



# 2017 ALZHEIMER'S AWARENESS SURVEY

DECEMBER 13, 2017

**Leger**  
THE RESEARCH INTELLIGENCE GROUP

# METHODOLOGY

## QUANTITATIVE RESEARCH INSTRUMENT

An online survey of 1,506 Canadians was completed between November 9 and 14, 2017, using Leger's online panel, **LegerWeb**. A probability sample of the same size would yield a margin of error of +/-2.5%, 19 times out of 20.

In order to qualify, respondents needed to indicate that they've never been diagnosed with dementia or Alzheimer's disease.

## ABOUT LEGER'S ONLINE PANEL

Leger's online panel has approximately 400,000 members nationally and has a retention rate of 90%.

## QUALITY CONTROL

Stringent quality assurance measures allow Leger to achieve the high-quality standards set by the company. As a result, its methods of data collection and storage outperform the norms set by WAPOR (The World Association for Public Opinion Research). These measures are applied at every stage of the project: from data collection to processing, through to analysis. We aim to answer our clients' needs with honesty, total confidentiality, and integrity.

# EXECUTIVE SUMMARY



# EXECUTIVE SUMMARY - STIGMA

## CANADIANS ACKNOWLEDGE THAT PEOPLE LIVING WITH DEMENTIA REGULARLY EXPERIENCE MANY FORMS OF STIGMA

- **Canadians believe that people living with dementia are likely to experience discrimination including:**
  - Being ignored or dismissed (58%)
  - Being frequently taken advantage of (57%)
  - Difficulty accessing appropriate services or supports (56%)
  - Being feared or met with distrust/suspicion (37%)
- **Those living with dementia experience far more stigma than those with physical health conditions.** For example, Canadians believe that:
  - Only 15% of those with physical health conditions may be **taken advantage of** as compared to 57% of those with a form of dementia
  - Only 14% of those with physical health conditions experience **physical or verbal abuse** as compared to 50% of those with a form of dementia
  - Only 23% of those with physical health conditions are **ignored or dismissed** as compared to 58% of those with a form of dementia
  - Only 23% of those with physical health conditions are **socially rejected or avoided** as compared to 54% of those with a form of dementia
- **Those who have personal experience with dementia perceive this discrimination even more strongly than those who have not. Canadians with personal experience of dementia cited the top forms of discrimination as:**
  - Being ignored or dismissed (61%) (vs. 55% for those without personal experience)
  - Difficulty accessing appropriate services and supports (60%) (vs. 51% for those without personal experience)
  - Being frequently taken advantage of (59%) (vs. 54% for those without personal experience)

## DESPITE THIS UNDERSTANDING, STIGMATIZING LANGUAGE SURROUNDING ALZHEIMER'S DISEASE AND DEMENTIA PERSISTS

- **Only half (49%) of Canadians say they have used non-stigmatizing language such as "Person with Alzheimer's disease or dementia" or "Person living with Alzheimer's disease or dementia."**
- **And, 51% of Canadians admit to using some type of stigmatizing language such as:**
  - Telling dementia-related jokes (30%)
  - Referring to someone as senile/crazy (22%)
  - Referring to someone as demented (11%)
- **Western Canadians are most likely to admit to telling inappropriate dementia-related jokes (Alberta - 38%, Manitoba/Saskatchewan- 37%, BC – 33%).**



# EXECUTIVE SUMMARY - STIGMA

## STIGMA BY ASSOCIATION: CAREGIVERS FEEL THE PERSONAL IMPACT, TOO

- **Results showed that 1 in 5 Canadians have experience caring for someone living with a form of dementia. Among this group, 52% have also personally experienced stigma or discrimination including:**
  - Difficulty accessing appropriate supports and services (19%)
  - Being excluded from participating in treatment or care decisions (15%)
  - Being ignored or dismissed (14%)
  - Social rejection/avoidance (13%)
- **One in five (19%) caregivers 'agree' that they sometimes feel embarrassed to be seen in public with the person they care for, while twice as many (41%) believe that their life would be better if they weren't caring for someone living with dementia. In BC, this rises to 40% and 67%, respectively.**
- **87% of caregivers wish that more people understood the realities of caring for someone with dementia, while two-thirds (65%) find the experience isolating. In Ontario, this rises to 95% and 80%, respectively.**

## COMFORT INTERACTING WITH SOMEONE WHO HAS DEMENTIA DEPENDS ON PRIOR CLOSENESS; EVEN THEN, FEW BOTHER TO LEARN MORE ABOUT THE DISEASE

- **72% would feel comfortable interacting with someone they already know who has dementia, yet only 39% would offer support for family or friends who were open about their diagnosis.**
- **When it comes to interacting with a stranger who has dementia, 36%, or 4 in 10, would be uncomfortable.**
- **Only 5% admit they would bother to learn more about the disease if someone close to them were to be diagnosed.**
- **Quebeckers are the least comfortable when it comes to interacting with people with dementia, with only 63% (as compared to 72% nationally) feeling comfortable interacting with someone they already know who has dementia. That decreases to 51% when it comes to interacting with a stranger who has dementia.**

## SELF-IMPOSED STIGMA IS A REALITY, TOO

- **56% of Canadians are concerned about being affected by Alzheimer's disease. Of greatest concern is their fear of being a burden to others, losing their independence and the inability to recognize family and friends.**
- **Half (50%) of all Canadians don't believe they could live well with dementia with more than a quarter (27%) going so far as saying that their life would be over if they had dementia.**
- **One in five (19%) would avoid seeking help for as long as possible, if they thought they had dementia, perhaps to avoid the associated stigma and embarrassment.**
- **46% of Canadians admit they would feel uncomfortable disclosing to family members if they had dementia, and even more would be uncomfortable telling friends (55%), co-workers (67%), and acquaintances (69%).**

# KEY FINDINGS

# KEY FINDINGS

## DEMENTIA IS AN ACCEPTED TERM – IN ENGLISH CANADA, THAT IS.

- Despite the fact that French-speaking respondents believe that “démence” is a medical term they’re accustomed to hearing, **54% of those surveyed in French find the term derogatory or offensive**. In contrast, only 16% of English respondents said the same about the term “dementia.” French-speaking respondents go on to point out that **the term “maladies neurodégénératives” is preferred**.

## DEVELOPING ALZHEIMER’S DISEASE (OR SOME OTHER FORM OF DEMENTIA) IS WORRISOME, SURE, BUT IT ISN’T NECESSARILY THE END OF THE WORLD.

- **Both Alzheimer’s disease and dementia rank among the top 5 conditions respondents are concerned about.** The two conditions are only outranked by cancer, heart disease, and stroke. It’s no surprise, then, that **54% are worried about developing dementia**.
- What worries them most about it is (a) **becoming a burden to others**, (b) **the loss of independence**, and (c) **the eventual inability to recognize family members and friends**.
- **Yes, life would be difficult** and they may not be able to live well; yes, they’d likely lose their job and their driver’s license; and yes, they’d likely face discrimination, **but it does not necessarily mean that their lives would be over**. Most, for example, are optimistic they’d still be able to participate in the activities they enjoy, contribute to society in some way, and be able to carry on conversations.

## SOME DIFFERENCES PERSIST BASED ON EXPERIENCE LEVEL, BUT NOTHING DRASTIC

- There is little to no significant difference between the average Canadian’s experience with Alzheimer’s disease and dementia compared to those who work in a healthcare profession (exposure is higher for this group, but concerns, worries, stigma, etc. are all comparable)
- Outside of showing slightly less worry for developing dementia and understanding experiences of those with dementia, respondents with no personal experience with dementia generally echo the sentiments of those who’ve been exposed to it in some way.



# KEY FINDINGS

## KNOWLEDGE LEVELS ABOUT DEMENTIA ARE ACTUALLY QUITE HIGH.

- Not only do **respondents realize that dementia isn't a normal part of aging**, they also realize that **people over the age of 65 aren't the only ones who need to worry about it**. No, Alzheimer's disease and dementia aren't one in the same, say respondents; and yes, dementia *is* just as serious as Alzheimer's disease.
- **Respondents do not believe you can tell a person has dementia just by looking at him or her**. They also do not believe that (a) **there's no point in talking to someone with dementia**, or that (b) **people with dementia are unable to carry on a conversation**.
- The only thing respondents appear divided on is whether or not people with dementia tend to be aggressive or agitated.

## COMFORT LEVELS DEPEND ON WHAT'S BEING ASKED OF THEM, UNLESS THEY'VE HAD SOME EXPOSURE TO DEMENTIA.

- **Seven-in-ten would be comfortable interacting with someone they know who has dementia** (though only 26% would be *very comfortable*), but **fewer (58%) would be comfortable interacting with a stranger who has dementia** (with only 13% stating they would be *very comfortable*). Of course, those with some sort of connection to dementia are more likely to be comfortable in either situation.
- **Most would be *uncomfortable* disclosing they have dementia to co-workers, acquaintances, and new people that they meet** (with three-in-ten saying they would be *very uncomfortable*). **Respondents are divided, however, as to how comfortable they would be disclosing they had dementia to family members**.
- **When it comes to telling others about *someone in their family who has dementia*, comfort levels rise to 60%** (though less than two-in-ten would be *very comfortable* doing so).
- Interestingly, those with a family history of dementia are more likely to feel comfortable disclosing their own dementia diagnosis, as well as the diagnosis of someone in their family.

# KEY FINDINGS

## NEGATIVE EXPERIENCES ARE COMMON

- **Many negative experiences are believed to be common for people living with dementia**, such as being ignored, dismissed, and taken advantage of; socially rejected or avoided; and being excluded from their own treatment and care decisions. It's also believed they have difficulty accessing the appropriate support, experience inadequate support, and have difficulty securing employment.
- **Relative to those living with a physical disability (like cancer, for example), respondents believe those living with dementia have it worse on all fronts. Relative to those living with physical disabilities or mental health conditions, however, it's a different story.** Respondents believe that those living with dementia are:
  - *worse off* in many respects, relative to those with physical disabilities (such as deafness or blindness), but tend to fare better at (a) finding employment, and (b) being accurately assessed in terms of their abilities.
  - *better off* in many respects, relative to those with mental health conditions (such as depression or anxiety, etc.), but are more likely to be taken advantage of, and are more often excluded from their own treatment and care decisions.

## CAREGIVERS ARE OVERBURDENED AND IN NEED OF ADEQUATE SUPPORT

- **Many of those who have cared for someone living with dementia haven't experienced *any* of the negative situations or behaviours that were listed. Half, though, have experienced at least one, such as inadequate support and/or difficulty finding support in the first place, the two most frequently selected situations.**
- It's a different story for the person they're actually caring for, however. About half (45%), for example, indicate that the person they care for has been excluded from participating in their own treatment and care decisions, and many can recall situations where that person was ignored, dismissed, and/or socially rejected, as well as underestimated. **Four-in-ten caregivers can also recall a time the person living with dementia had trouble with inadequate support and/or difficulty finding support in the first place.**
- **In all cases, the person they care for is *much more likely* to have experienced each of the situations/behaviours listed, relative to caregivers themselves.**
- **Caring for someone living with dementia can be hard. Not only can it be isolating, say caregivers, it can get overwhelming at times due to a lack of support.** Perhaps as a result, **the vast majority (87%) wishes more people were aware of what it's like to be a caregiver for someone with dementia.**

# WHERE STIGMA PERSISTS



# THERE IS A STRONG STIGMA AROUND BEING BURDENSOME OR BEING A RESPONSIBILITY

What worries you most about being diagnosed with dementia?

