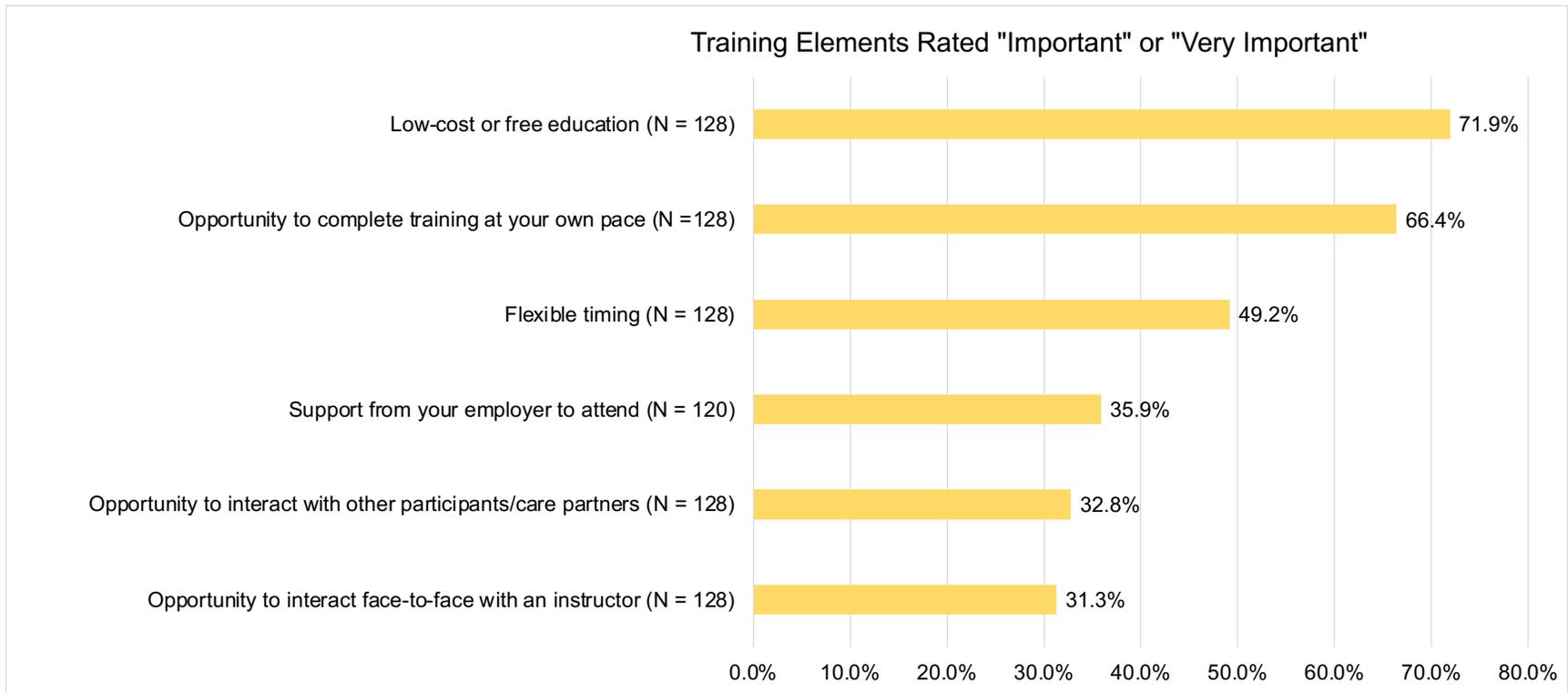
28. For workshops, generally what times of day would work best? (Check all that apply)



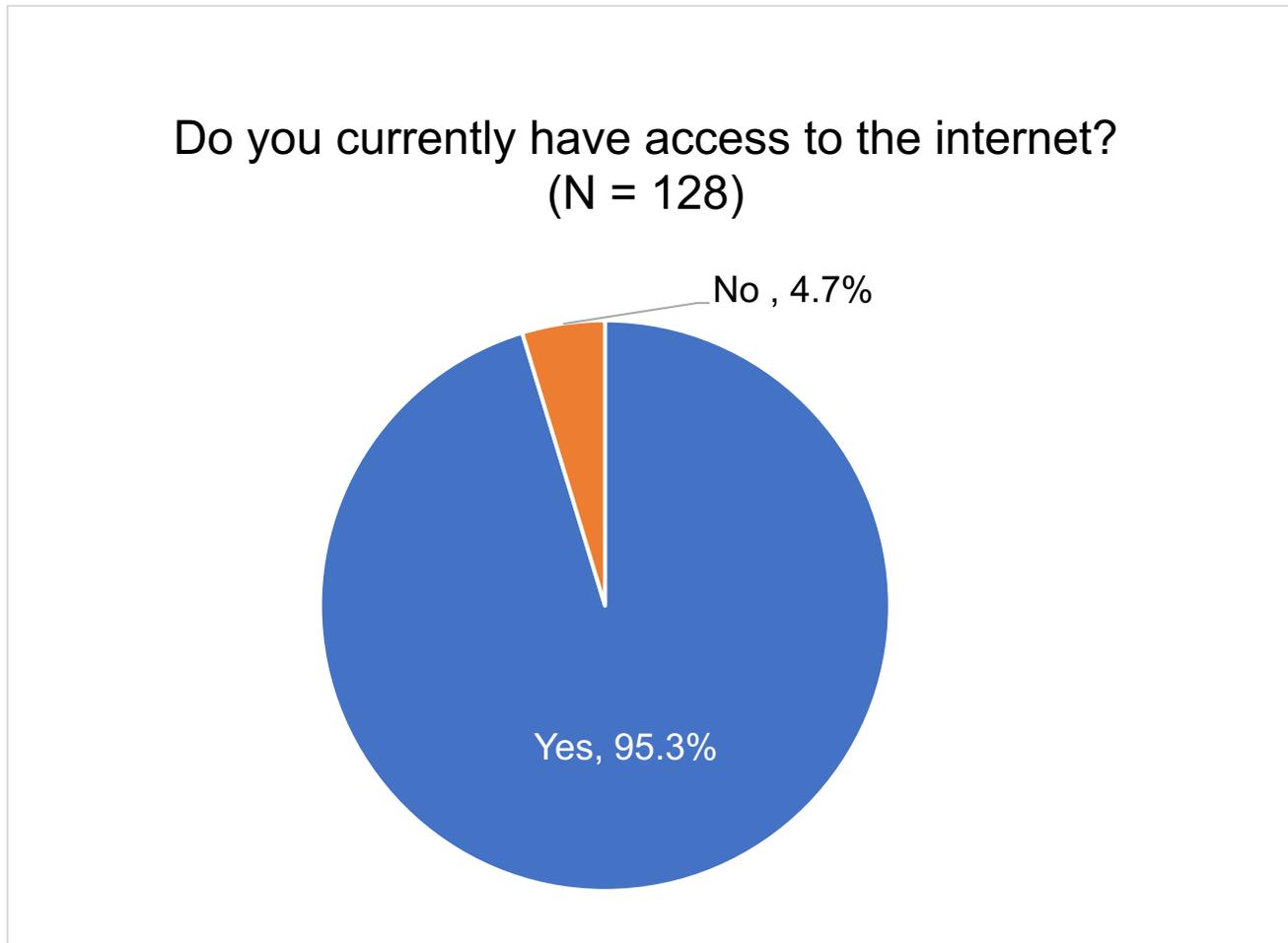
29. What types of learning materials are most helpful to you? Select your **TOP THREE**



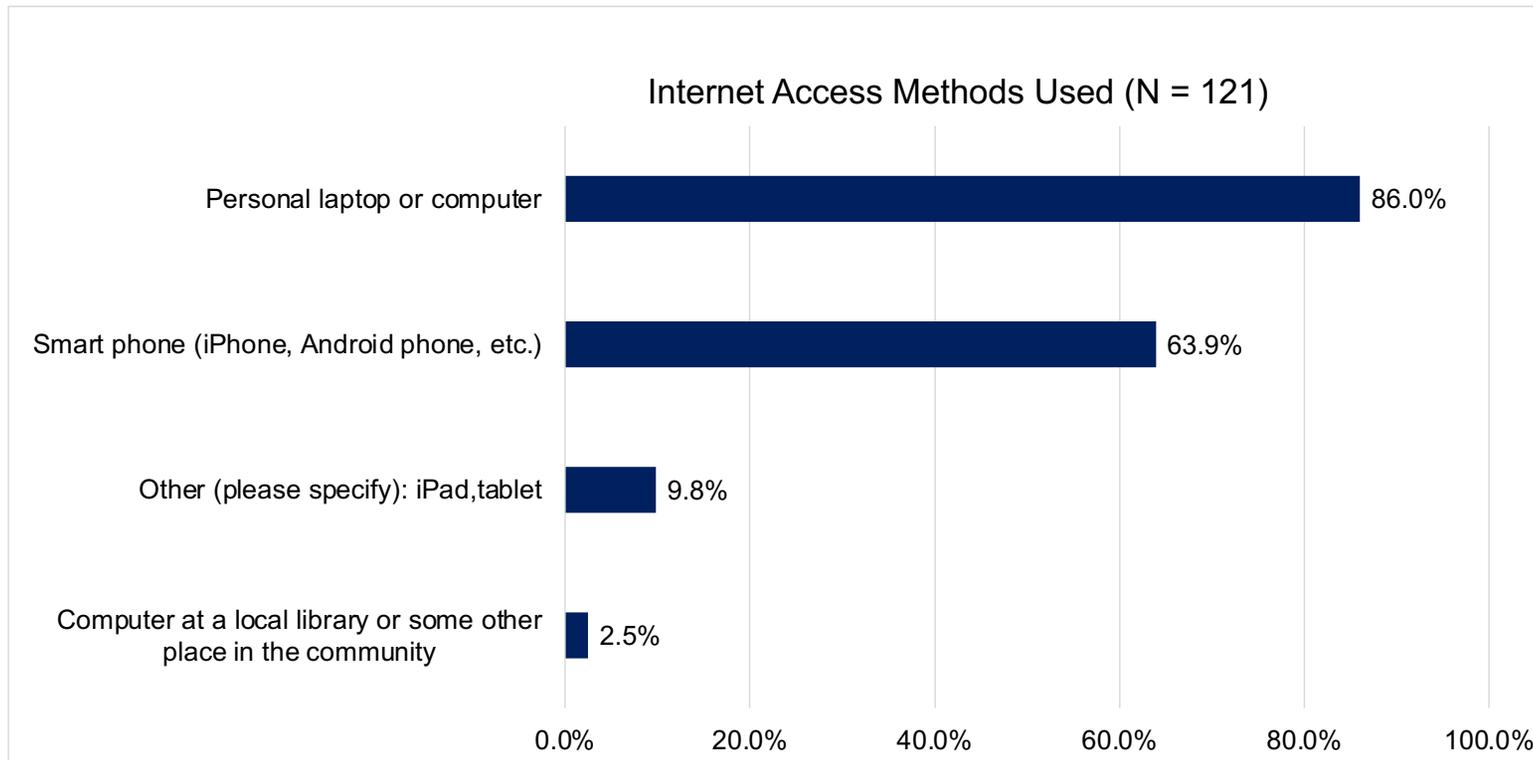
30. How important are the following to you when it comes to learning?