**61% (1<sup>st</sup>)**

*Becoming a burden on others/my family*

**41% (6<sup>th</sup>)**

*Concerned about who will take care of me*

43% agree that 'people with dementia are unable to care for themselves'

Among caregivers

**59%**

*Agree that they've felt  
burdened by the lack of  
support*

**41%**

*Agree that sometimes they feel that  
life would be better if they weren't  
caring for someone living with  
dementia*

**19%**

*Agree that sometimes they  
have been embarrassed to  
be seen in public with the  
person they care for*

# THERE IS A SENSE FOR A NEED TO 'HIDE' TO AVOID STIGMA OR REJECTION

**19%**

*Agree that if they thought they might have dementia, they would avoid seeking help for as long as possible*

**19%**

*Agree that sometimes they've been embarrassed to be seen in public with the person they care for*

**24%**

*Agree that if they had dementia their friends and family would avoid them*

**37%**

*Believe that being feared or met with distrust or suspicion is a common experience for people living with Alzheimer's disease or other dementias*

**38%**

*Agree that if they had dementia they would not want others to know*

**54%**

*Believe that social rejection or avoidance is a common experience for people living with Alzheimer's disease or other dementias*

**46%**

*Agree that if they had dementia they would feel ashamed or embarrassed*



# STIGMA ARISES AROUND THE IDEA OF “VALUE” OR “WORTH” TO SOCIETY

## Contributions to society

**24%**

*Disagree that if they had dementia they could still contribute to society*

**17%**

*Disagree that people with dementia can still contribute to society*

**51% believe that those living with Alzheimer's disease or dementia have difficulty accessing employment**



# MISCONCEPTIONS AND STIGMATIZING LANGUAGE ABOUND

**30%**

*Proportion of people who have made 'dementia jokes' ("He has old timer's disease" or "She's losing her marbles")*

**44%**

*Agree that people with dementia tend to be aggressive or agitated*



# DETAILED RESULTS

1. **DESCRIBING DEMENTIA**
2. LEVELS OF WORRY AND CONCERN  
REACTIONS TO A DIAGNOSIS  
A DIAGNOSIS OF FUTURE DEMENTIA
3. KNOWLEDGE  
BELIEFS  
COMFORT LEVELS
4. PERCEIVED COMMON EXPERIENCES
5. CAREGIVERS' EXPERIENCES
6. UNEXPERIENCED PERCEPTIONS

# "DEMENTIA" IS AN ACCEPTED, MEDICAL TERM (AT LEAST IN ENGLISH CANADA)

Eight-in-ten agree that the term "dementia"/"démence" is a medical one that they're accustomed to hearing. Most (68%) also agree the term accurately describes somebody living with Alzheimer's disease (or another, similar condition). As a result, only a quarter (24%) believe the term is derogatory or offensive in nature.

It is important to note here that "démence," the term used in the French translation of the survey, is over *three times more likely* to be seen as derogatory than its English counterpart "dementia" and, thus, *less likely* to be viewed as a medical term French-speaking respondents are accustomed to hearing.

## AGREEMENT LEVELS

Dementia is a medical term I'm accustomed to hearing

80%

16%

Dementia accurately describes somebody living with Alzheimer's disease or other similar conditions

68%

25%

Dementia is a derogatory or offensive term

24%

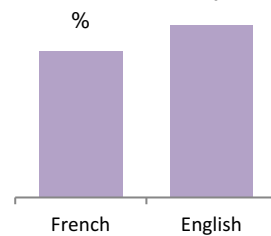
67%

No discernible difference between those with no dementia experience and those with this experience

■ AGREE (NET)  
■ DISAGREE (NET)  
■ I don't know / I prefer not to answer

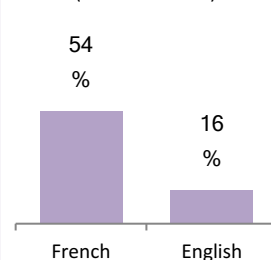
## SURVEY LANGUAGE

(% WHO AGREE)



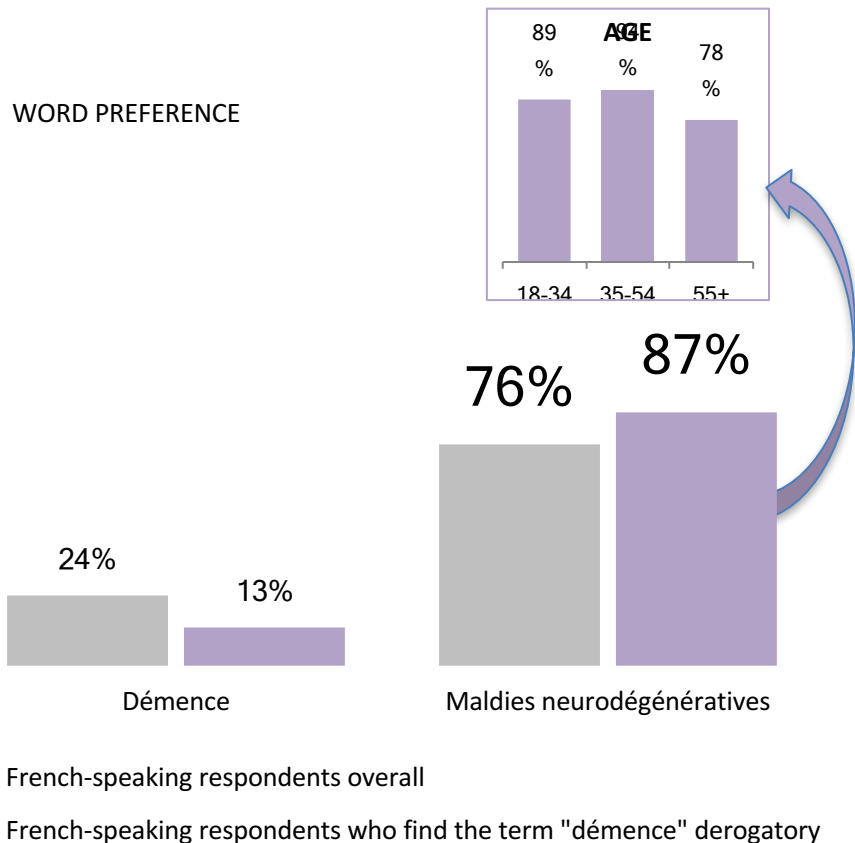
## SURVEY LANGUAGE

(% WHO AGREE)

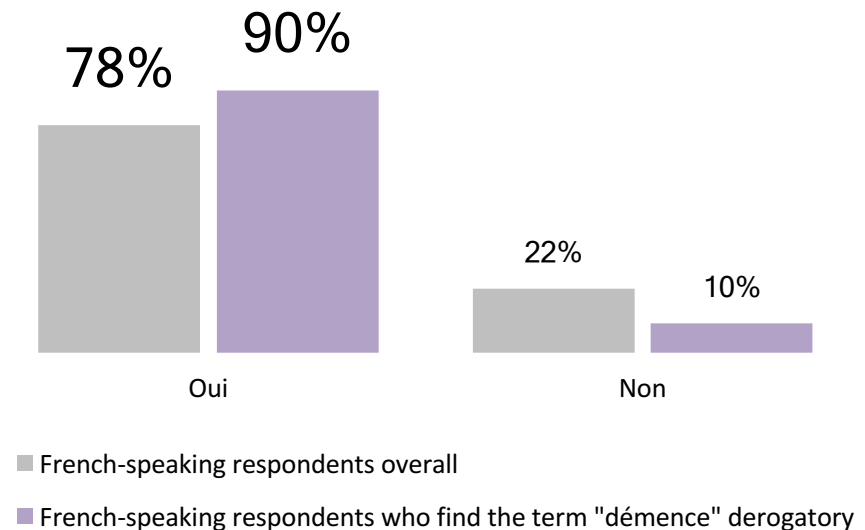


# FOR FRANCOPHONES, “DÉMENCE” (DEMENTIA) CARRIES A MORE NEGATIVE CONNOTATION

Playing off the results of the previous slide, it is quite apparent that **Francophones prefer the term “maladies neurodégénératives” over “démence.”** Preference for ‘maladies neurodegeneratives’ drops noticeably after age 54.



Si le terme démence s'avère un terme négatif pour vous, préférez-vous utiliser le terme « maladies neurodégénératives? »



F3 Préférez-vous utiliser le terme démence ou maladies neurodégénératives?

F4 Si le terme démence s'avère un terme négatif pour vous, préférez-vous utiliser le terme « maladies neurodégénératives » ?

Bases: French-speaking respondents overall (n=368), as well as those who find the term "démence" derogatory at QF1 (n=201).

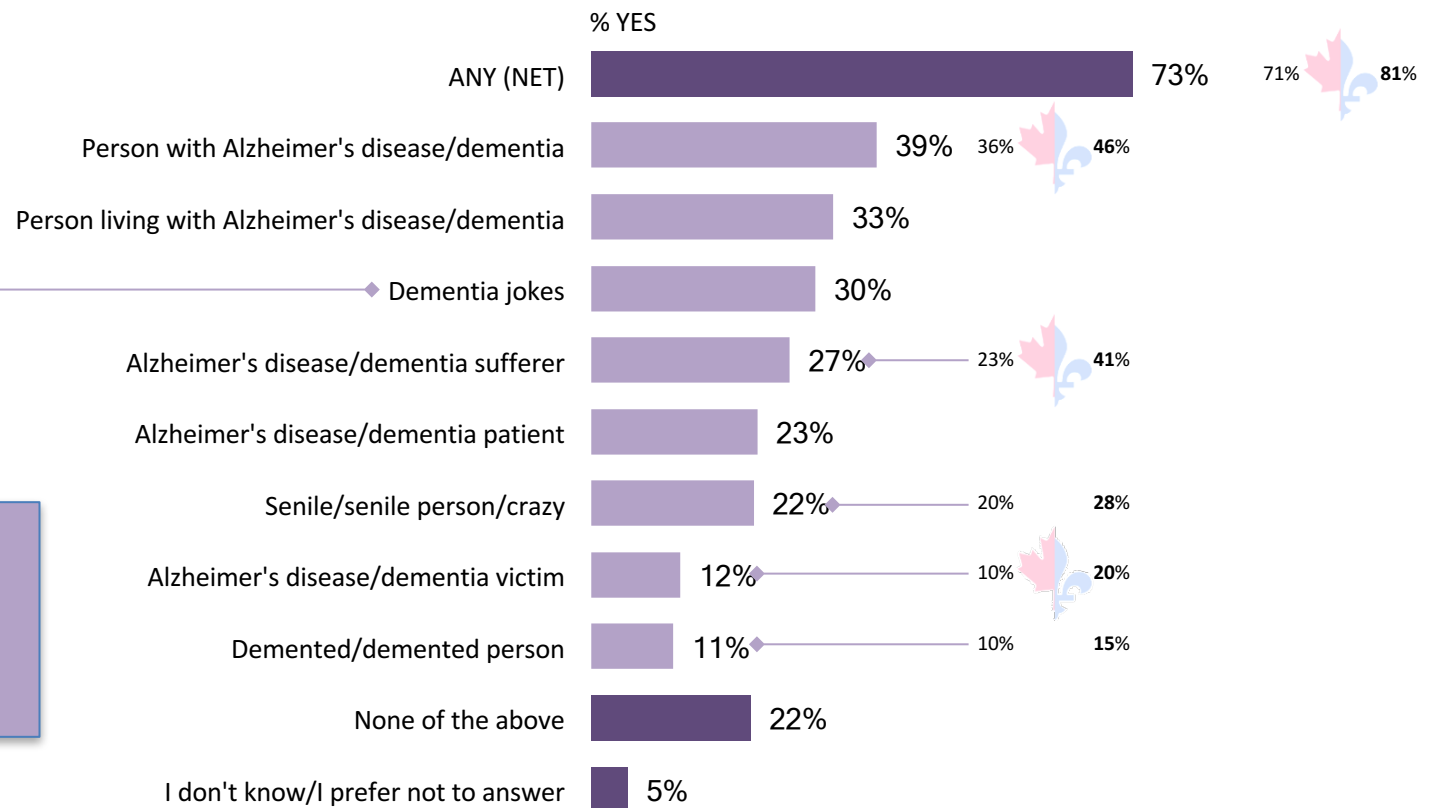
# THREE-IN-TEN ADMIT TO USING DEMENTIA-RELATED JOKES