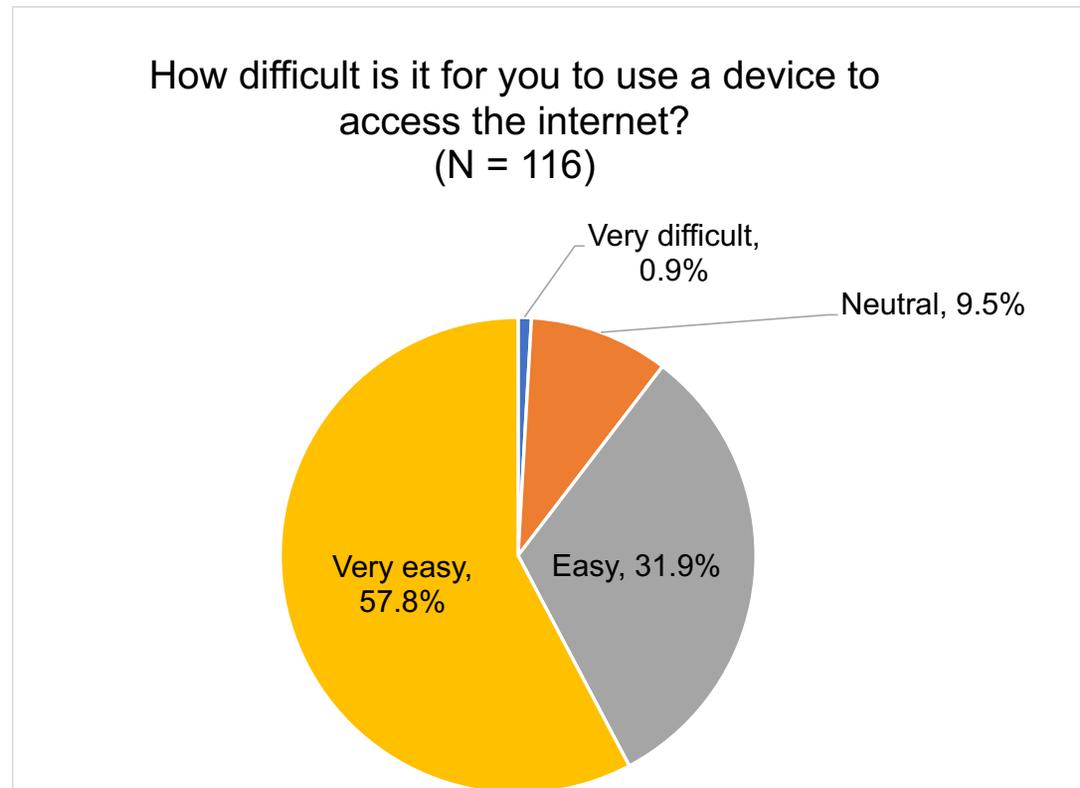
31. Do you currently have internet access?



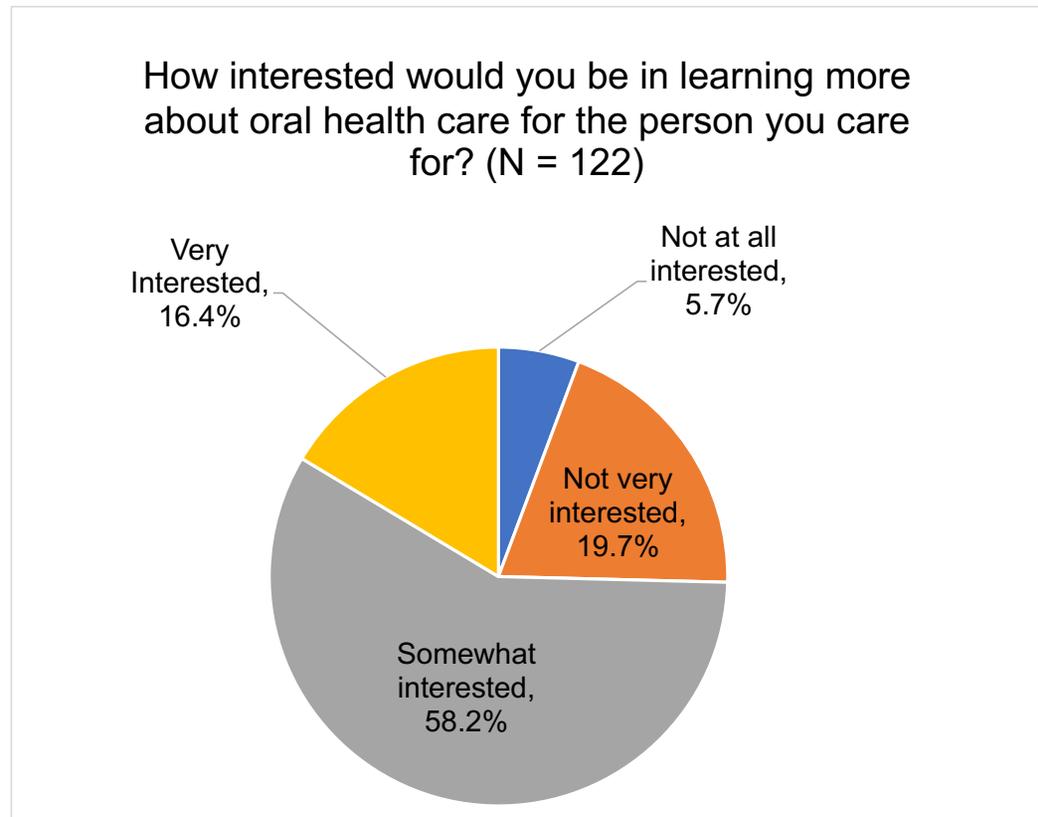
32. If you currently access the internet how do you get online? Please check all that apply.



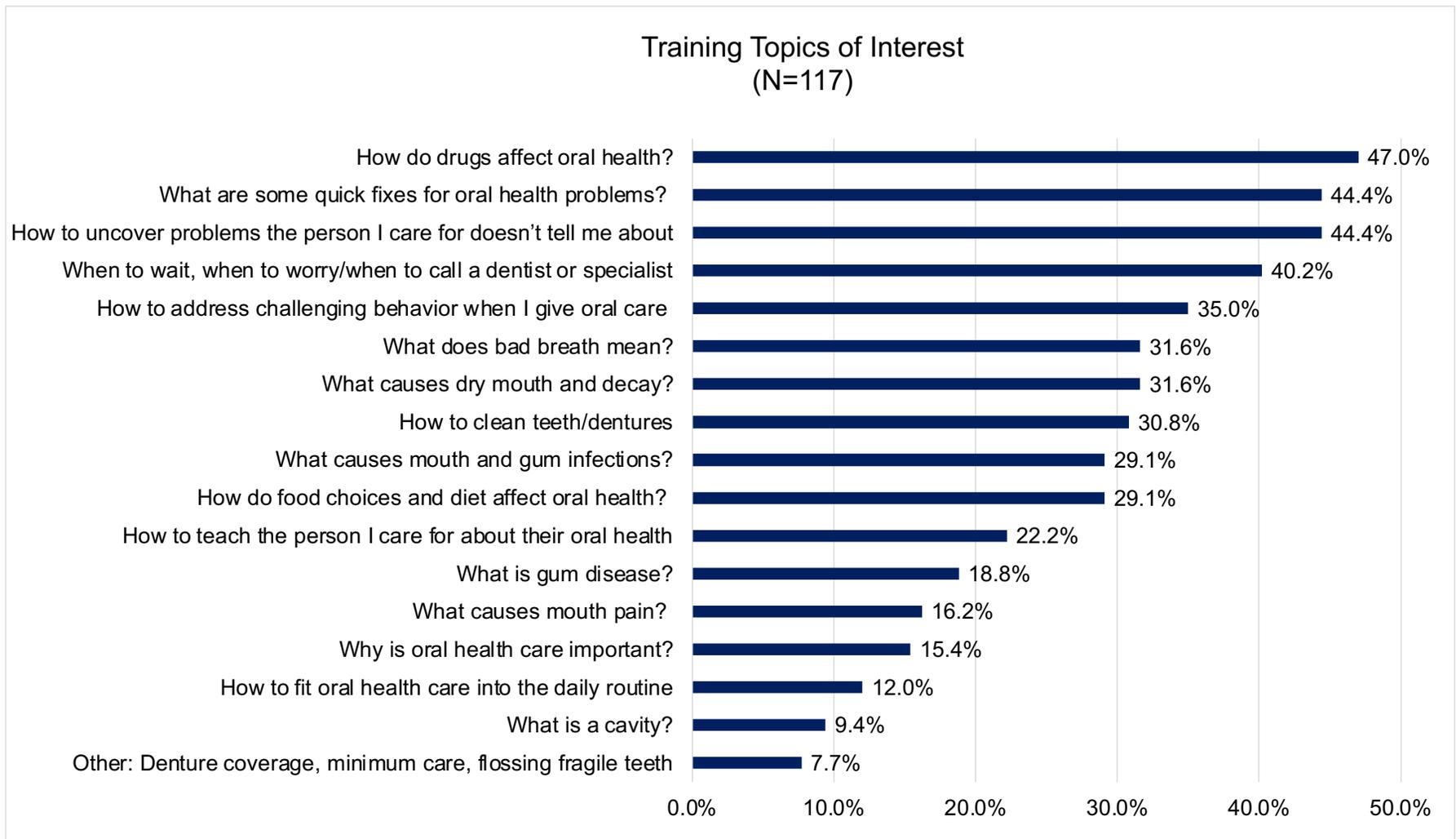
33. How difficult is it for you to use a device to access the internet?



34. How interested would you be in learning more about oral health care for the person you care for?



**35. Please check the oral health issues that you would want to learn about:
(Please check all that apply)**



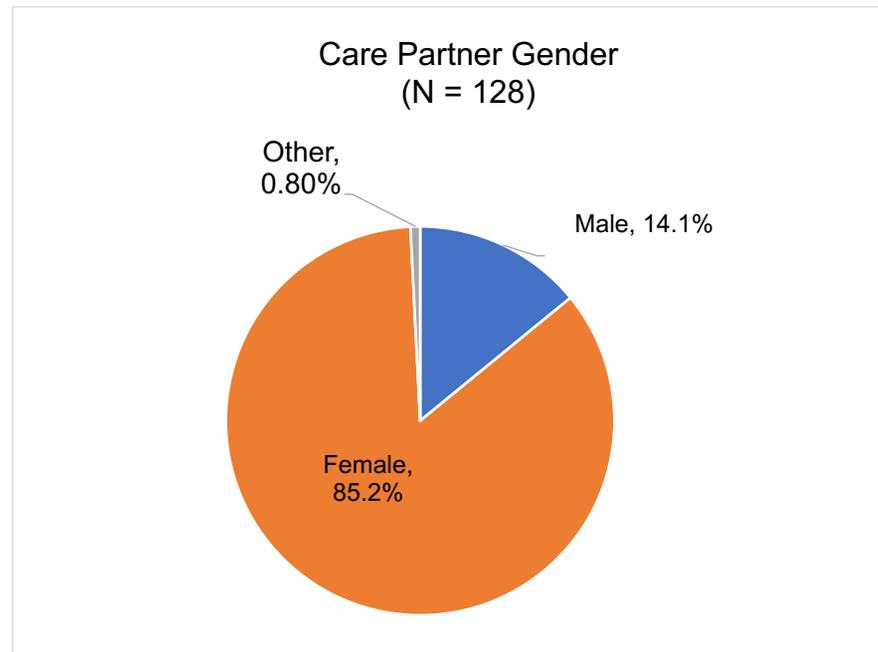
Section 4: Care Recipient/Partner in Care Demographics

Caregiver/Care Partner

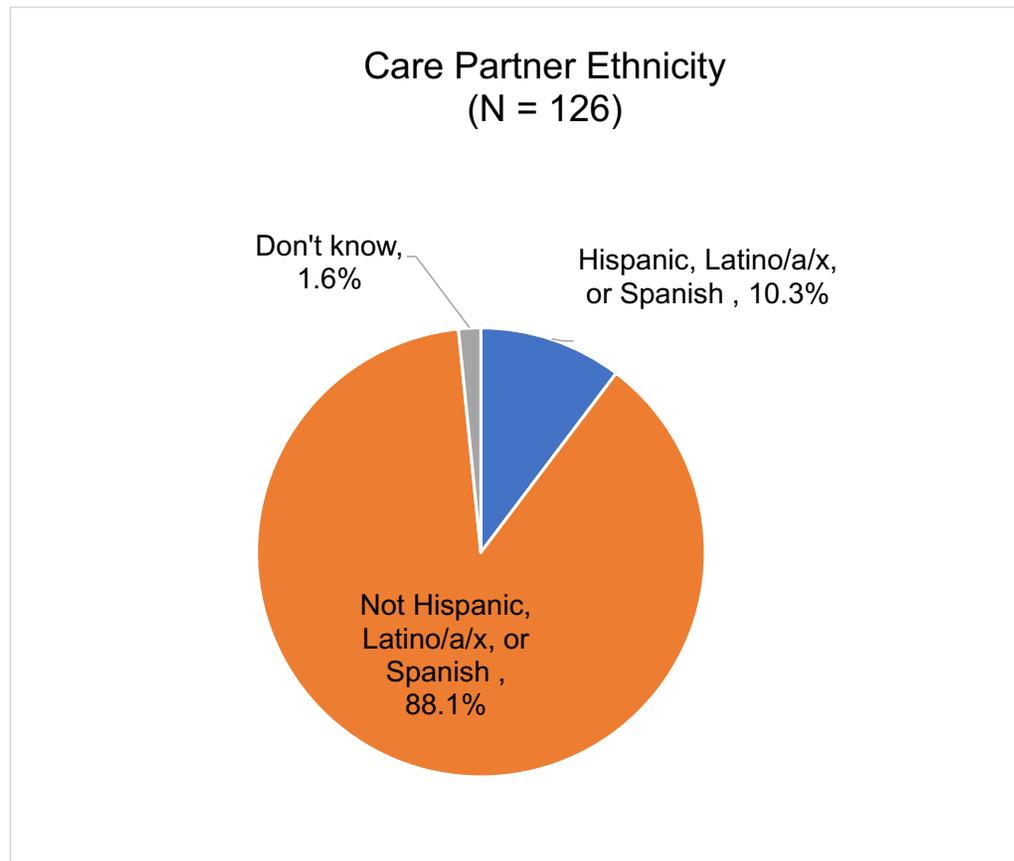
36. What is your age?