While many (39%) have used the phrase “a person with Alzheimer’s disease / dementia”, and three-in-ten have used “a person *living* with Alzheimer’s disease / dementia” and/or “Alzheimer’s disease or dementia sufferer,” the remaining phrases have been used less frequently. Three-in-ten (30%) admit to using dementia-related jokes, such as “*I can’t remember, I must have dementia.*”

Not surprisingly, language plays an important part here. Quebecers (and, by extension, those who took the survey in French), for example, are more likely to have used many of the phrases listed below (relative to the RoC\*). Those who state that they’ve employed none of the phrases listed below tend to be Anglophones (24% vs. 13% of those who took the survey in French), men ( 25% vs. 18% of women), and those with a personal connection to dementia (26% vs. 19% who do not).

**EXAMPLES:**  
 “I can’t remember, I must have dementia”  
 “He has old-timer’s disease”  
 “She’s losing her marbles”

There is no discernible difference among age groups for any of these descriptions



Q7 Have you ever used any of the following language to describe a situation or person?

Base: All (n=1506).

\* RoC = the rest of Canada.



# DETAILED RESULTS

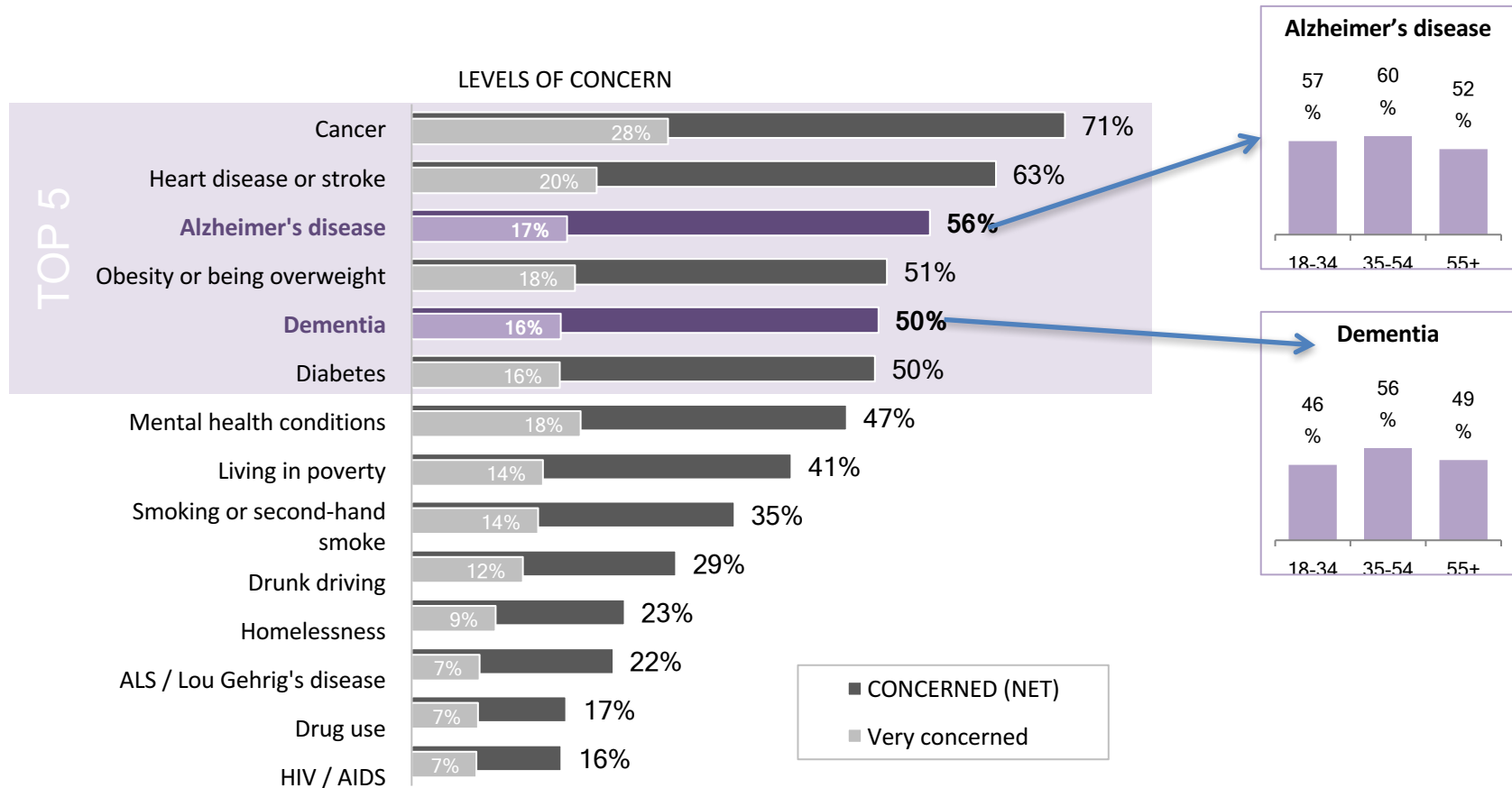
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6. UNEXPERIENCED PERCEPTIONS

# DEVELOPING ALZHEIMER'S AND/OR DEMENTIA ARE TOP CONCERNS

About six-in-ten (56%) are concerned about being affected by Alzheimer's disease at some point in their life. The percentage for dementia is somewhat lower (50%). Nearly two-in-ten indicate that they're *very concerned* about being affected by Alzheimer's disease and/or dementia.

Few of the conditions listed below are of equal or greater concern to respondents (i.e. only cancer, heart disease, and/or stroke are of greater concern, while obesity and diabetes are of equal concern).

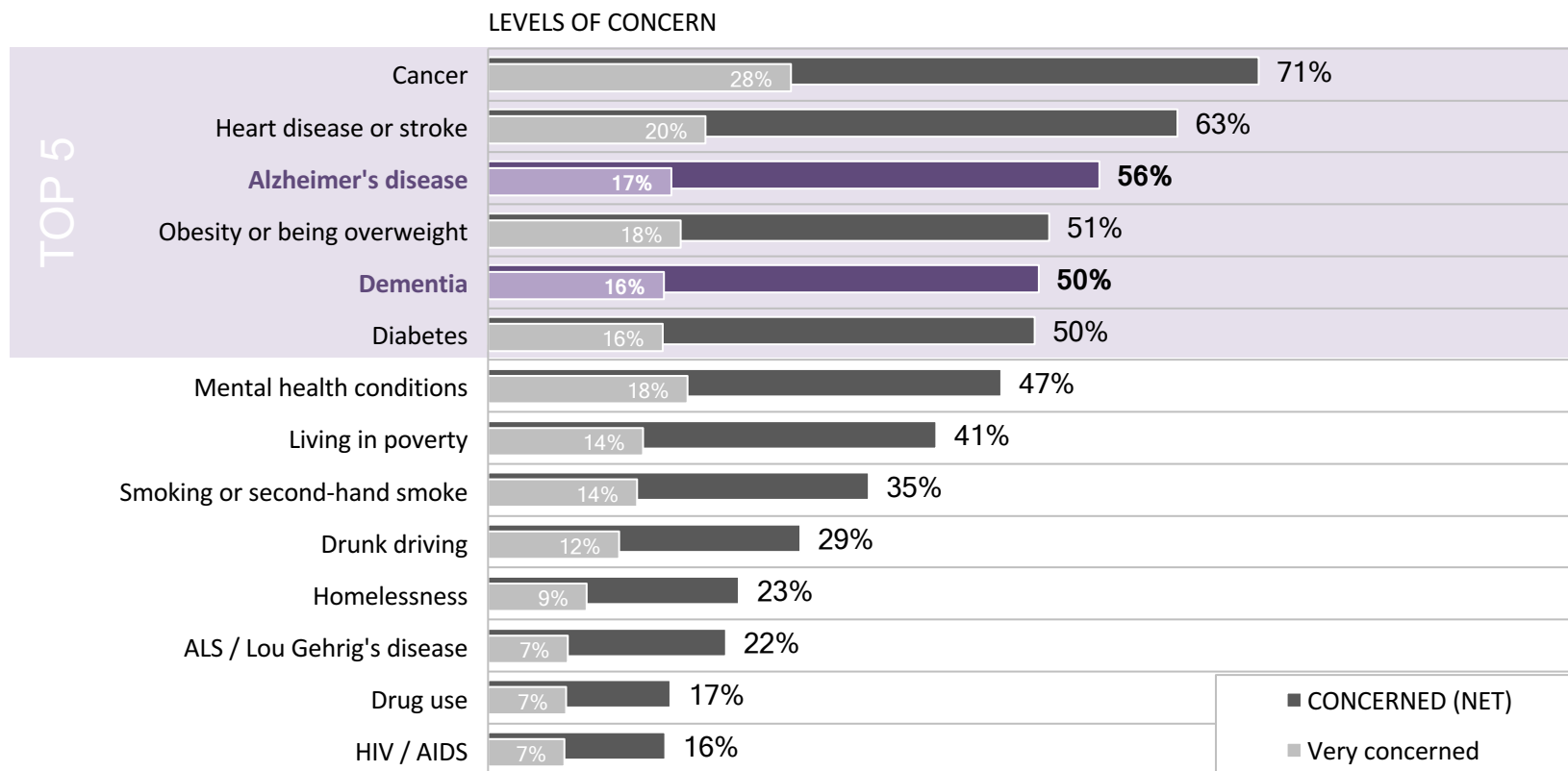
Middle-aged Canadians show the highest levels of concern when it comes to being affected by Alzheimer's disease or dementia in their lifetime.