- The average age of care partners who responded to the survey: 61 years
- Age range: 28-85

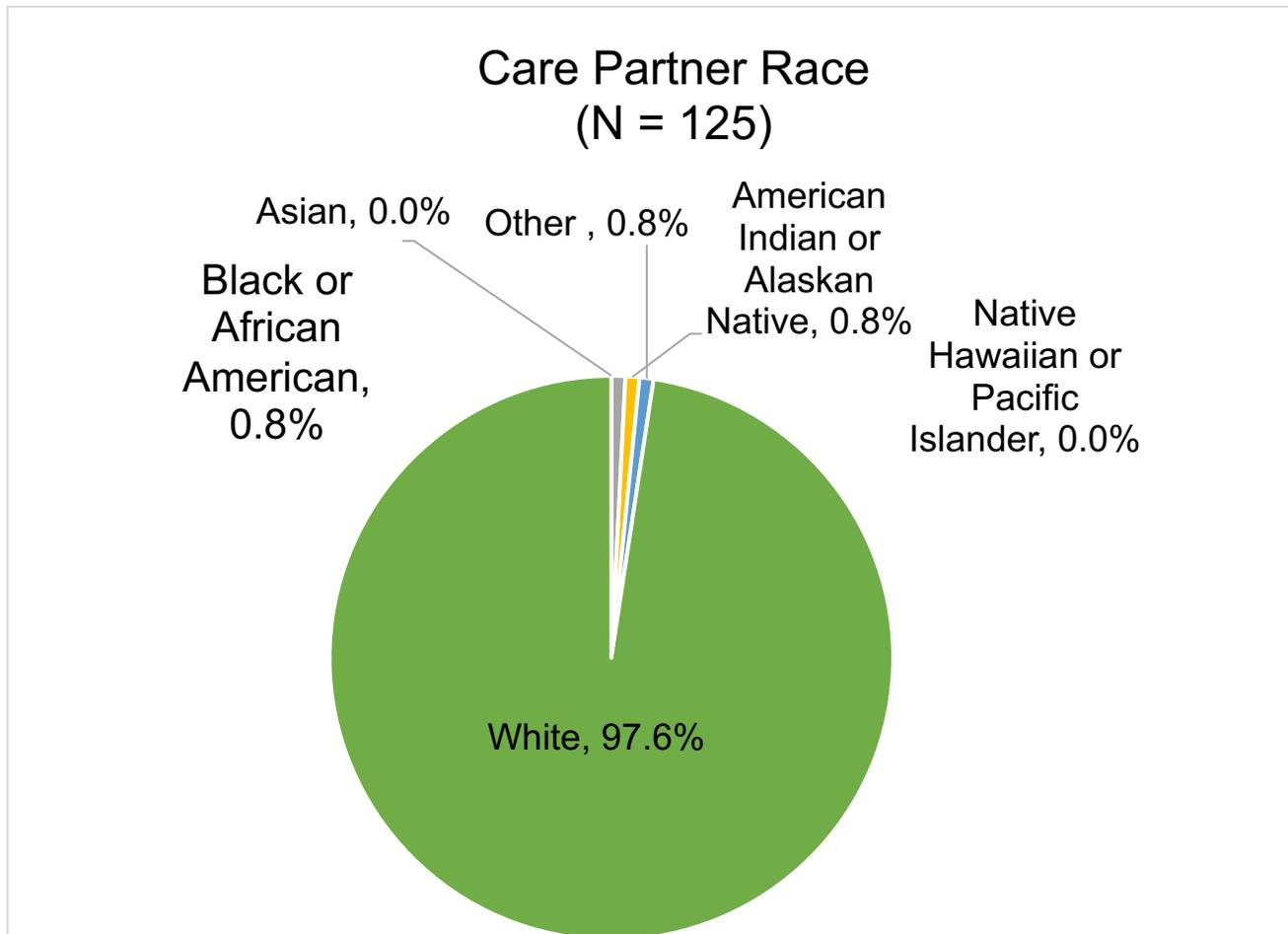
37. What is your gender:



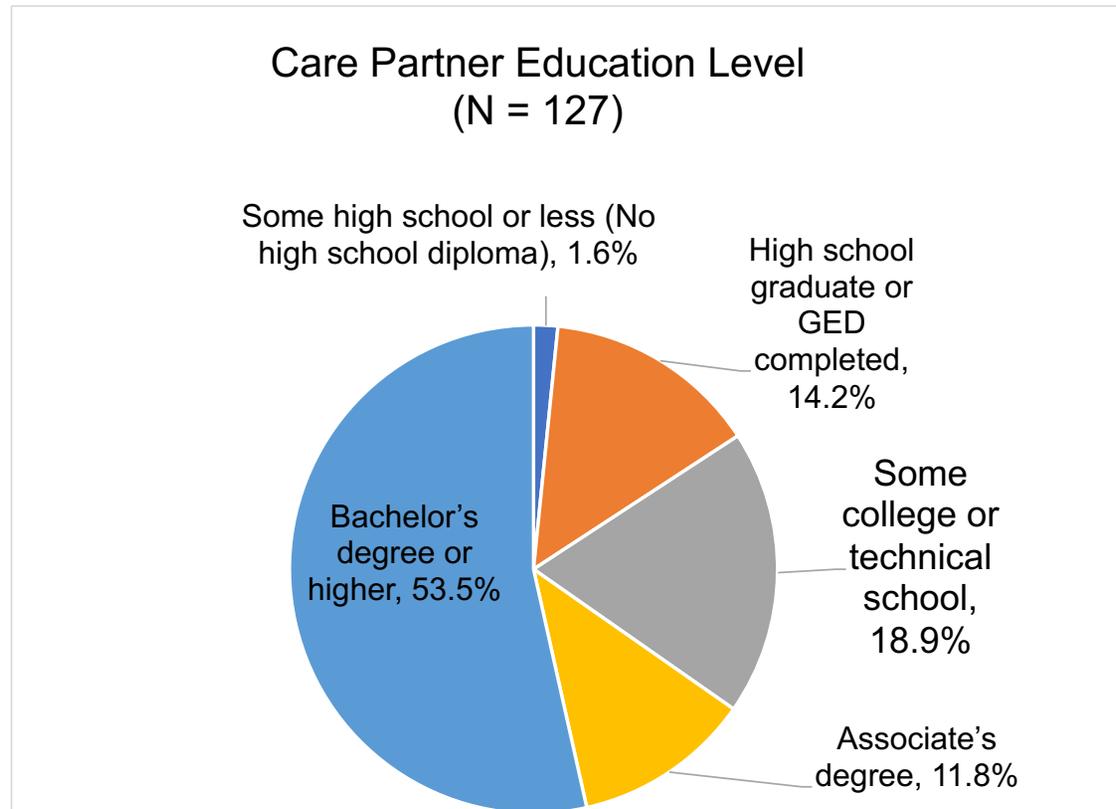
38. Are you of Hispanic, Latino/a/x, or Spanish origin?



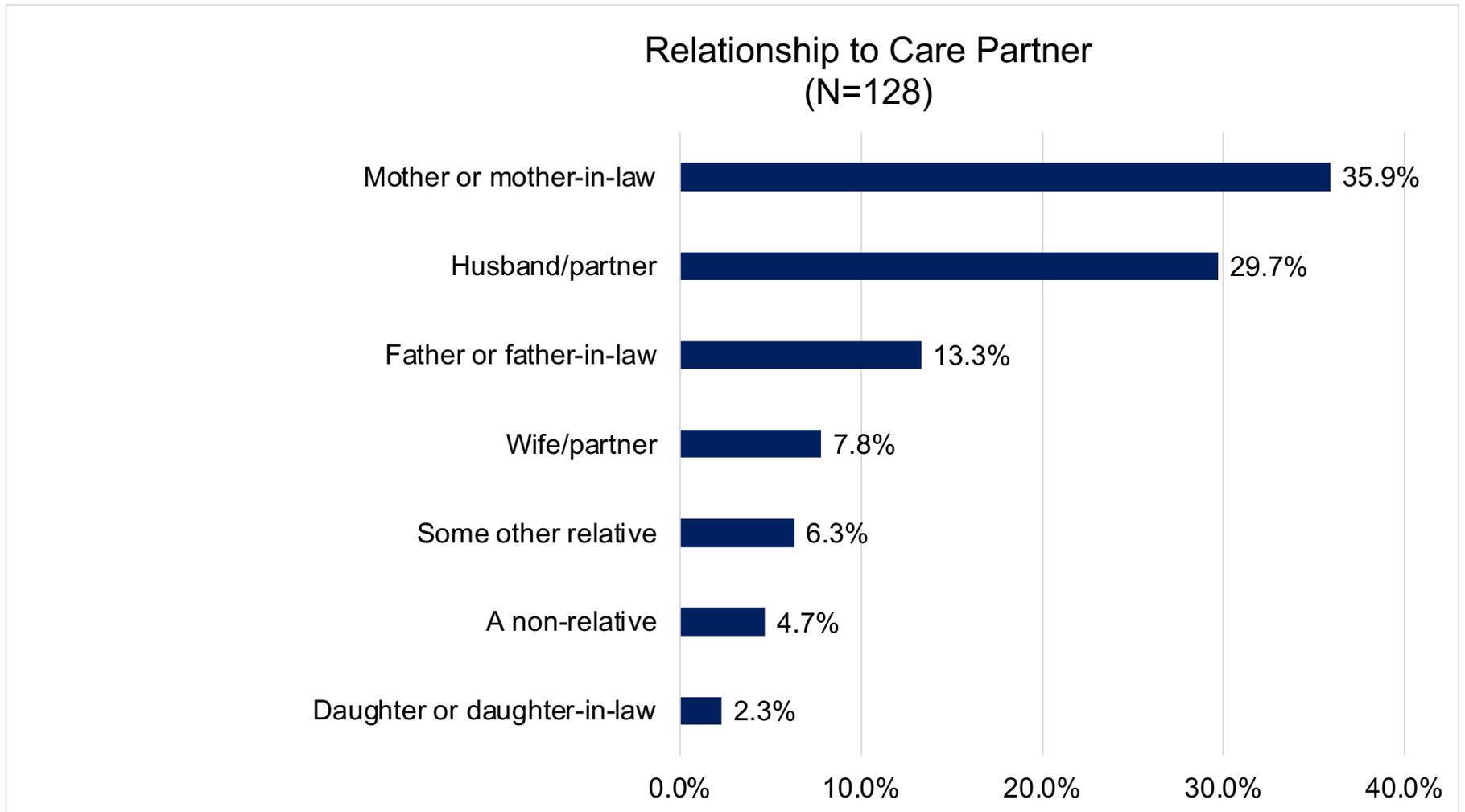
39. What is your race? (Check ALL that apply.)



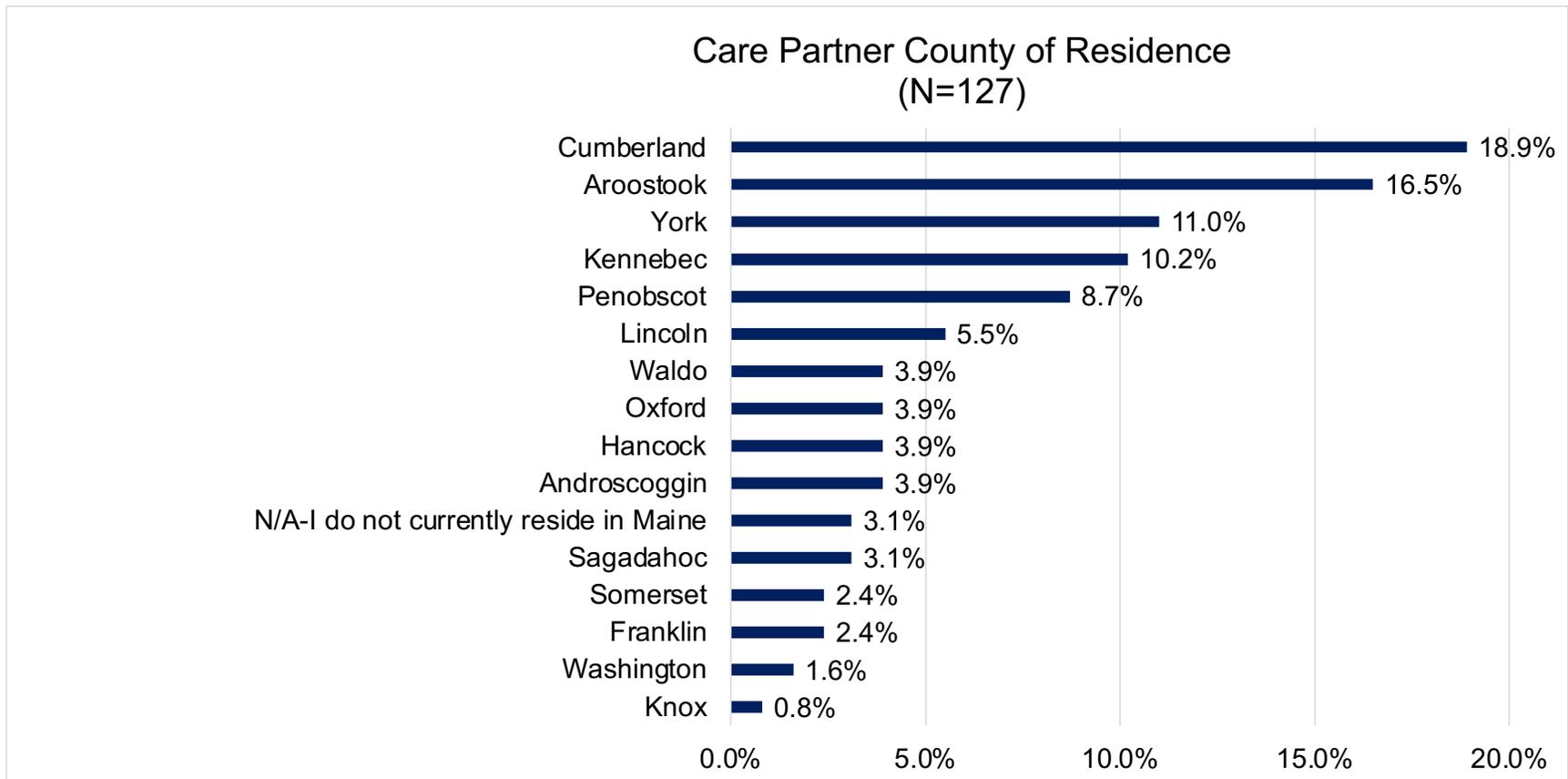
40. What is the highest grade or level of school you have completed?



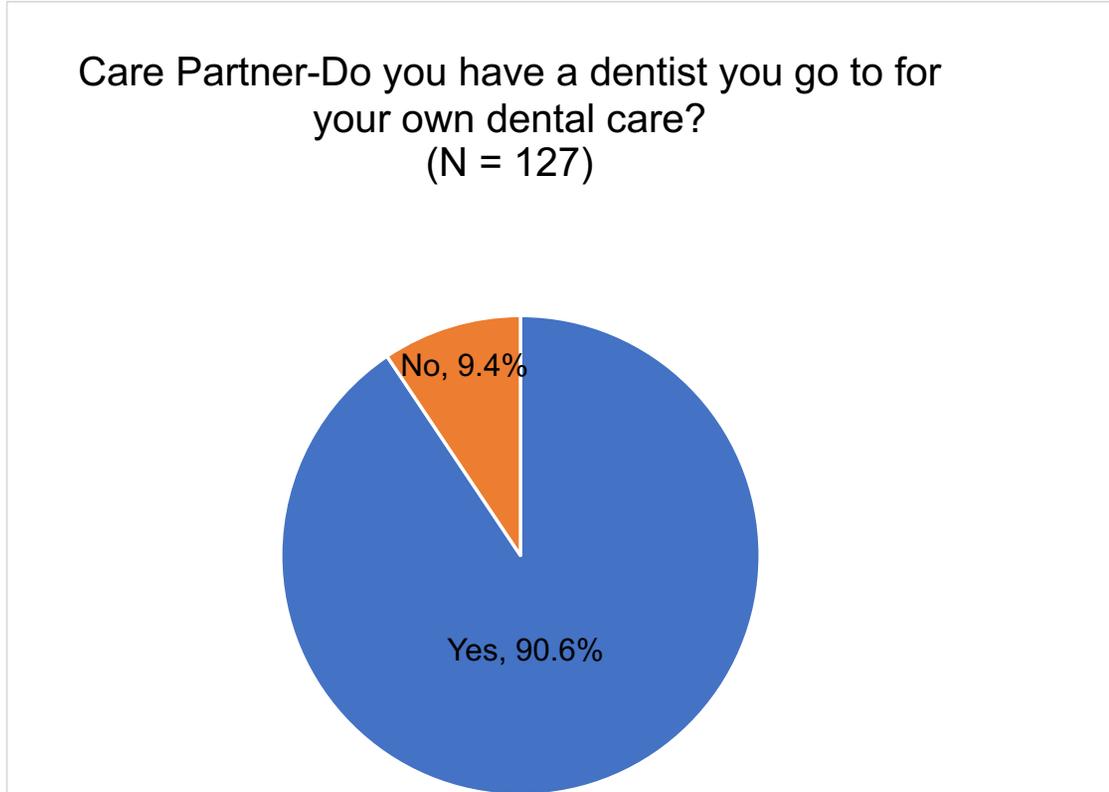
**41. What is your relationship to the person you are caring for?
They are my:**



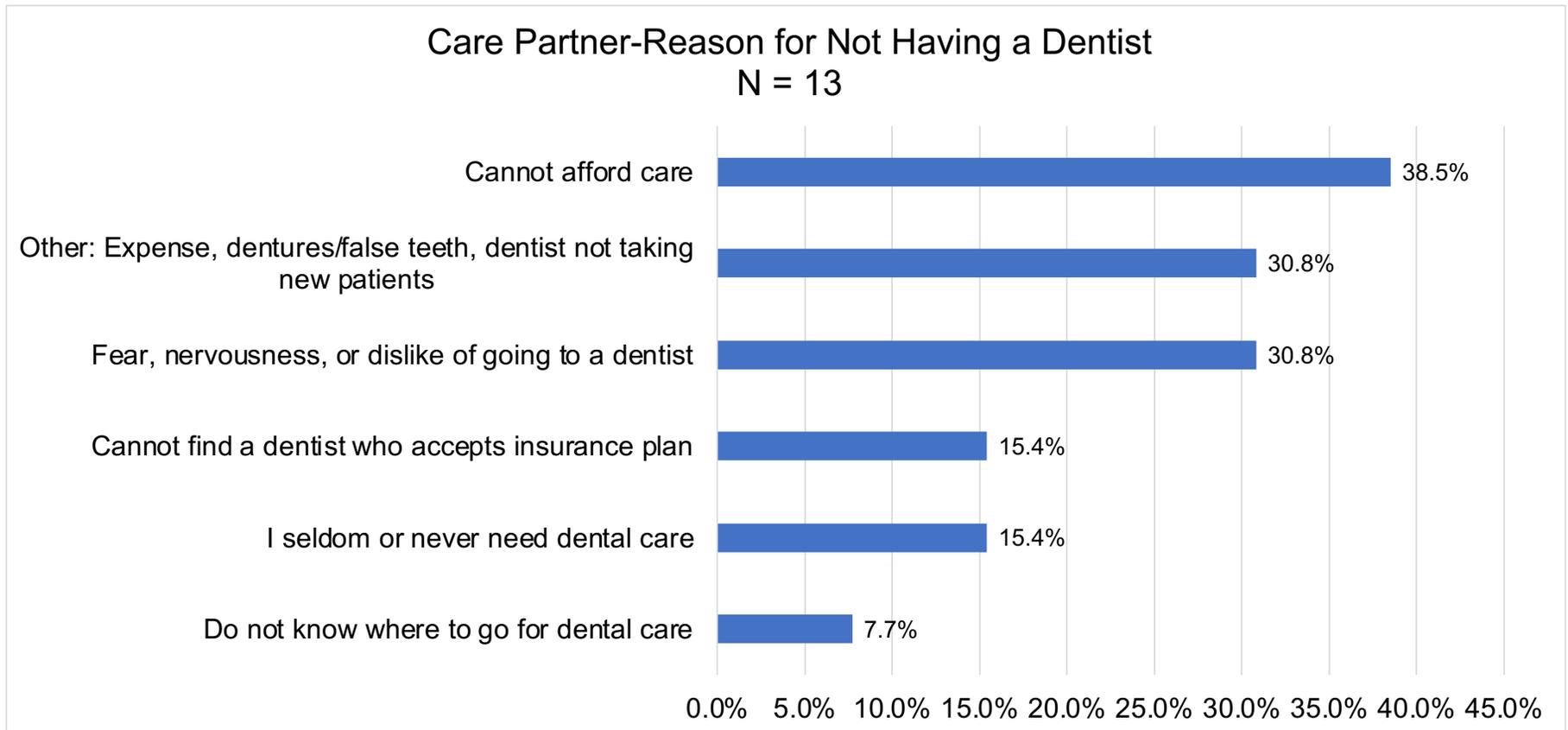
42. In which Maine county do you live? Check one.



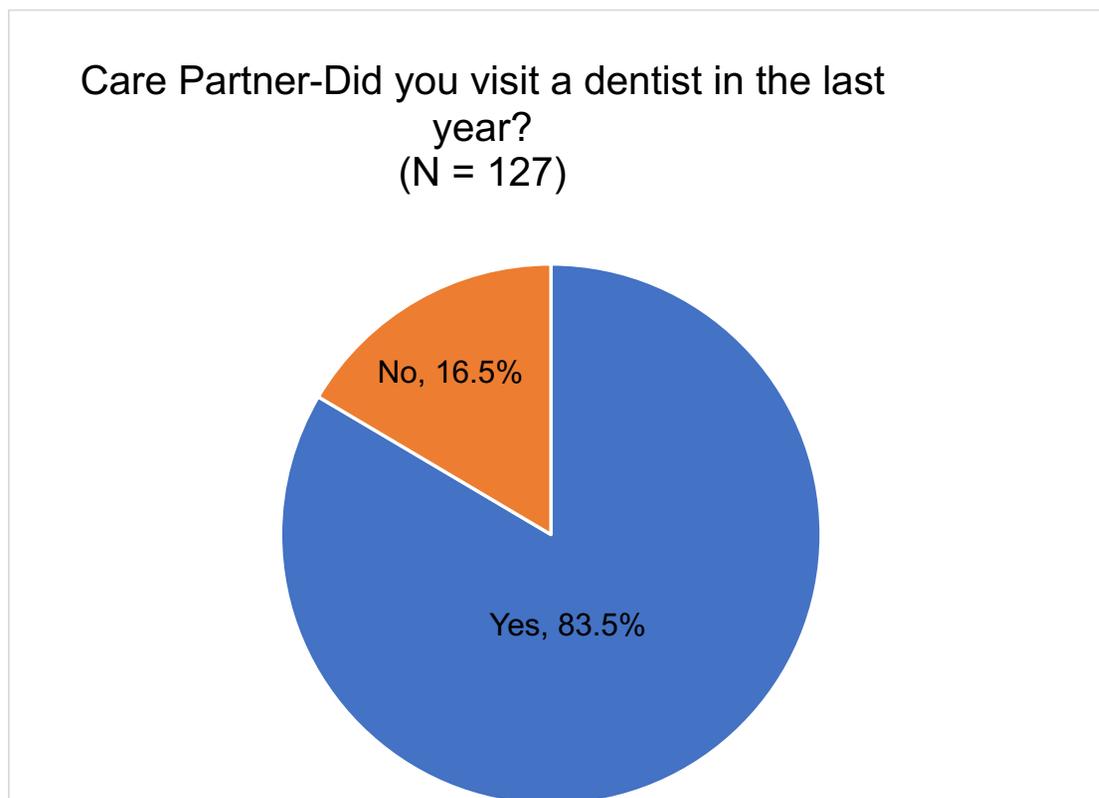
43. Do you have a dentist you go to for your own dental care?