# DEVELOPING ALZHEIMER'S DISEASE AND/OR DEMENTIA ARE TOP CONCERNS

Demographically, levels of concern for both Alzheimer's disease and dementia are higher among: women (59% and 56%, respectively), those under 65 (58% and 52%), and those with a connection to dementia (i.e. they know someone with dementia, they have a family history of dementia, or they've cared for someone with dementia). **With respect to dementia alone, levels of concern are *three times higher* among those who, later in the survey, were worried about developing dementia themselves (74% vs. 24% among those who are not worried). For Alzheimer's disease, the difference – though still large – isn't quite as wide (78% vs. 31% among those who are not worried).**

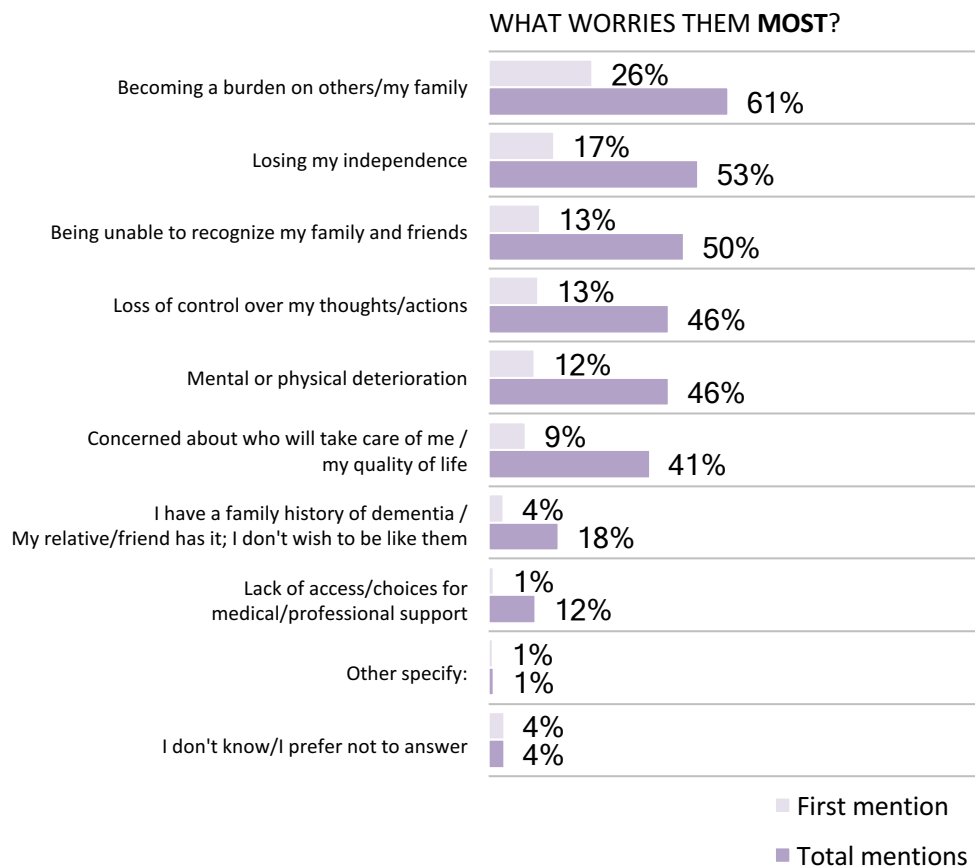
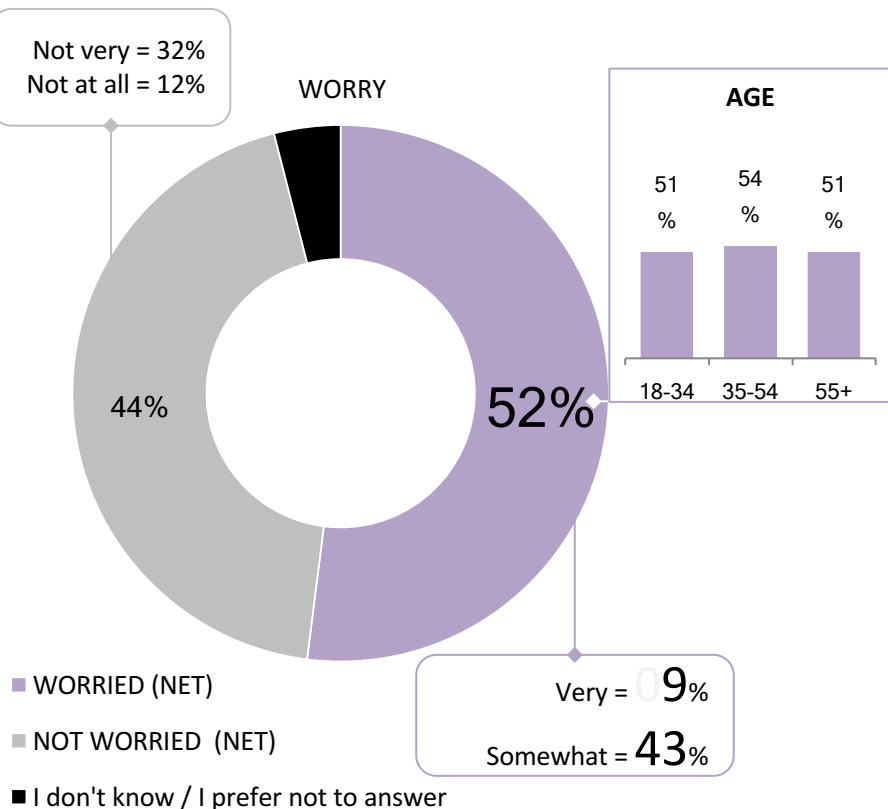
**Levels of concern for either condition overlap quite a bit:** 80% of those concerned about developing Alzheimer's disease are also worried about developing dementia, and 89% of those concerned about developing dementia are also worried about developing Alzheimer's disease.



# WHAT WORRIES THEM MOST IS BECOMING A BURDEN TO OTHERS

**About half (52%) are worried about developing dementia**, especially those concerned about being affected by either Alzheimer's disease (72%) or dementia (76%) at some point in their lifetimes (vs. 27% who are unconcerned), as well as those with a connection to dementia (i.e. they know someone with dementia [58%], they have a family history of dementia [70%], or they've cared for someone with dementia[66%]). **Levels of worry are equal across age groups.**

Though many things about the disease worry respondents, **what worries them *most* is becoming a burden to others, the loss of independence, and the inability to recognize family and friends.**



Q9 How worried are you about developing dementia?

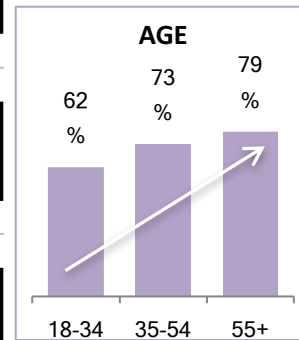
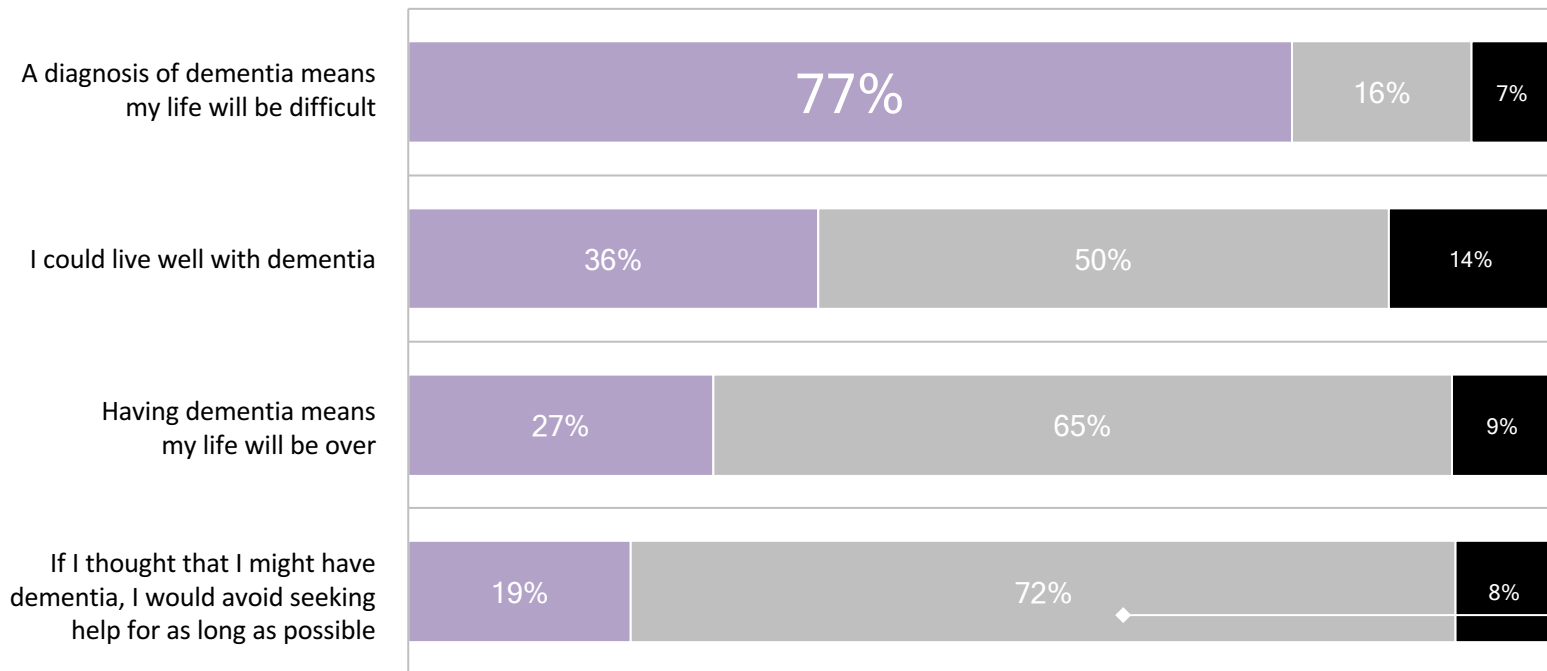
Q10 What would you most worry about if you were diagnosed with dementia?

Bases: All (n=1506).

# LIFE WOULD BE DIFFICULT, BUT RELATIVELY FEW WOULD AVOID SEEKING HELP

Nearly eight-in-ten (77%) agree that a diagnosis of dementia would mean that their lives would be difficult. Perhaps as a result, half do not believe they could live well with the disease. This does not necessarily mean, that their lives would be over, however. In fact, it looks as though most would seek help soon after their diagnosis (seeing as 72% do not believe they'd avoid seeking help for as long as possible), especially women (77% vs. 66% among men), those 65+ (82% vs. 69% among those under 65), and those who have known someone with dementia (77% vs. 65% among those who have not). In fact, levels of *disagreement* with this last statement rise steadily with age.