44. What are the main reasons you do NOT have a dentist you usually go to for dental care? [Choose up to THREE answers]

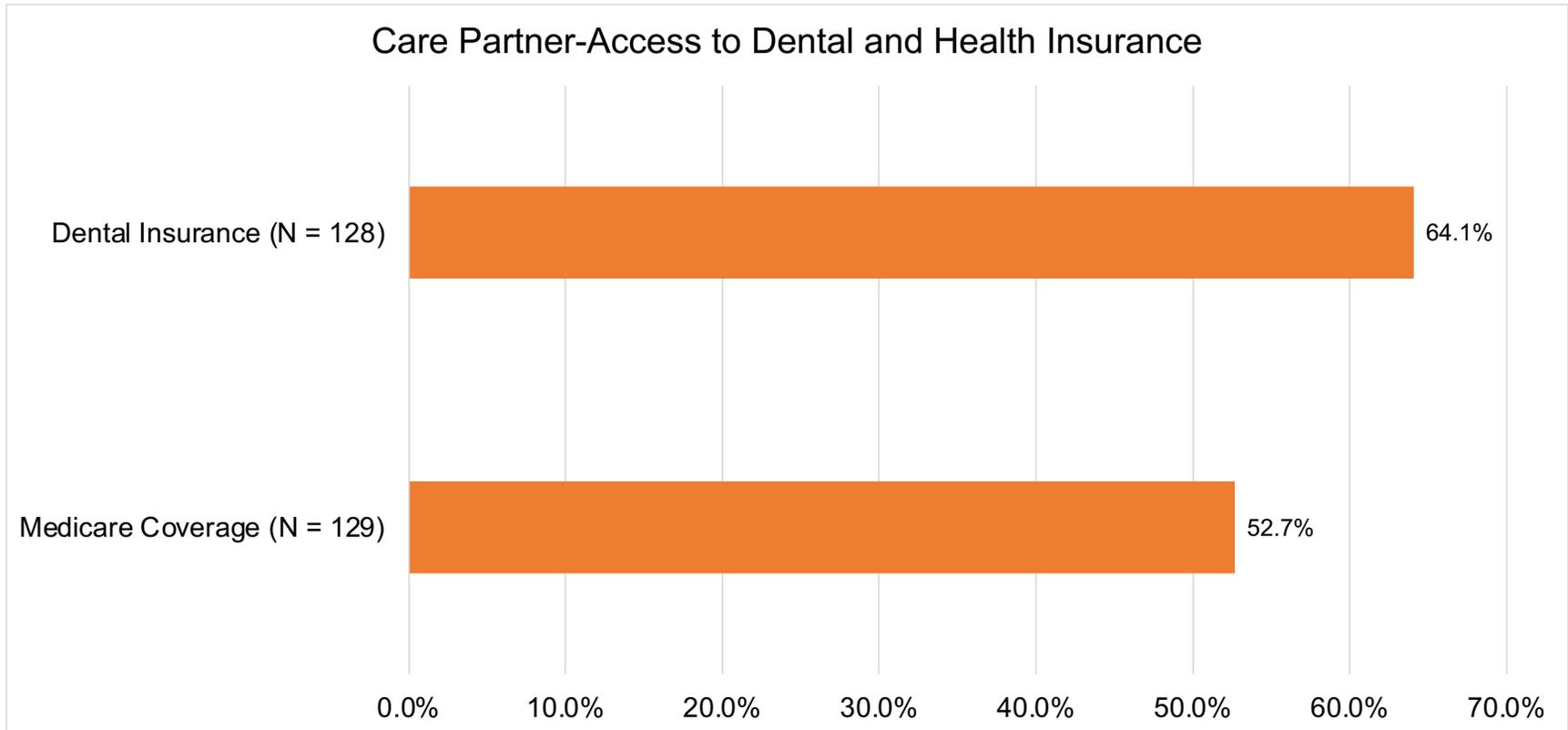


45. Did you visit a dentist or a dental clinic for any reason within the past 12 months? Include visits to dentists and dental specialists, such as orthodontists and oral surgeons, as well as dental hygienists.

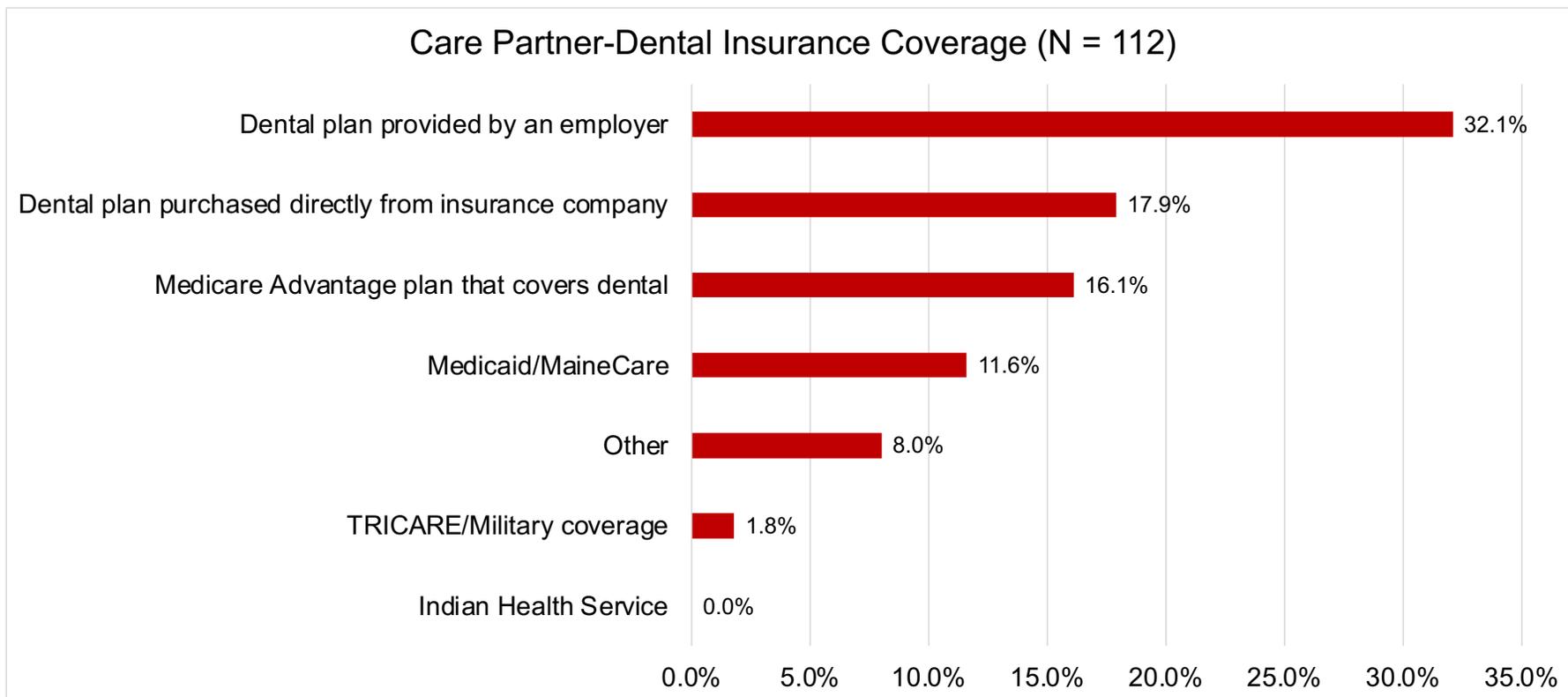


46. Are you currently covered by Medicare for medical insurance?

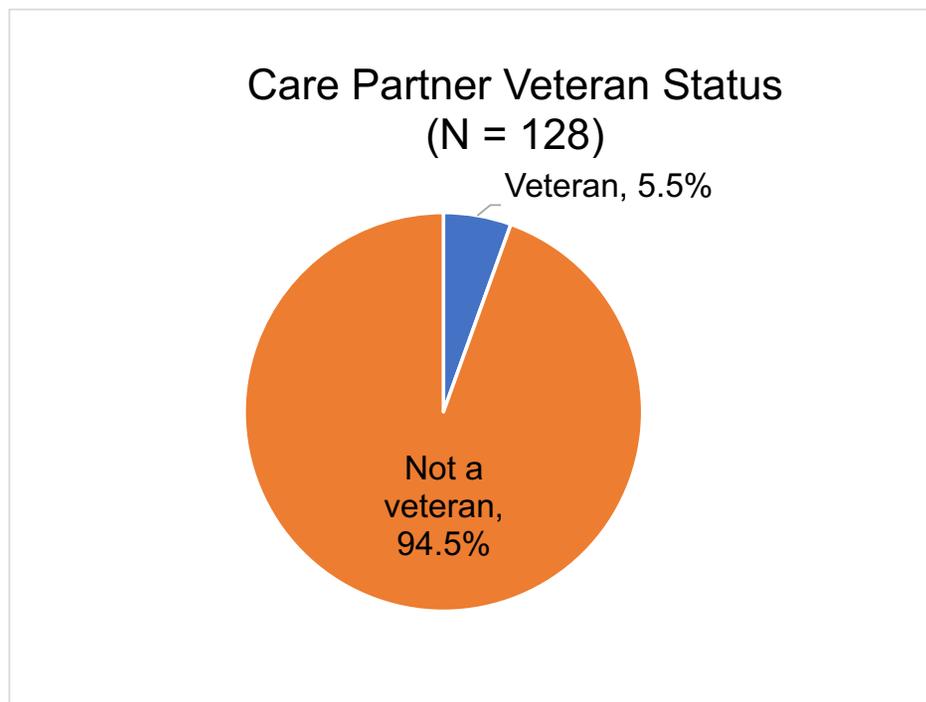
47. Do you currently have access to dental insurance coverage?



48. During the past 12 months, if were you covered by dental insurance coverage, which insurance(s) did you have? (check all that apply)



49. Are you a veteran?

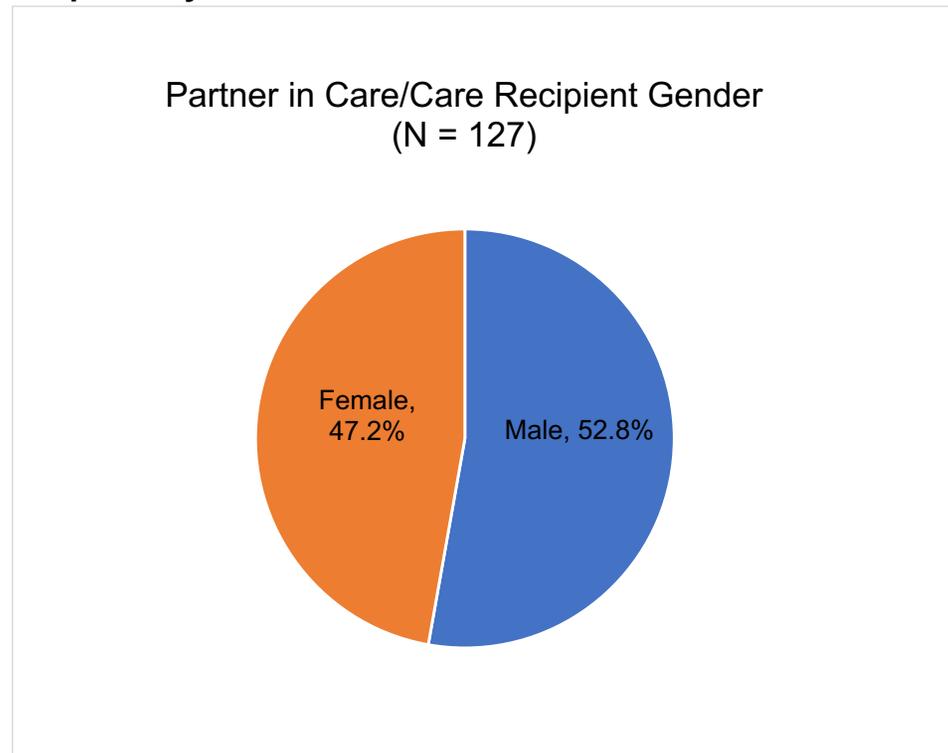


Partner in Care/Care Recipient

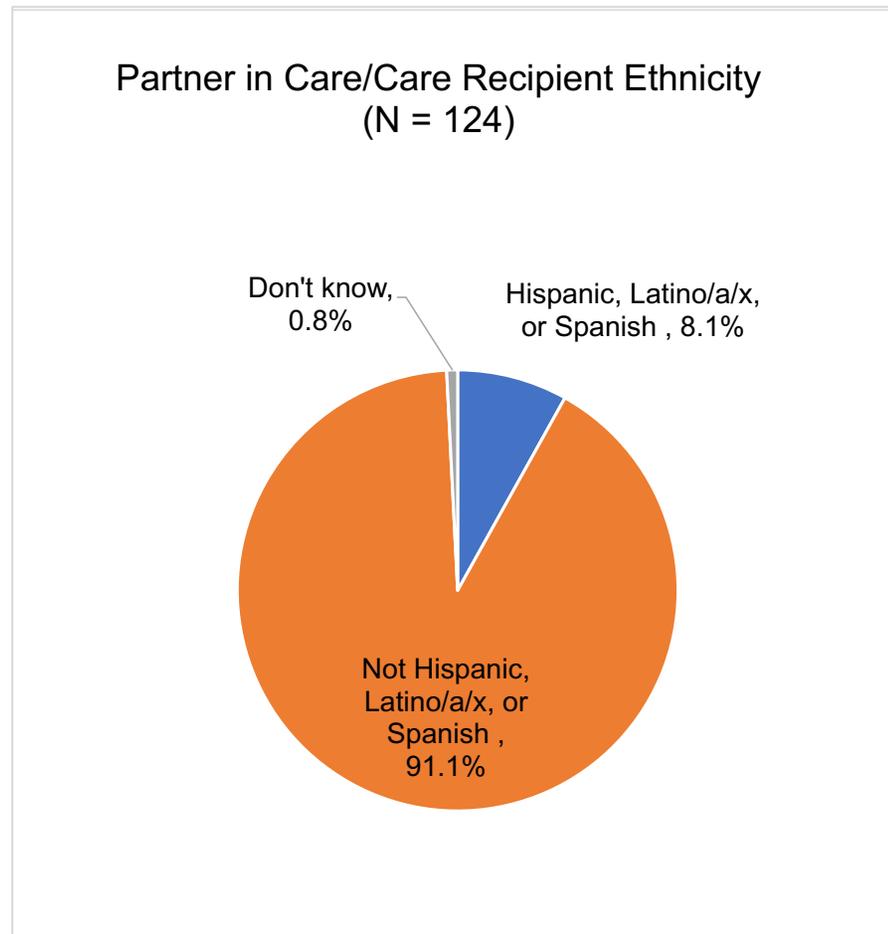
50. What is the age of the person you care for?

- The average age of partners in care/care recipients: 80
- Age range: 43-101*
- *The survey was designed to target caregivers of individuals 65 and older, however, caregivers were asked to respond for the person they provide the most care for if caring for multiple individuals. As a result, some of the partners in care were younger than 65.

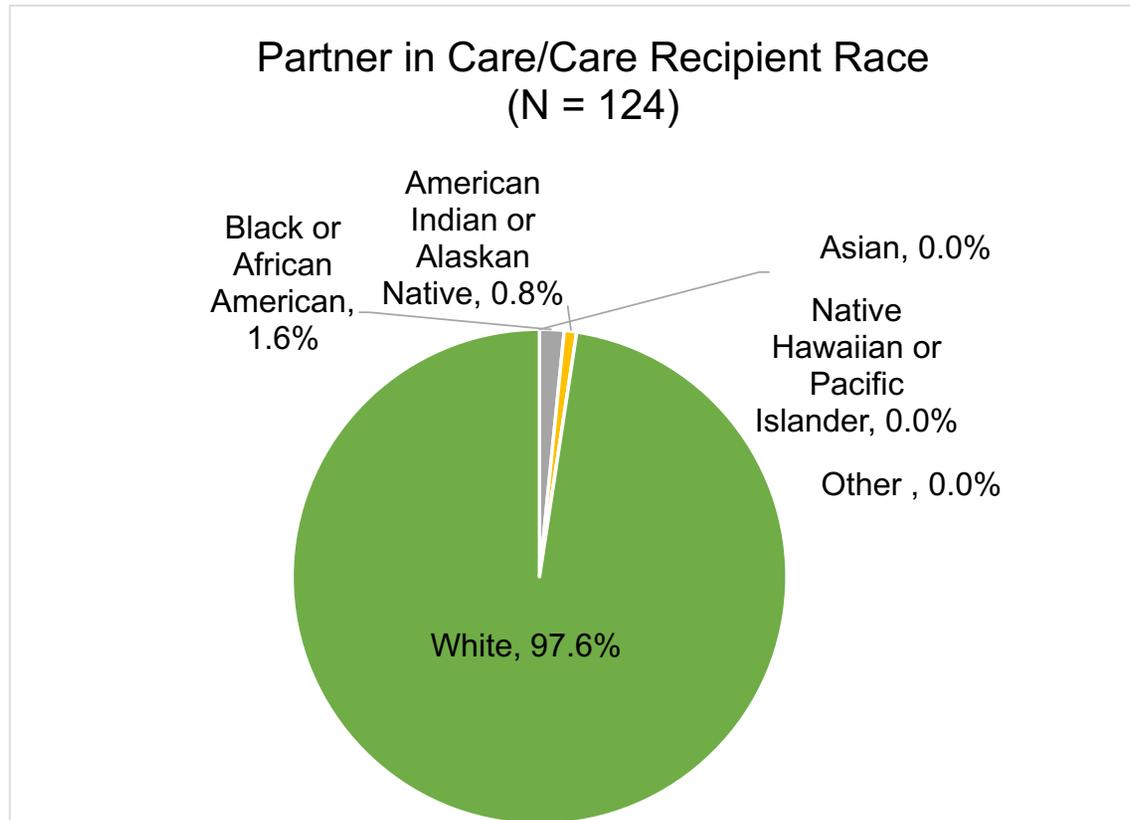
51. What is the gender of the person you care for?



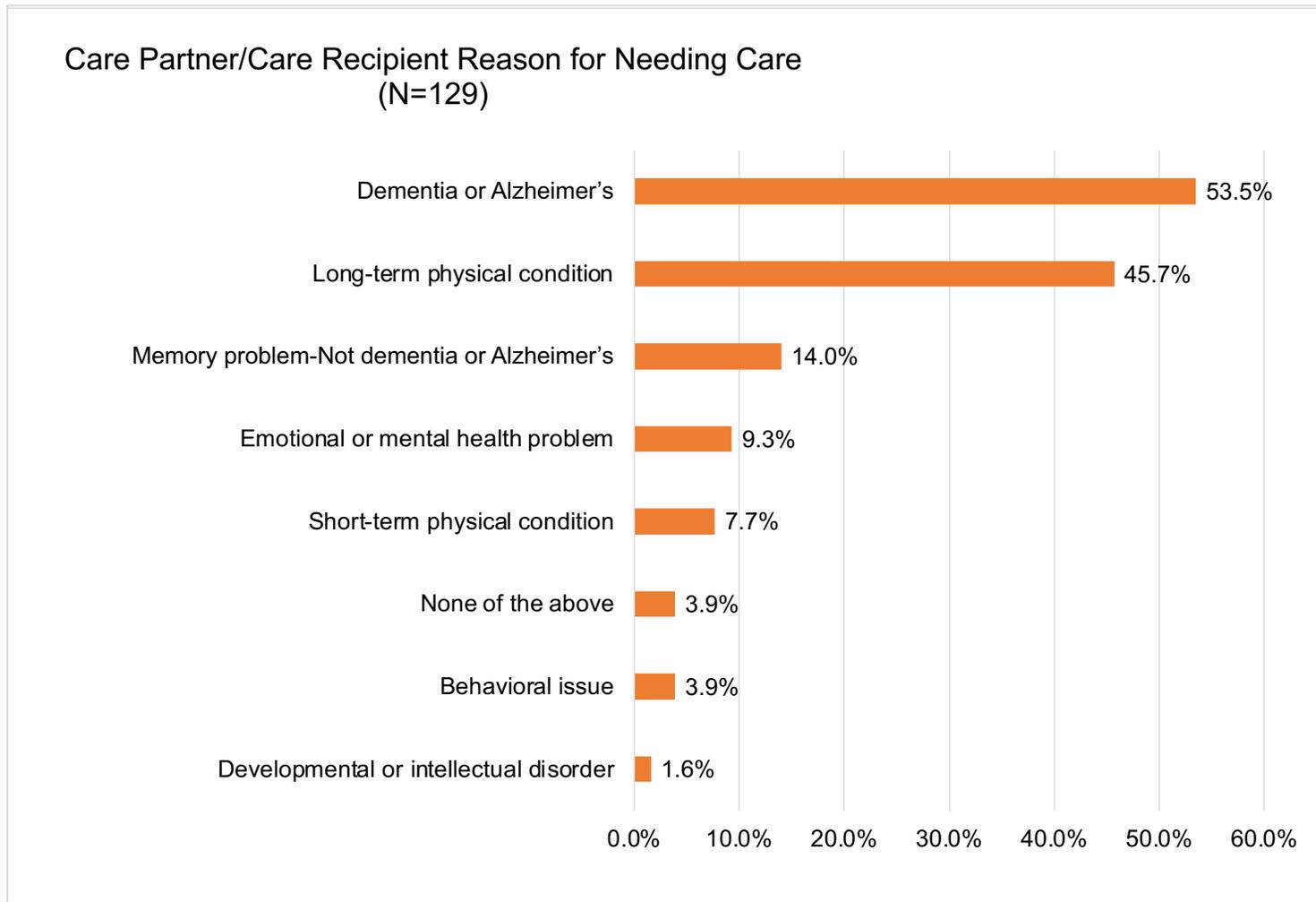
52. Is the person you care for of Hispanic, Latino/a/x, or Spanish origin?