## AGREEMENT LEVELS



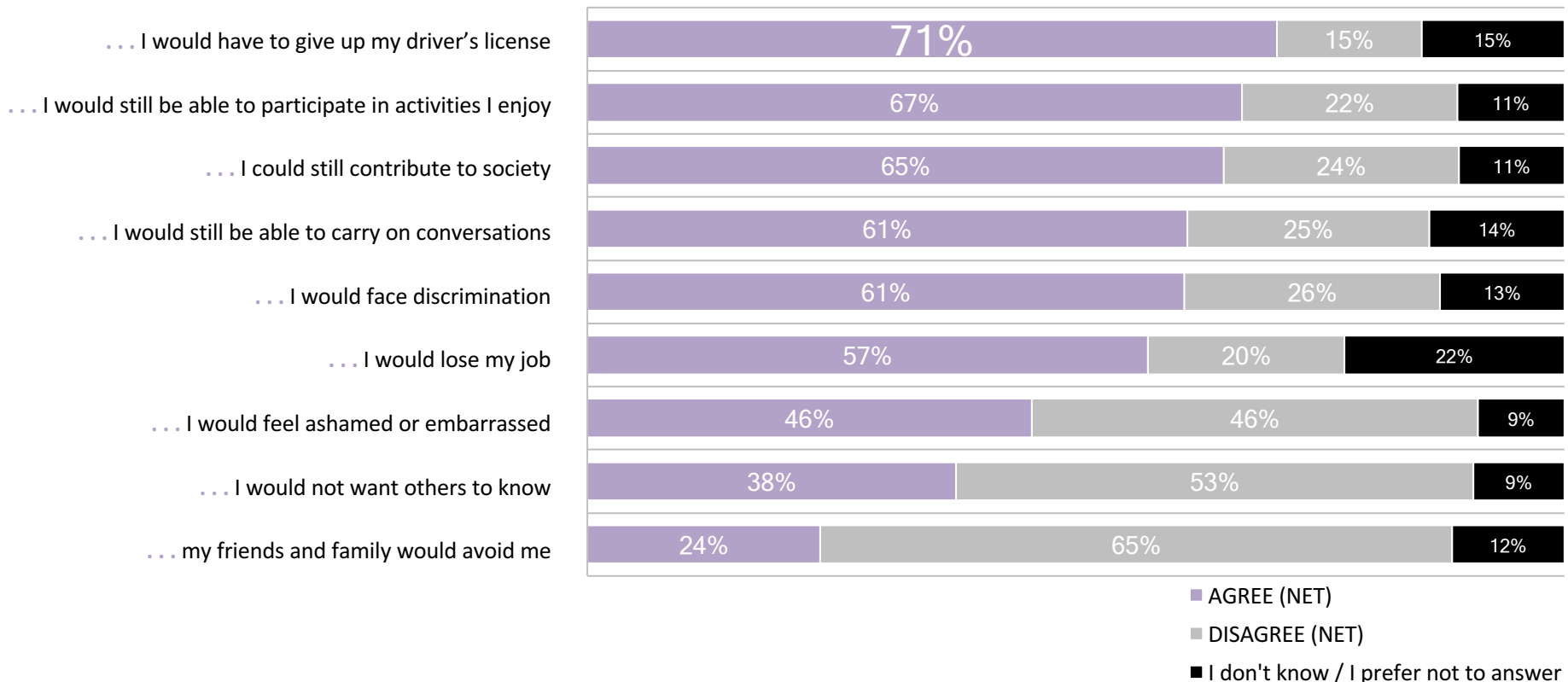
■ AGREE (NET)  
■ DISAGREE (NET)  
■ I don't know / I prefer not to answer

# IF THEY WERE DIAGNOSED WITH DEMENTIA, 61% BELIEVE THEY WOULD FACE DISCRIMINATION

If they thought they had dementia, most respondents believe they would (a) have to give up their driver's license, and (b) lose their job. Most also believe they would face discrimination. Despite these negative fallouts, most are optimistic that they'd still be able to participate in the activities they enjoy, contribute to society in some way, and be able to carry on conversations. Furthermore, most believe that family and friends would not avoid them.

**Would they feel ashamed or embarrassed by the diagnosis? It's debatable:** while 46% believe they would (especially those under 65 [48%]), just as many would not (especially those over 65 [56%]). It is telling, though, that many (38%) would not want others to know they had been diagnosed with dementia (a percentage that holds steady with age).

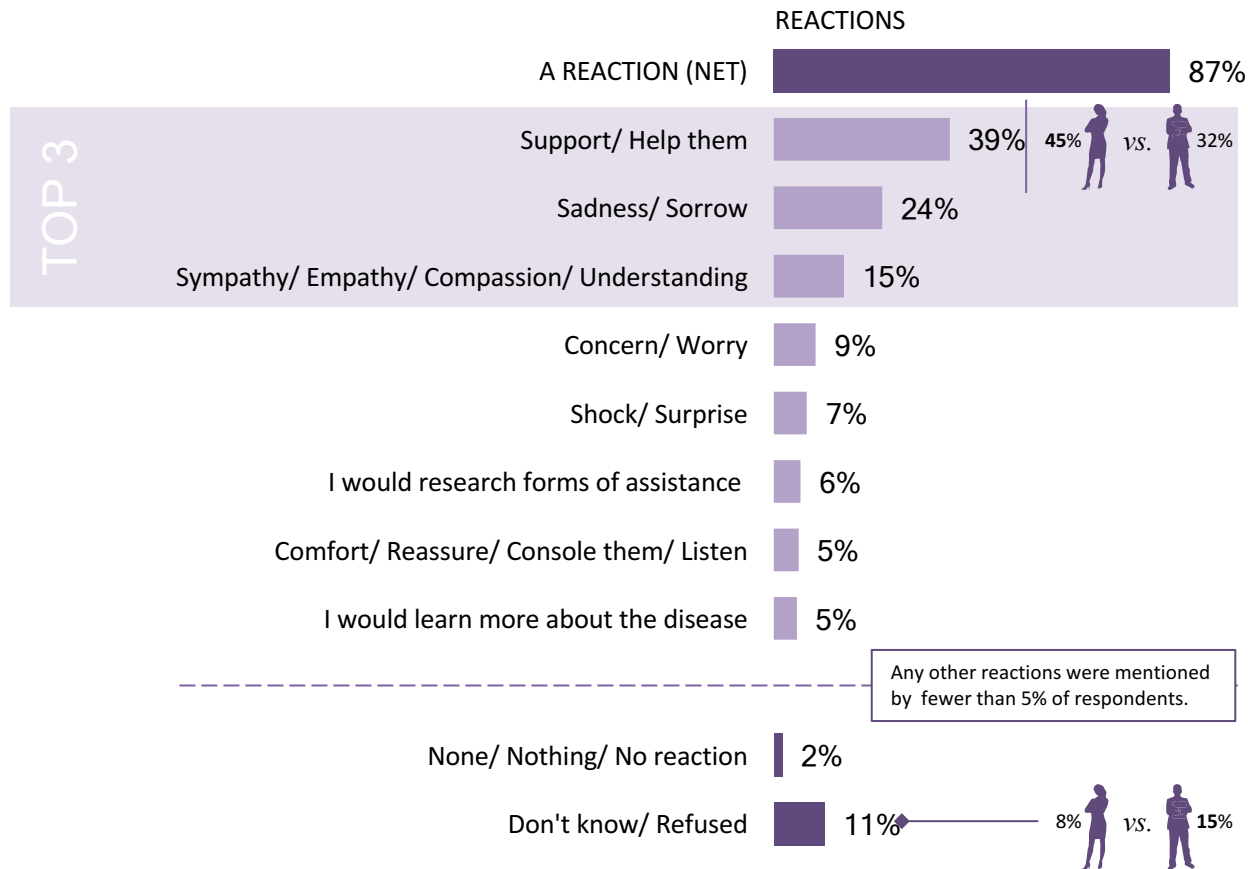
## If I had dementia ... AGREEMENT LEVELS





# MANY BELIEVE THEY WOULD OFFER SUPPORT

When asked how they would react if a family member, friend, or co-worker told them that he or she was recently diagnosed with dementia, **many (39%) would offer support**, especially women (45% vs. 32% of men), as well as those who either (a) know someone with dementia (43% vs. 32% among those who do not) and/or (b) who've cared for someone living with dementia (45% vs. 37% among those who has not). **Feelings of sadness/sorrow and/or sympathy were also noted more frequently than another emotion or feeling** (24% and 15%, respectively).

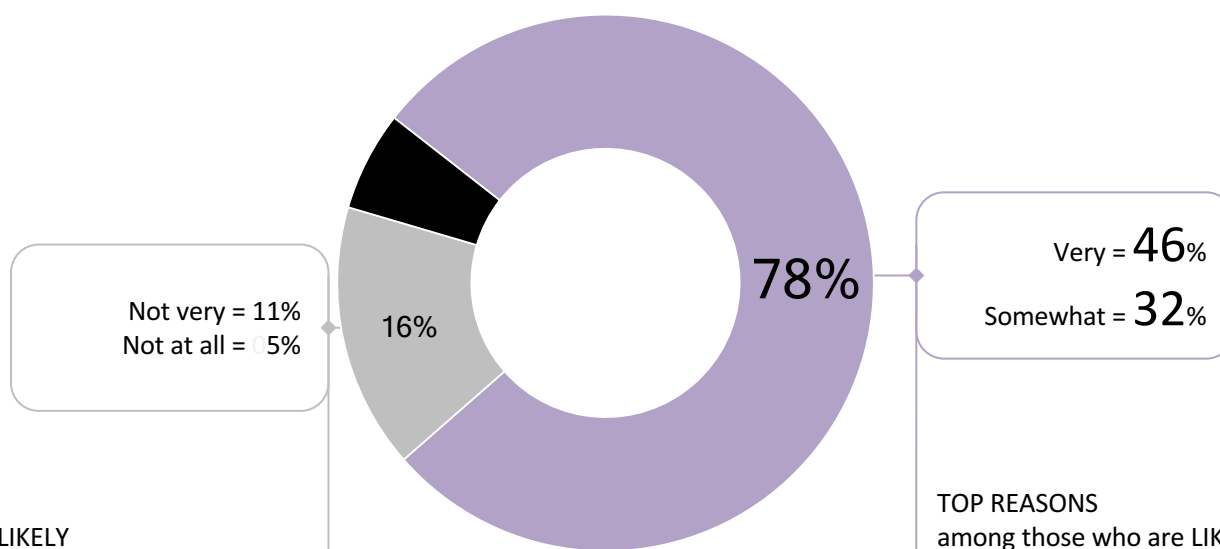


# 78% WOULD LIKE TO KNOW AHEAD OF TIME

If they could receive a diagnosis, potentially years prior to developing symptoms of dementia, 78% likely would get it, with nearly half (46%) indicating they'd be *very likely* to do so. This is especially true among those concerned about being affected by dementia (82%) and/or Alzheimer's disease (81%) at some point in their lifetimes, and remains high across age groups. (On the contrary, those who wouldn't want to know are statistically more likely to be **unconcerned** about being affected by dementia and/or Alzheimer's disease in their lifetimes.)

The main reasons for wanting to know revolve around prepping for the future, while the main reasons for not wanting to know revolve around staving off worrying about the future.

LIKELIHOOD



- LIKELY(NET)
- UNLIKELY (NET)
- I don't know / I prefer not to answer

TOP REASONS  
among those who are LIKELY

To be/get prepared/ready	31%
To take actions to prevent / slow the progression of dementia	21%
I could plan ahead	12%

TOP REASONS  
among those who are UNLIKELY

I don't want to worry about the future	28%
I do not want to know	26%
Would make me feel anxious / worried	16%
There is no treatment / cure / can't change the inevitable	12%

Q12 If you could receive a diagnosis prior to developing symptoms of dementia – potentially years before – how likely would you be to want to know this information?

Q13 Why would you . . . want to know if you were at risk for developing symptoms of dementia?

Bases: LIKELY (n=1186) / UNLIKELY (n=234).