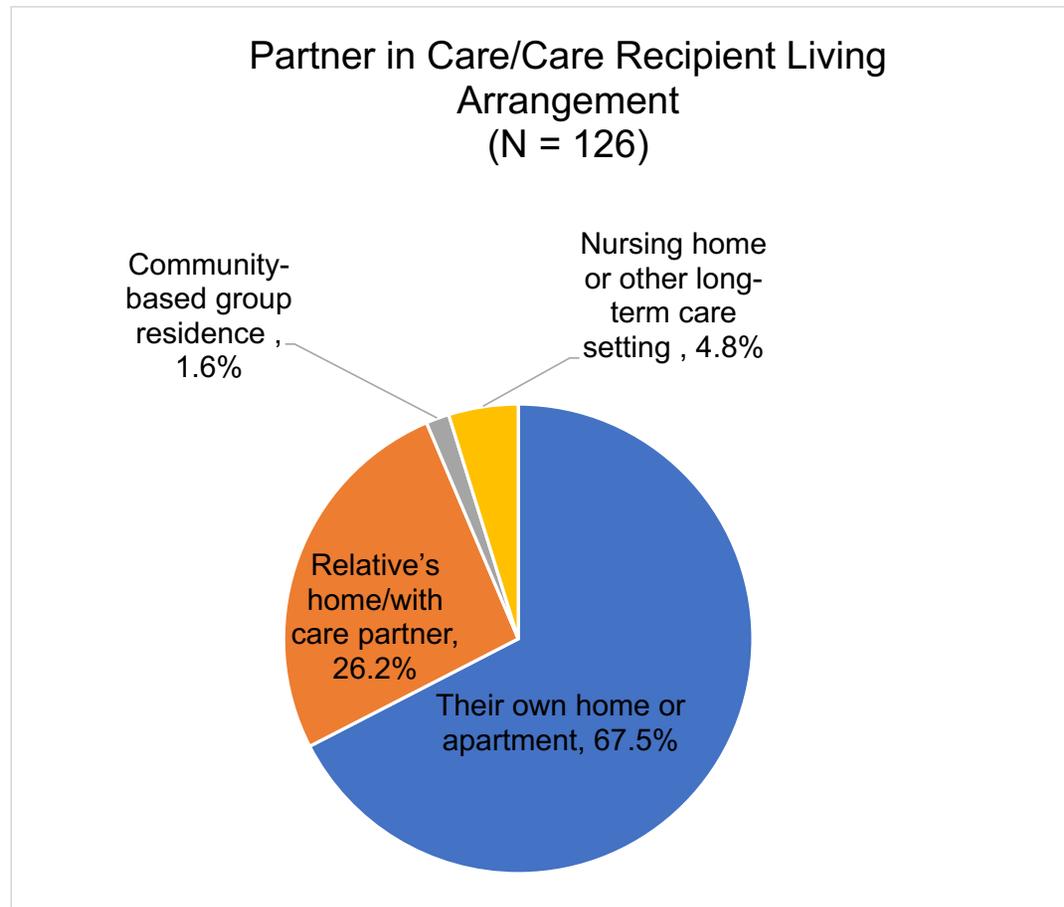
53. Which one or more of the following would you say is the race of the person you care for? (Check ALL that apply.)



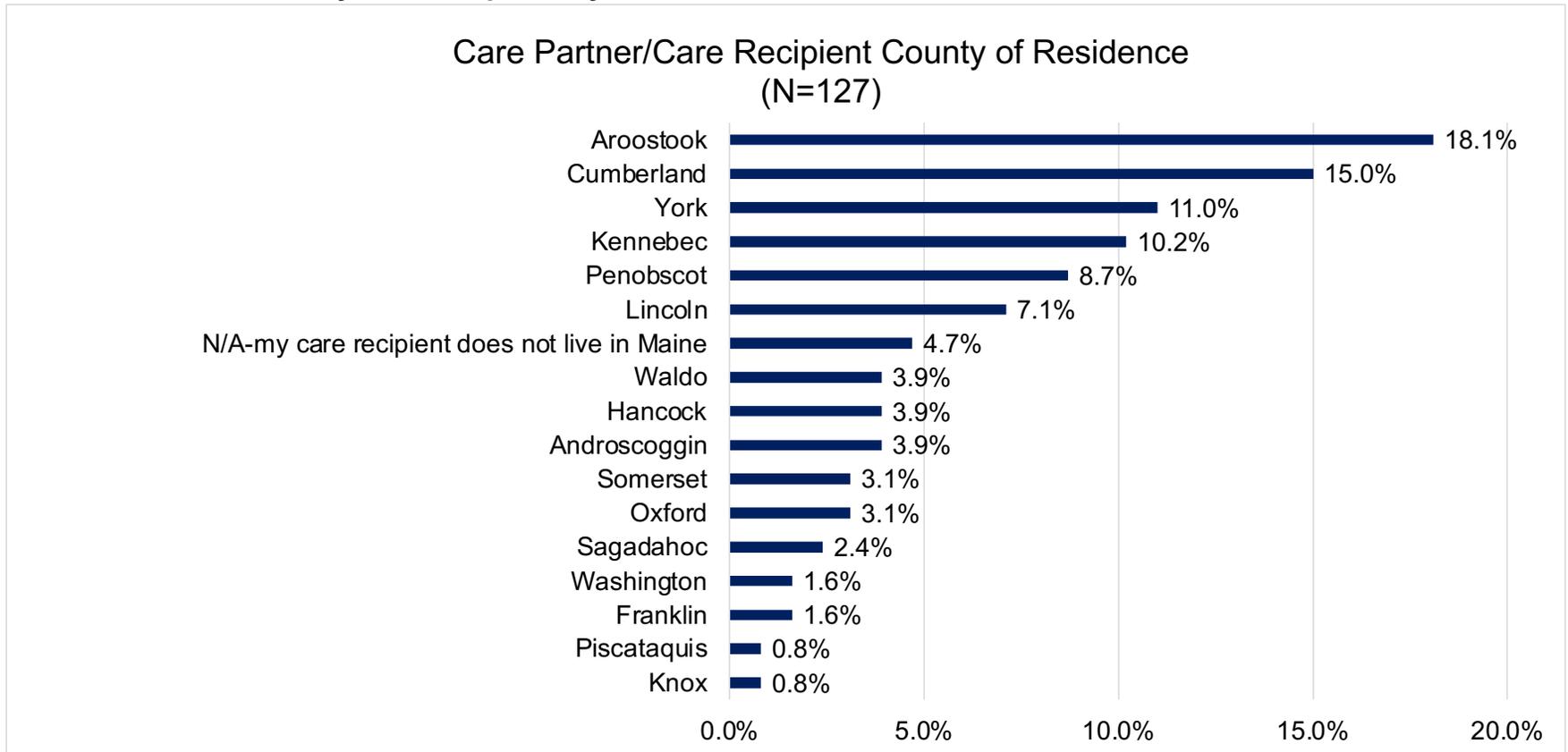
54. Why does this person need care? Please check all that apply:



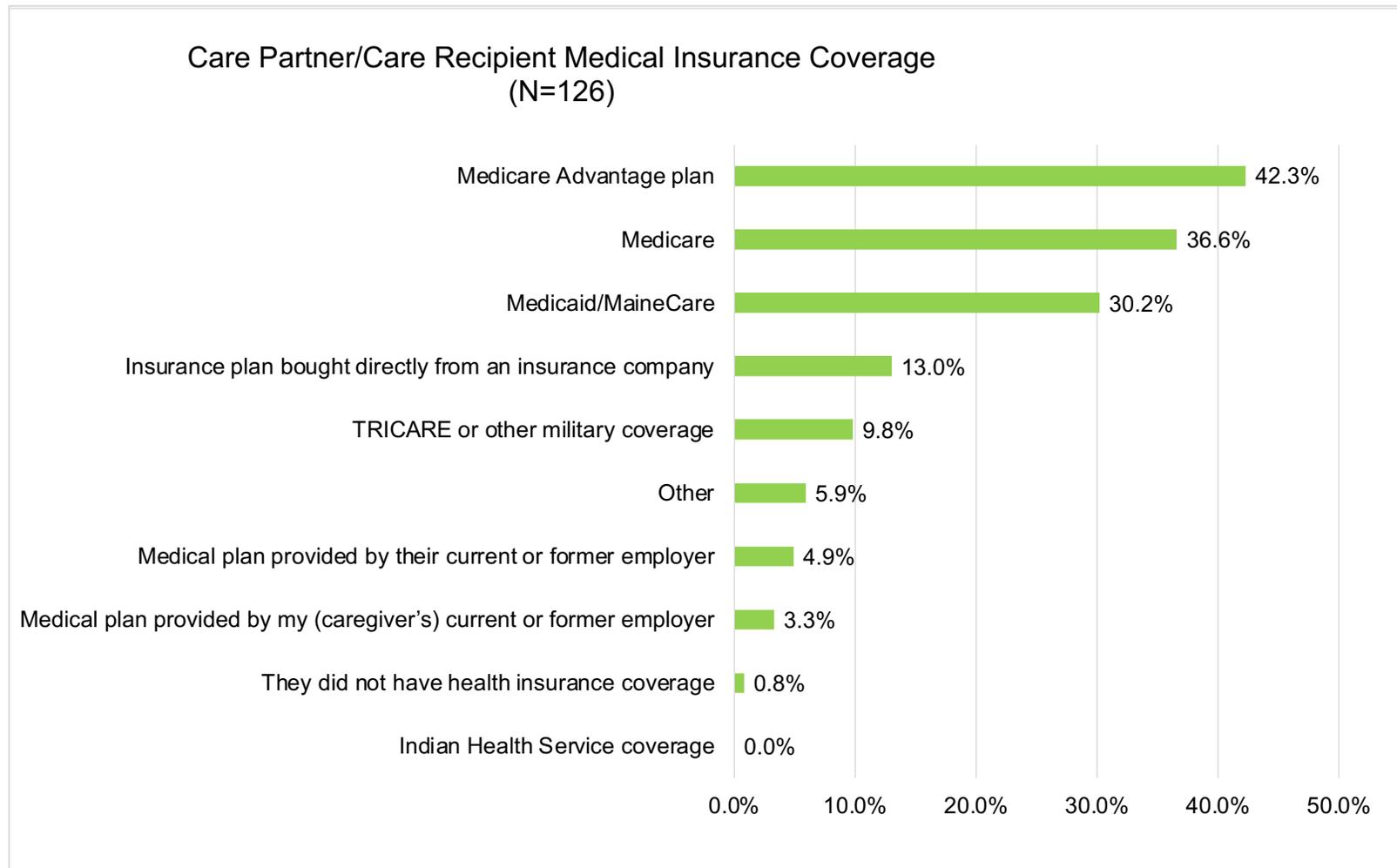
55. Where does this individual live?



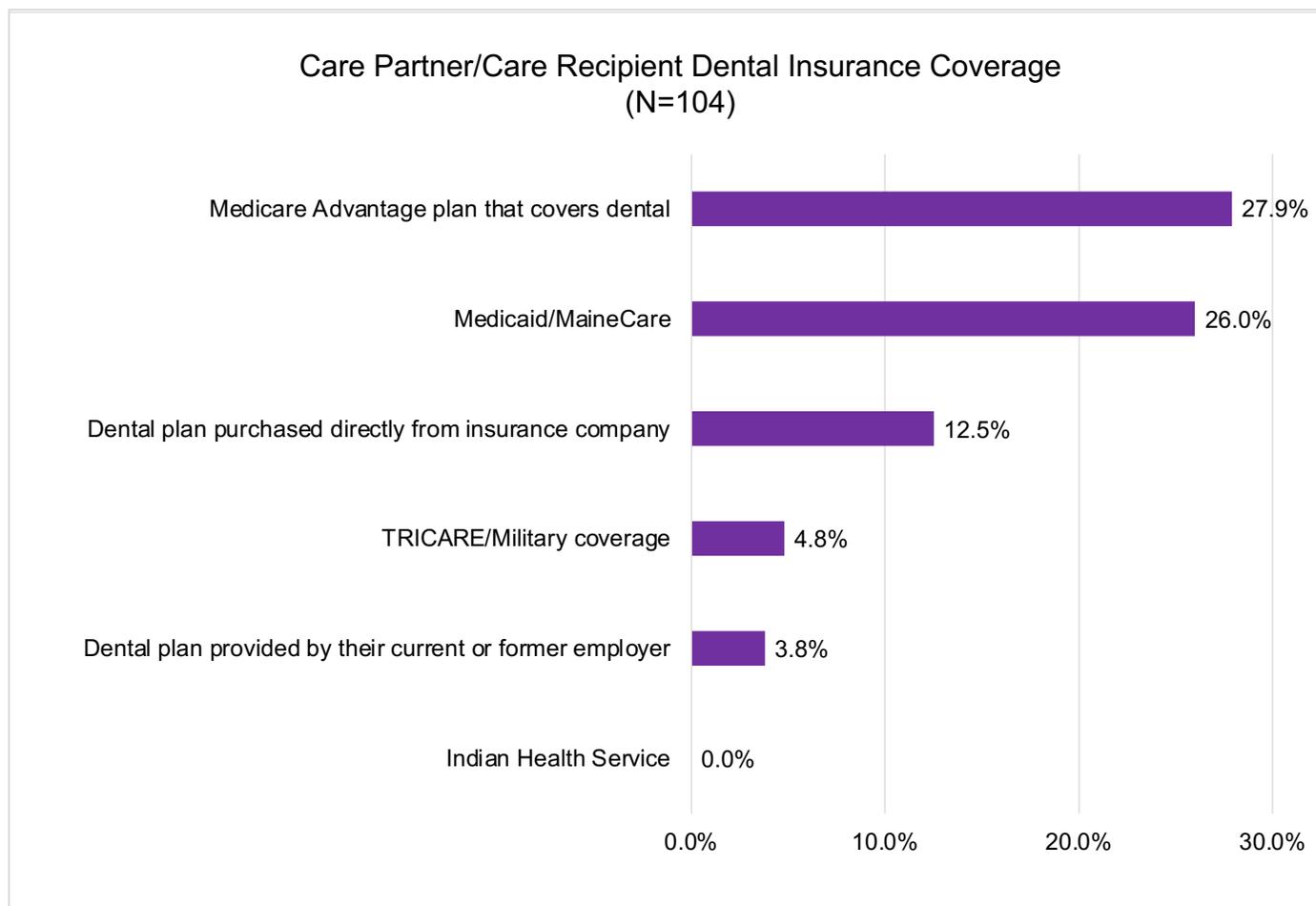
56. In which Maine county does the person you care for live? Check one.