# DETAILED RESULTS

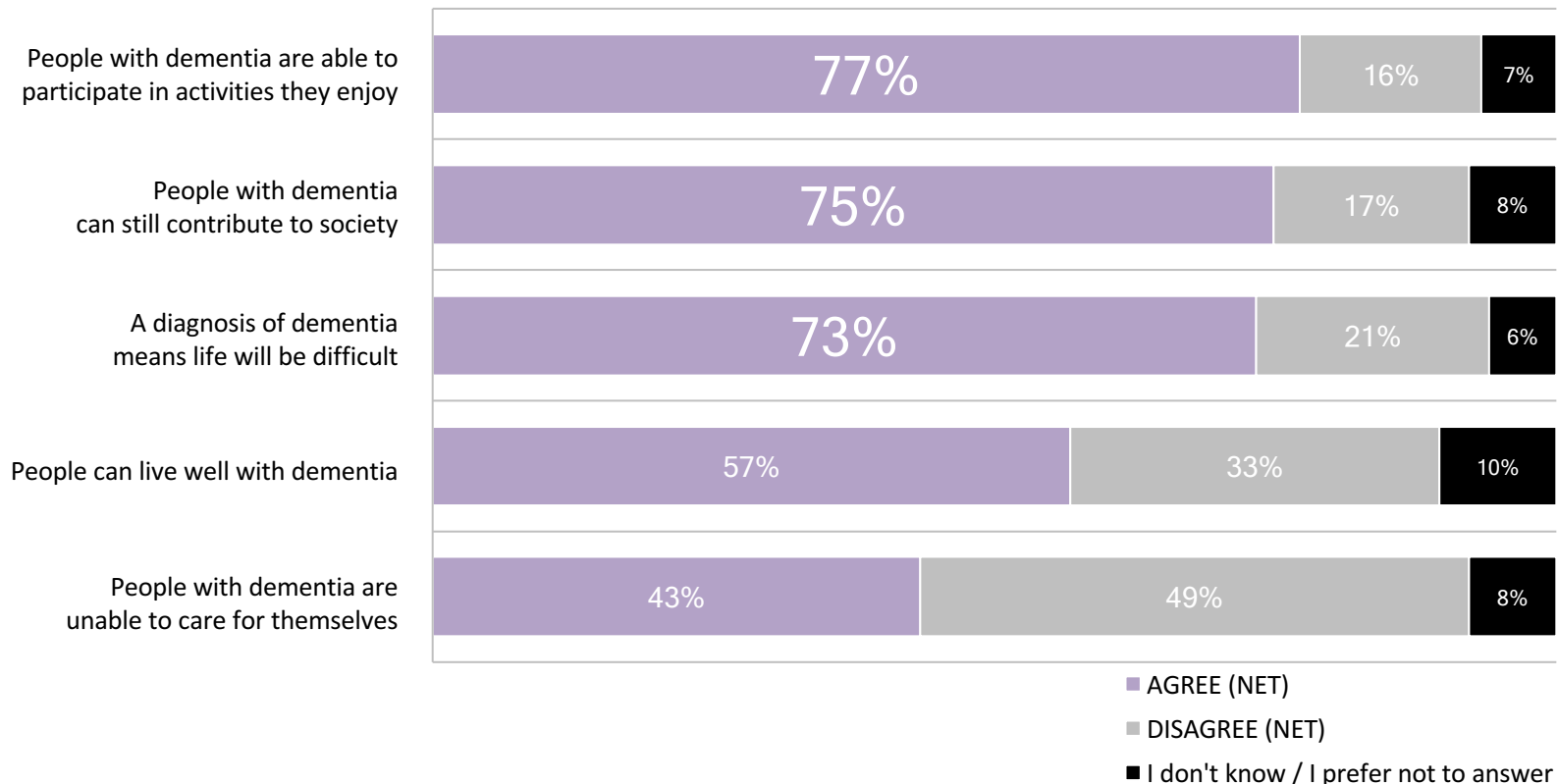
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# CAN PEOPLE WITH DEMENTIA TAKE CARE OF THEMSELVES?

## RESPONDENTS ARE DIVIDED

Though a diagnosis of dementia means life will be difficult, say respondents, it also means that the affected person can still (a) contribute to society, and (b) participate in activities that they enjoy. Despite these affirmations, though, fewer (57%) believe that people can “live well” with dementia. In fact, many (43%) believe that people with dementia are unable to care for themselves – especially those who have known someone with dementia (47% vs. 39% among those who have not). Curiously, though, no differences exist between those who have cared for someone with dementia and those who have not.

### AGREEMENT LEVELS

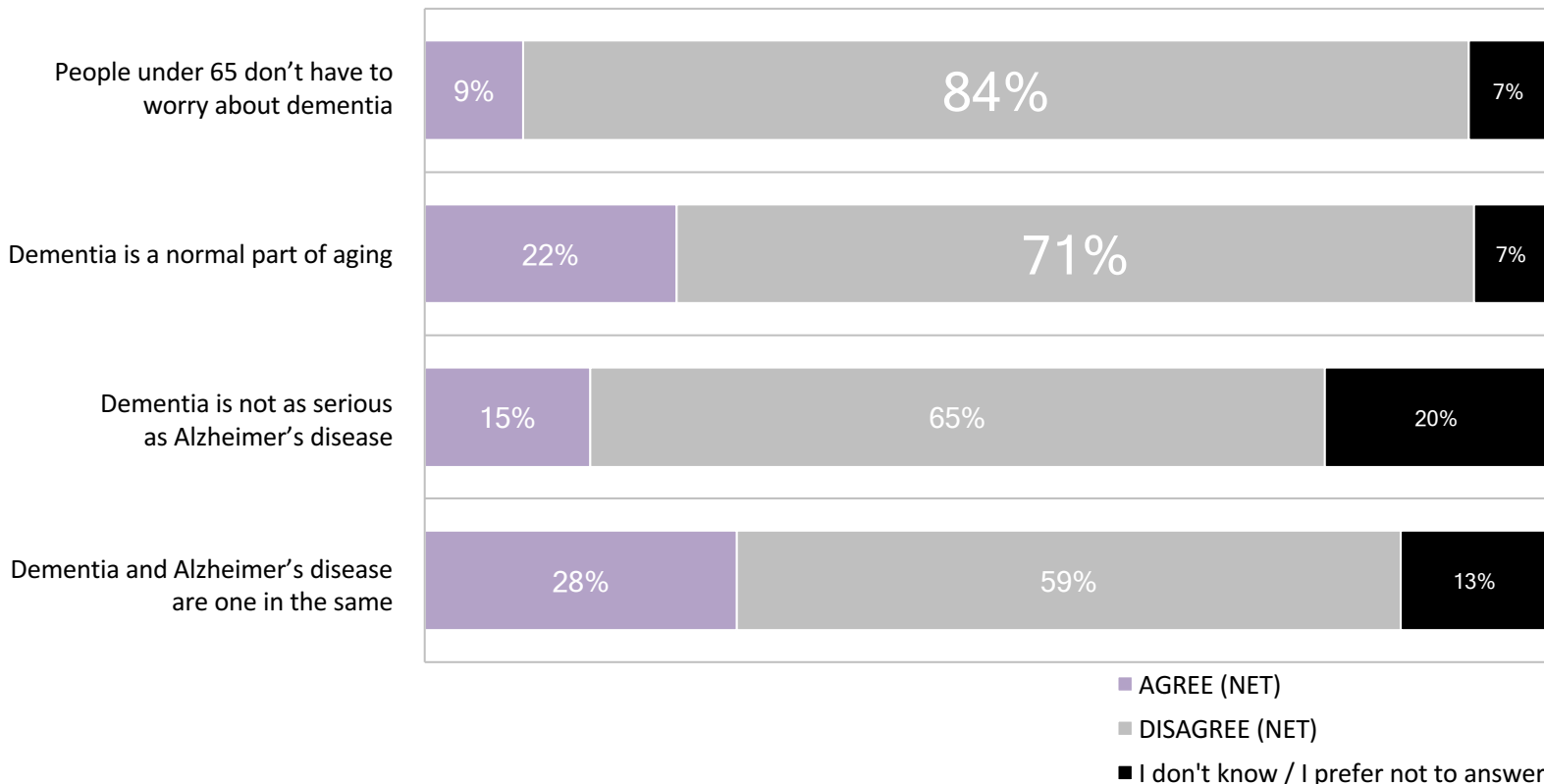


# RESPONDENTS DEMONSTRATE THAT THEY'RE QUITE KNOWLEDGEABLE ABOUT DEMENTIA

Overall, respondents are knowledgeable about each of the aspects of dementia mentioned below. Most (84%), for example, *disagree* that people under the age of 65 needn't worry about dementia (especially those 55+: 91%). Most also do not believe that dementia is a normal part of aging (especially those 55+: 76%), that dementia isn't as serious as Alzheimer's disease, or that dementia and Alzheimer's disease are one in the same. It is important to note, though, that **one-in-ten have no idea whether or not dementia and Alzheimer's disease are one in the same, and two-in-ten have no idea whether or not dementia is as serious as Alzheimer's disease.**

In all instances, **those more likely to be unsure tend to be those with no connection to dementia** (i.e. they don't know someone with dementia, they have no family history of dementia, nor have they cared for someone with dementia).

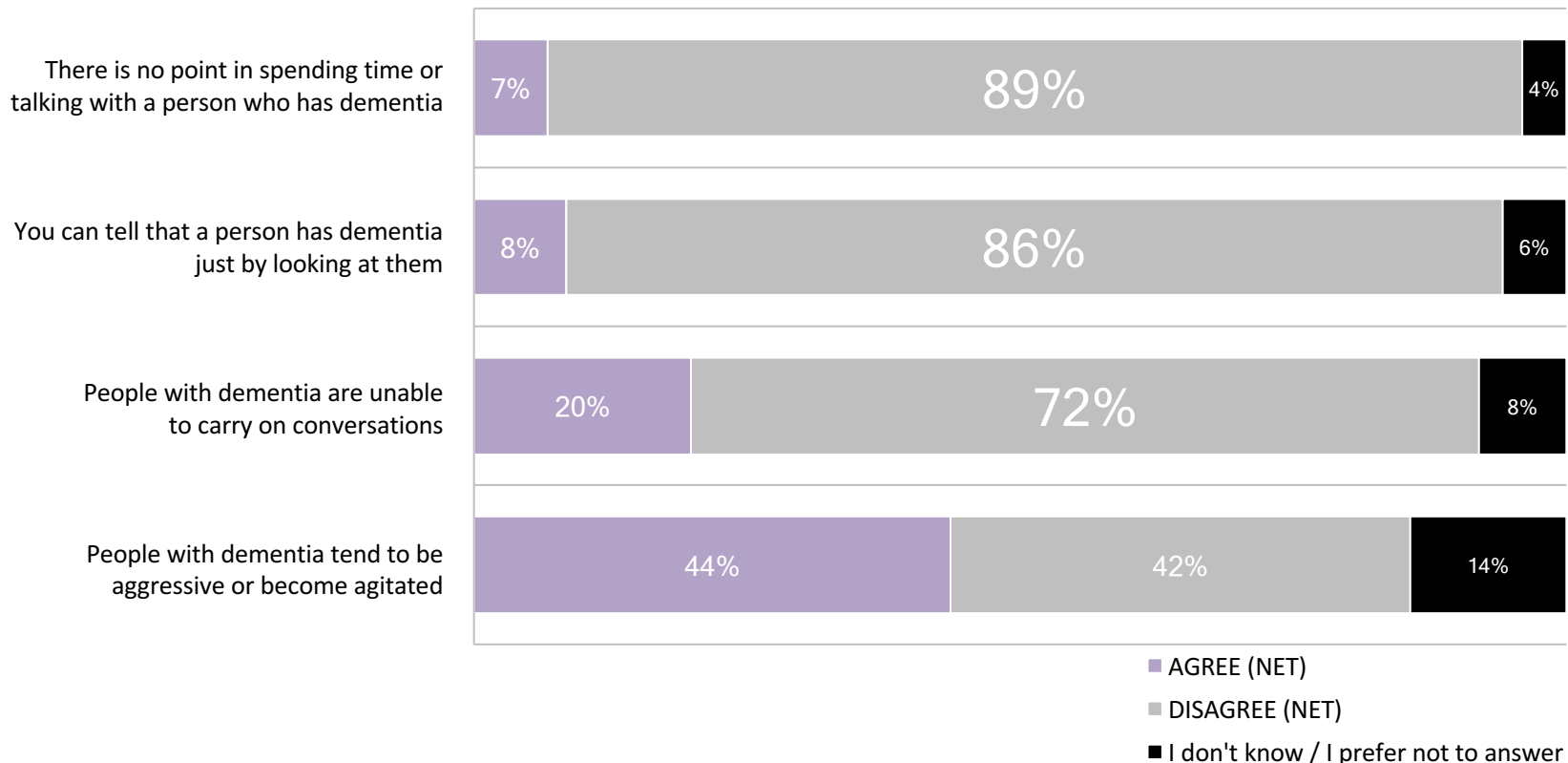
## AGREEMENT LEVELS



# YOU CAN'T TELL A PERSON HAS DEMENTIA JUST BY LOOKING AT THEM

Most respondents **do not** agree that there'd be no point to spending any time with a person who has dementia (especially those who have known someone with dementia [94%]). Nor do respondents agree that (a) people with dementia are unable to carry on a conversation, or that (b) you can tell that a person has dementia just by looking at them (especially those who have known someone with dementia [77% and 91%, respectively]). The only statement that respondents become divided on is whether or not people with dementia tend to be aggressive or become agitated (though respondents who have cared for someone with dementia are more likely to agree: 51% vs. 42% among those who have not).

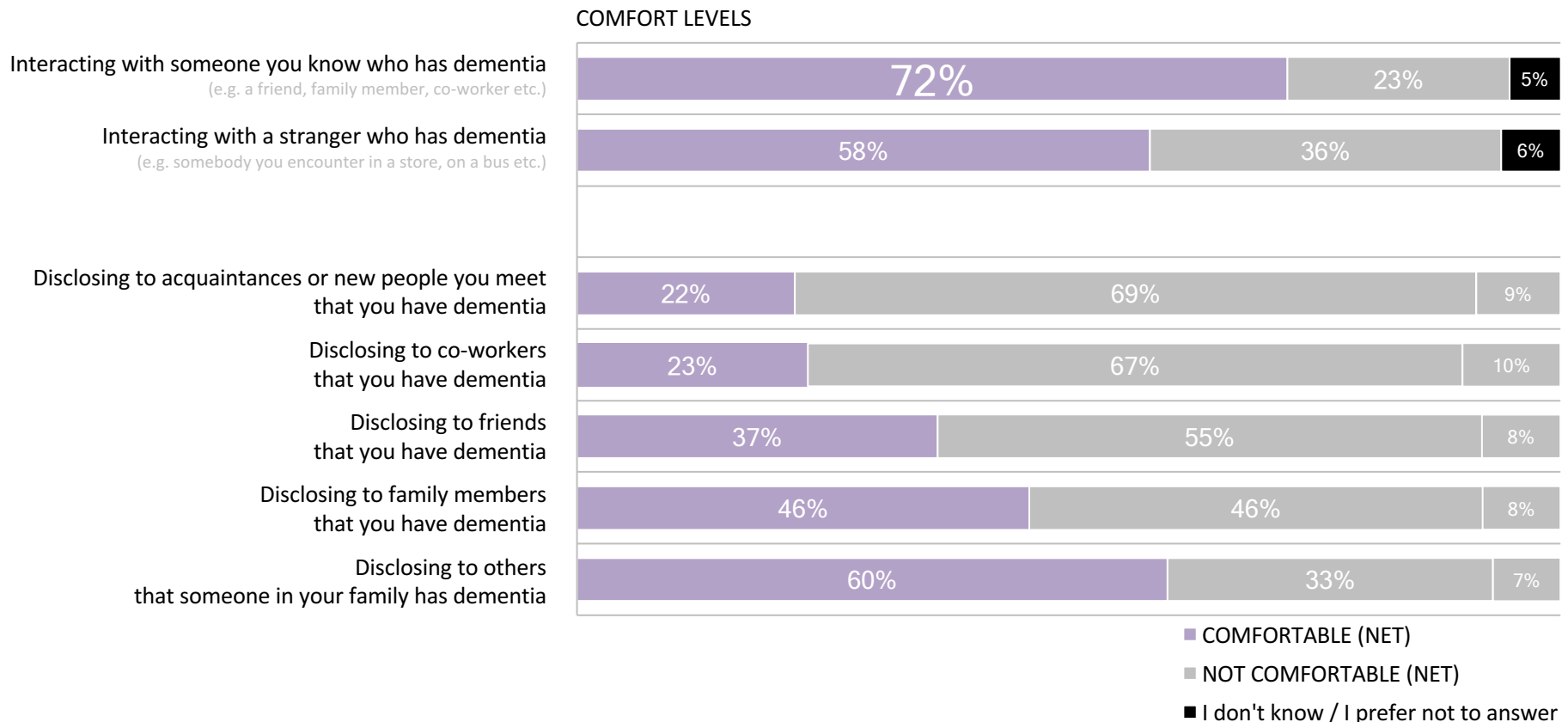
## AGREEMENT LEVELS





# RELATIVELY FEW ARE *VERY COMFORTABLE* INTERACTING WITH SOMEONE WHO HAS DEMENTIA

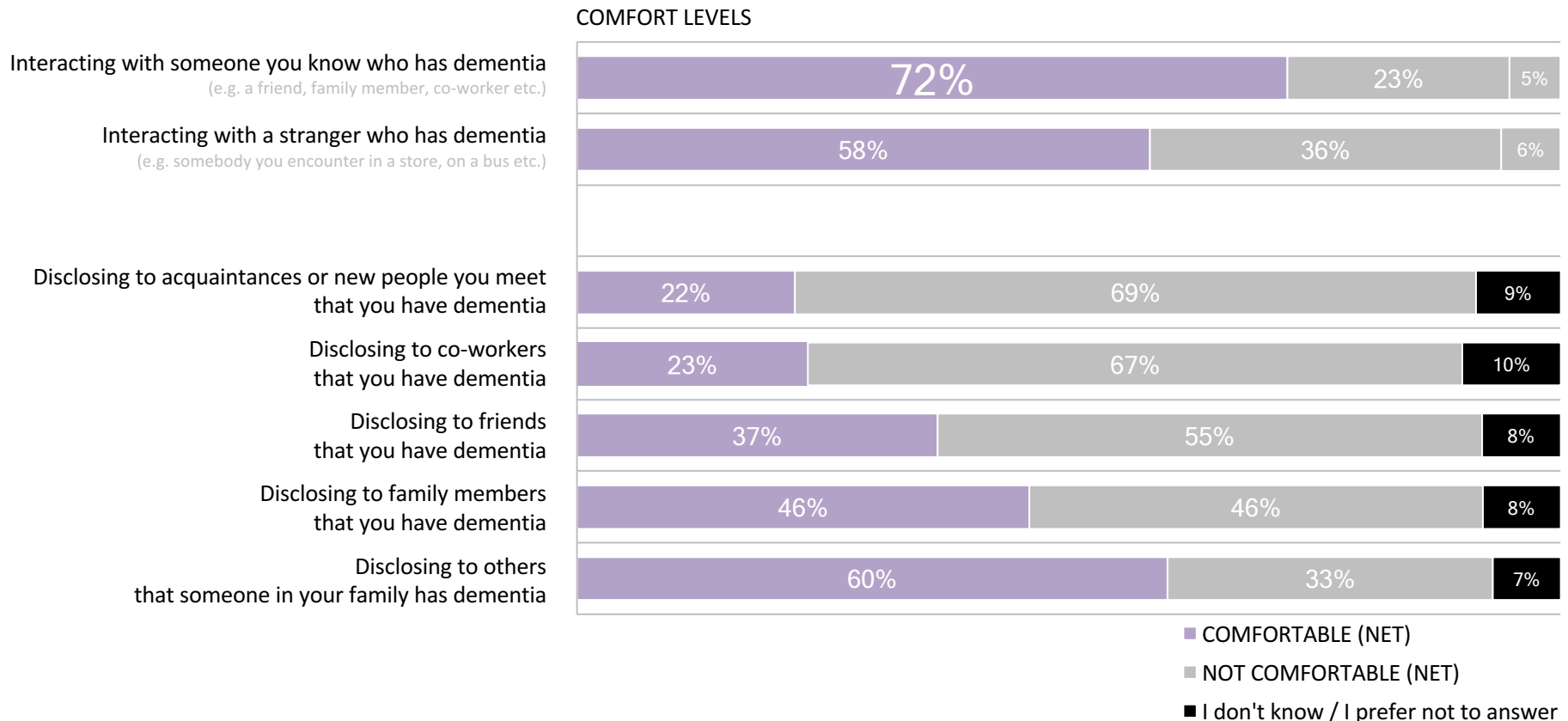
Seven-in-ten would be *comfortable* interacting with someone they know who has dementia (though only 26% would be *very comfortable*), but fewer would be *comfortable* interacting with a stranger who has dementia (with only 13% stating they would be *very comfortable*). Overall, though, those with some sort of connection to dementia (i.e. they know someone with dementia, they have a family history of dementia, or they've cared for someone with dementia) are *more likely* to be *comfortable* in either situation. The same is true for women (78% and 64%, respectively, relative to 66% and 52% among men).



# IT WOULD BE UNCOMFORTABLE TO DISCLOSE TO OTHERS THAT THEY HAVE DEMENTIA

Most would be *uncomfortable* disclosing they have dementia to co-workers, acquaintances, and new people that they meet, with three-in-ten saying they would be *very uncomfortable*. Respondents are divided, however, as to how comfortable they would be disclosing they had dementia to family members: about half (46%) would be *comfortable*, while just as many (46%) would be *uncomfortable*. When it comes to telling others about *someone in their family who has dementia*, comfort levels rise to 60% (though less than two-in-ten would be *very comfortable* doing so).

Demographically, those with a family history of dementia are *more likely* to feel *comfortable* disclosing their dementia diagnosis with both family members (51%) and friends (43%); they're also *more likely* to feel *comfortable* disclosing to others that someone in their family has dementia (75% vs. 54% among those with no family history).