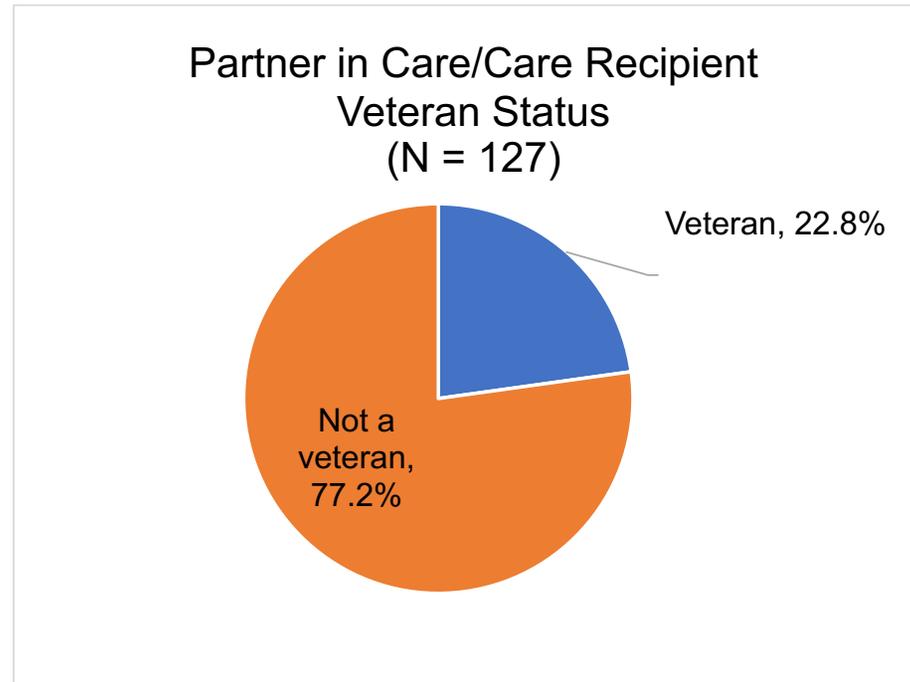
57. In the past 12 months, what medical insurance coverage did the person you care for have? (check all that apply)



58. During the past 12 months, if your care recipient was covered by dental insurance, which insurance(s) were they covered by? (check all that apply)



59. Is the person you care for a veteran?



Open Response Comments



Comments shared highlight specific difficulties in accessing dental care and providing oral health care to their partners in care. Some comments elaborated on specific responses within the survey. Responses below are organized by theme:

Direct Questions/Requests (Pulled from all comments)

Remedy for dry mouth, especially in the morning

Education/training for caregivers helping persons living with dementia or intellectual disabilities, positive ways to deal with behavioral issues and tips on educating on proper care

How best to keep regular brushing habits when you cannot be with care recipient 100 percent of the time

Specifics of regular dental care for care recipient, how to floss correctly, how to clean under bridge

How to address dentures not fitting and sores in mouth

How to prompt action by asking questions to care providers

Finding a program to help pay for dental care, find specialist who accepts Medicaid

How to know how much I should worry about denture care - she has had for 50 years

How to motivate partner to go to dentist

Recorded training to include captions for hearing impaired viewers

Comments by Theme/Category

Caring for someone with dementia/Alzheimer's or memory problems

As a dementia/alzheimer's patient mom is very defensive about whether she has brushed her teeth. It's just a **challenge all the way around**- she used to be very vigilant with her teeth. Also as a caregiver- **adding a dental appointment to a slew of doctor appointments/lab tests/PT feels daunting**. It's hard to get her and I ready and out the door.

I am very fortunate, my mom takes excellent care of her teeth. They always tell me that when we go to the dentist for a cleaning (2x per year). Despite her dementia and advanced age, she brushes at least 2x a day. She also always uses dental piks-mostly after meals to remove food that gets stuck in her teeth/receding gum line. She uses a dental rinse too-basic Walmart mouthwash. **She does suffer from dry mouth-especially in the morning! Wish I had a remedy for this!** It makes me feel bad. She has a glass of water in her bathroom or next to her bed every night! It is **very hard to get to dental or doctor appointments**. Moves very slow in the AM, sleeps often to 2:00 in the afternoon and doesn't like to leave the house! Thank you for trying to make life better/easier for people!

I'm glad you'll be offering caregiver education on this important topic. I know other **caregivers who really struggle with helping a person living with dementia or intellectual disabilities manage oral care**, especially going to the dentist. Dentists aren't all comfortable in these situations either

It isn't easy to always know if they are brushing regularly due to cognitive decline. If asked, may say "no" when actually did brush that morning/evening. Q- How best to keep regular brushing habits when can not be with them 100% of time.

My mother has always taken excellent care of her teeth, "I want to be buried with every tooth still in my head." Is something she often said. I am trying to honor her wishes by caring for her teeth the way she used to before her dementia progressed to the later stages. The staff at her dentist's office is great about going slow and talking her through things when she gets scared but they haven't really been able to help me much with specifics of her dental care. They say, "Keep doing what you're doing her teeth look good." I have been relying on Teepa Snow videos for help. Thank you again for addressing this very real need.

None, prior hx caring for mother with Alzheimer's disease

Care issues involving dentures/false teeth

As my mom is aging and subsequently losing weight and bone mass, her **dentures don't fit** as well as they once did. This is resulting in increasing **sores in her mouth**. I have no idea how to address them and it does not seem to be a priority for any of the "paid" care team. **Would love to know more, even if just to prompt action by asking questions which is how things generally get addressed for the elderly**. If you don't bring it up, it rarely gets addressed. Thank you for your focus on this important issue.

As people live longer I think my mother stopped worrying about her teeth around 75 thinking she wouldn't live longer than 5 years or so. She will be 99 in July and her teeth (she has partial denture) are now loose from gums and make it hard to have a good variety of diet. Q10a: She is 98 years old and sometimes **it feels that we are taking an appointment from someone else**.

I care for my mother-in-law and my mom. Both have dentures and have to pay out-of-pocket for any alignments or repairs. Neither can afford it. I have been unable to find a program that will help them.

My mother is able to care for her dentures. However, the bottom set is not comfortable and she doesn't always use them. We have had them adjusted several times, but she prefers not to use them. Since she experiences difficulty swallowing some foods, this is not an ideal situation.

My mother has had **dentures for 50 years and has never gone to the dentist** (that I am aware). Now she has Alzheimer's and **does not regularly clean her dentures** (or even regularly take them out...like when going to bed). I am wondering, given all the other challenges and challenging behavior, how much I should worry about dental care - which battles to choose if you will.

Barriers/challenges to oral health care

He has had three appointments with UNE in Portland. Next time they will do a cleaning and that was the intention. **Appointments are too long** but need a dentist to call upon when needed. Will check into the VA dental help. He stopped going for regular cleaning because of the **costs**. Now it's **fear-based and anxieties**.

I try to brush my spouse's teeth but he says that **hurts** and he would rather do it himself. Instructions on how to brush someone else's teeth would be helpful.

I'm at a loss how to motivate/manipulate/manage to get my wife to the DDS.

It was very difficult to get in to see the dentist for repairs-**long wait time due to COVID**.

It would be wonderful if dental practitioners came to the home. **Difficult to get some elderly (due to mobility issues) to the dentist**. One can dream.

It's really hard when it's your parent who doesn't want to care for their oral hygiene and fight you

My father is very defiant regarding his oral care. I would love to understand what are some positive ways of dealing with behavioral issues and tips on educating him on proper care.

My husband has only 7 teeth left. He **refuses to let me handle his oral health**, always has. It has a huge **impact on communication...hard to understand...and nutrition** (all his food has to be cooked to mush or finely chopped and yet he doesn't like soft textures) He was fitted for dentures but a bone fragment emerged while he was getting used to them and he won't try again. He says he brushes and flosses but I don't believe he does, or only does intermittently. He hates to be supervised.

My mother is **resistant to going to the dentist**, even though she knows it is important. What suggestions do you have to help her get past her resistance to seeking dental care. She will go if she has dental pain.

No problem identifying and helping to find care for oral issues. However, it can be expensive. Finding a **dentist or endodontist who will take Medicaid is almost impossible**. A budget for an older adult does not necessarily allow for private dental insurance. When I first started caring for my mother, she had multiple dental problems. She had not seen a dentist in years. The issues were fixed, but the cost was out-of-pocket. Something needs to be done to help older adults to have dental coverage through insurance.

Problems with chewing and swallowing when they have few chewing teeth and have to chew with incisors.

Q13: She does not understand at all. She is on a 6 month old level/ has seizures- very otistic anxiety when out around different people and especially doctors office. Q17: We have to brush her teeth and she doesn't let us do much (she bites).

Q18: As much as possible. Q23: From medications? Q25: She can't spit/ won't let us use floss and scared of water flosser (water pik).

Q25: (Brushes); he was asked to use these [electric toothbrushes], but he is not used to them and only **becomes frustrated** by them. (Rinses and washes): Olive leaf complex (Barlean's). (Floss aids): When reminded.

This survey assumes that all patients can communicate, have control over bodily functions, etc. The person I am with has **extreme difficulty with the dentist** and the only way that the dentist can do any dental work is at the hospital with her under anesthesia which is not a good option except in emergencies due to the potential affects of the anesthesia on them. As they cannot control their bodily functions it is quite an effort to brush their teeth everyday and try and use a water pik minimally because they cannot spit out the water. I find this survey very frustrating.

Would love to see traveling dentists/hygienists who are able to go into people's homes to assist with care. transportation is so challenging it becomes a deterrent for care. Oral care IS healthcare. It is so odd to me that Medicare does not cover dentures, routine cleanings, fillings, etc.

Comment on general oral care practices, other comments

Had a deep cleaning for my person and now have a cleaning every 4 months versus 6.

In Maine, in my opinion, by the time the Mainer is elderly, its usually too late to address their dental needs. There needs to be **free dental care for all Mainers**. I am a social worker and I all too often see most of my clients, as well as Mainers on the street with extremely poor dental hygiene. They either never went to a dentist when they were younger, or never taught the importance of brushing and flossing. In the year 2022, it is now time for state representatives, insurance companies and the medical community to recognize the importance of dental needs and make them readily available. **Poor dental hygiene effects the overall health of an individual, as well as their mental health.**

recorded training should include captions for hard of hearing and deaf viewers. Please ensure these and all trainings are more accessible by including captions.

How to floss correctly. How to clean under a bridge.

Regarding regular dental check-ups: In my mom's case, she has maybe one filling and for some reason has a great history of not needing a dentist. She is also getting close to the end, so it probably won't be an issue. Regarding comfort level in talking with care recipient about oral health concerns: She wouldn't make sense of what I talked about anyway.

She has diabetes which presents additional concerns.

Thank you for this survey. It is so important to learn about proper dental care. I am always open to education classes to help my husband.

The government should provide dental care for everyone.