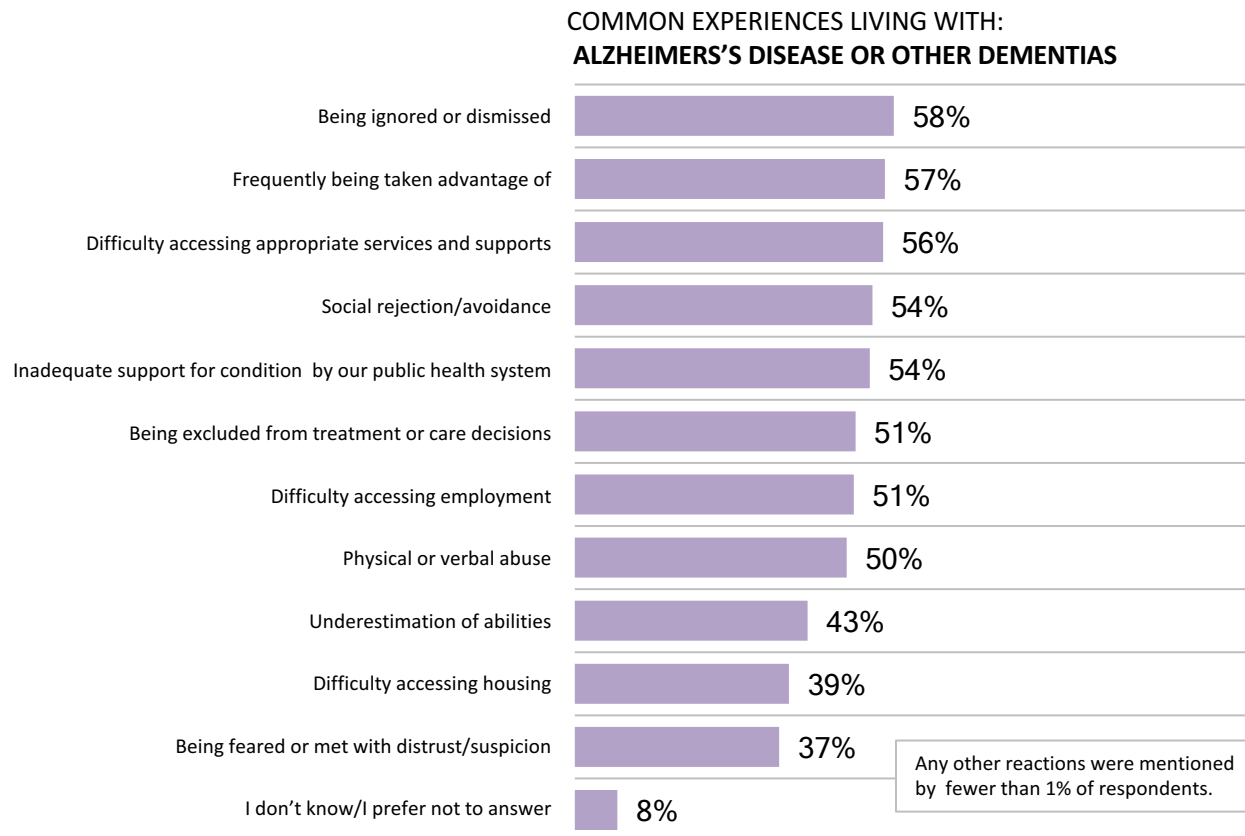


# DETAILED RESULTS

1. DESCRIBING DEMENTIA
2. LEVELS OF WORRY AND CONCERN  
REACTIONS TO A DIAGNOSIS  
A DIAGNOSIS OF FUTURE DEMENTIA
3. KNOWLEDGE  
BELIEFS  
COMFORT LEVELS
4. **PERCEIVED COMMON EXPERIENCES**
5. CAREGIVERS' EXPERIENCES
6. UNEXPERIENCED PERCEPTIONS

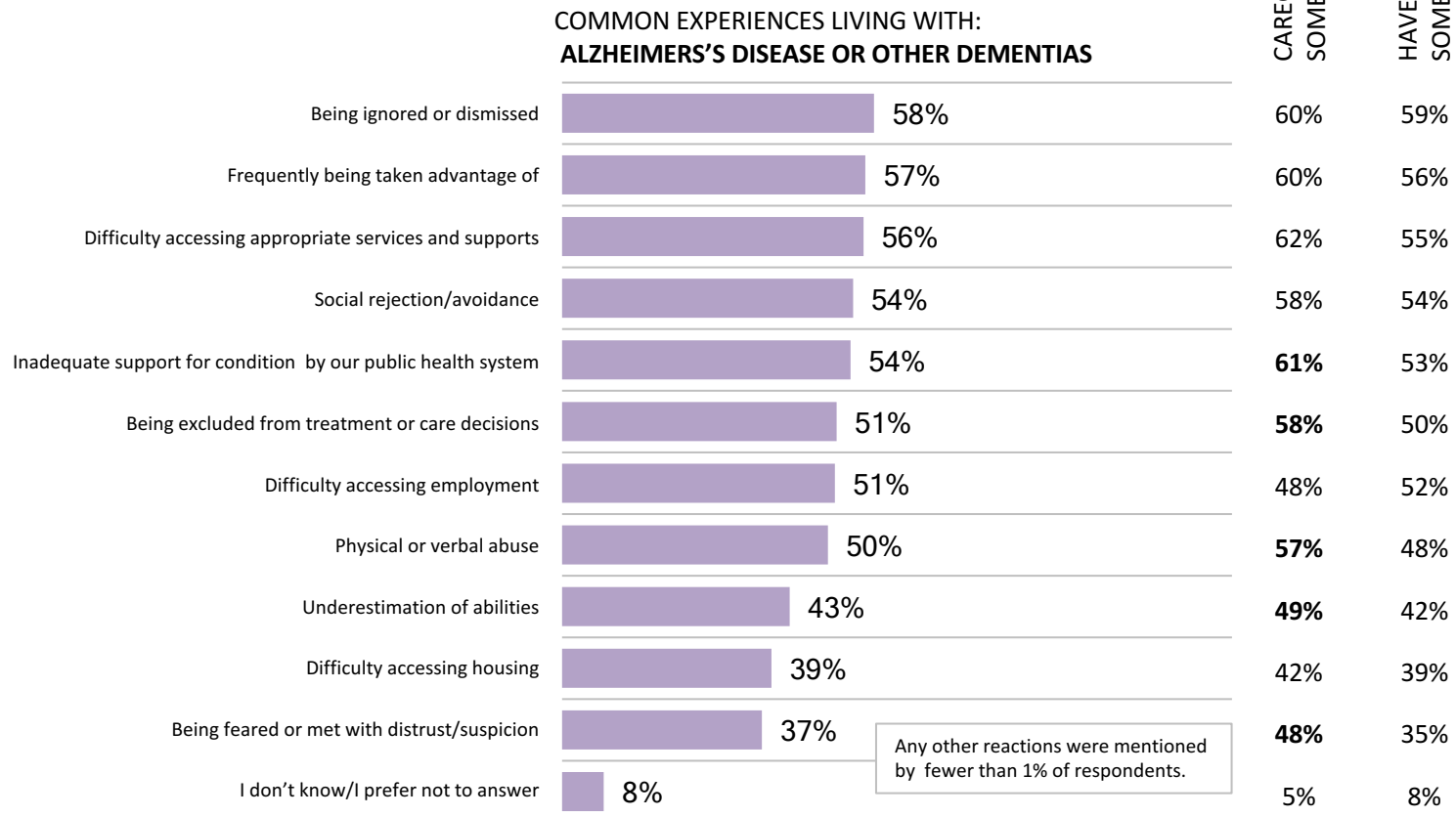
# MANY NEGATIVE EXPERIENCES ARE BELIEVED TO BE COMMON FOR PEOPLE LIVING WITH DEMENTIA

Over half believe that people living with dementia (such as Alzheimer's disease) are commonly (a) ignored or dismissed, (b) taken advantage of, (c) face social rejection and/or avoidance, and (d) exclusion from their own treatment and/or care decisions. They also have difficulty accessing the appropriate support, experience inadequate support, and have difficulty securing employment. Physical and/or verbal abuse is thought to be common as well (50%).



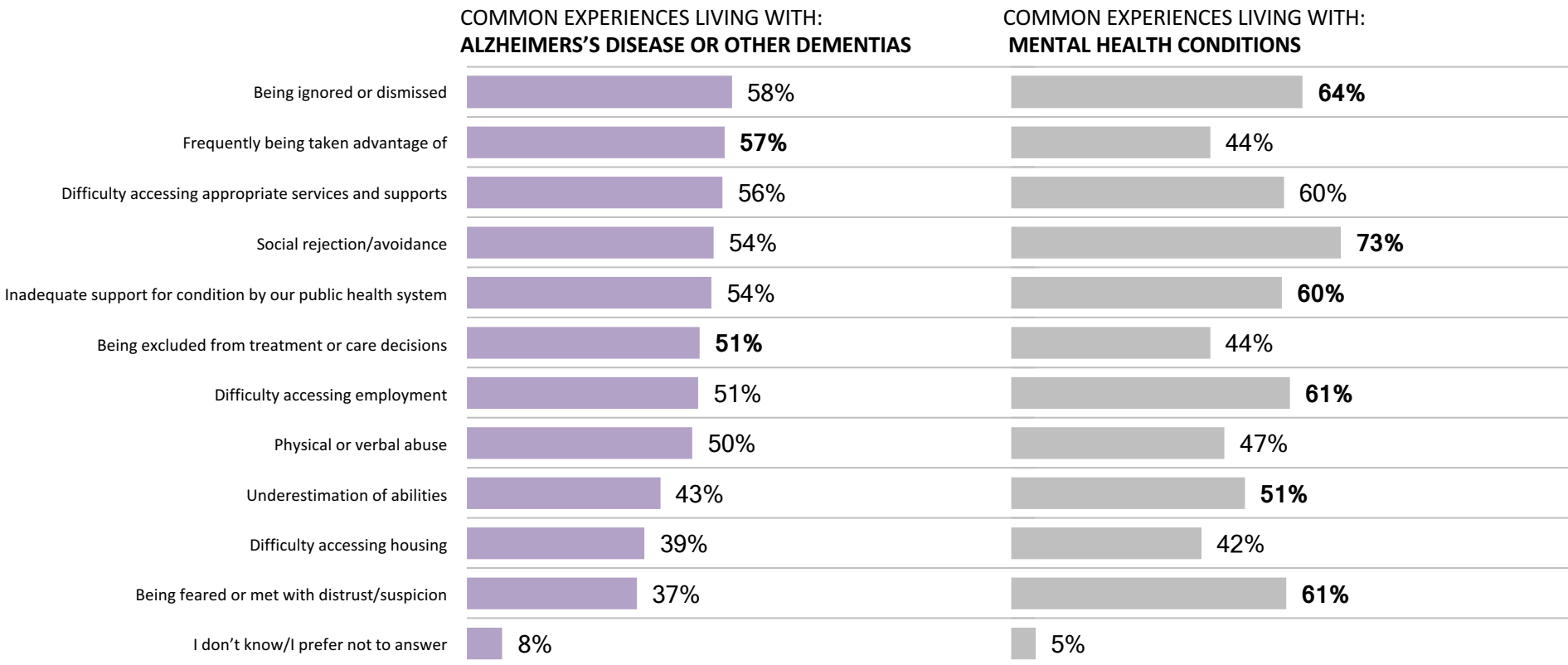
# MANY NEGATIVE EXPERIENCES ARE BELIEVED TO BE COMMON FOR PEOPLE LIVING WITH DEMENTIA

Interestingly, in all but one case (i.e. difficulty accessing employment), **those who know someone with dementia were significantly more likely to believe each experience was common** (relative to those who do not know anyone with dementia). Interestingly, it's not the same for those who've actually cared for someone living with dementia. Relative to those who've never cared for someone with dementia, **caregivers are more likely to note the following to be common experiences: inadequate support, exclusion from treatment and care decisions, physical or verbal abuse, underestimation of abilities, and being feared or met with distrust/suspicion.**



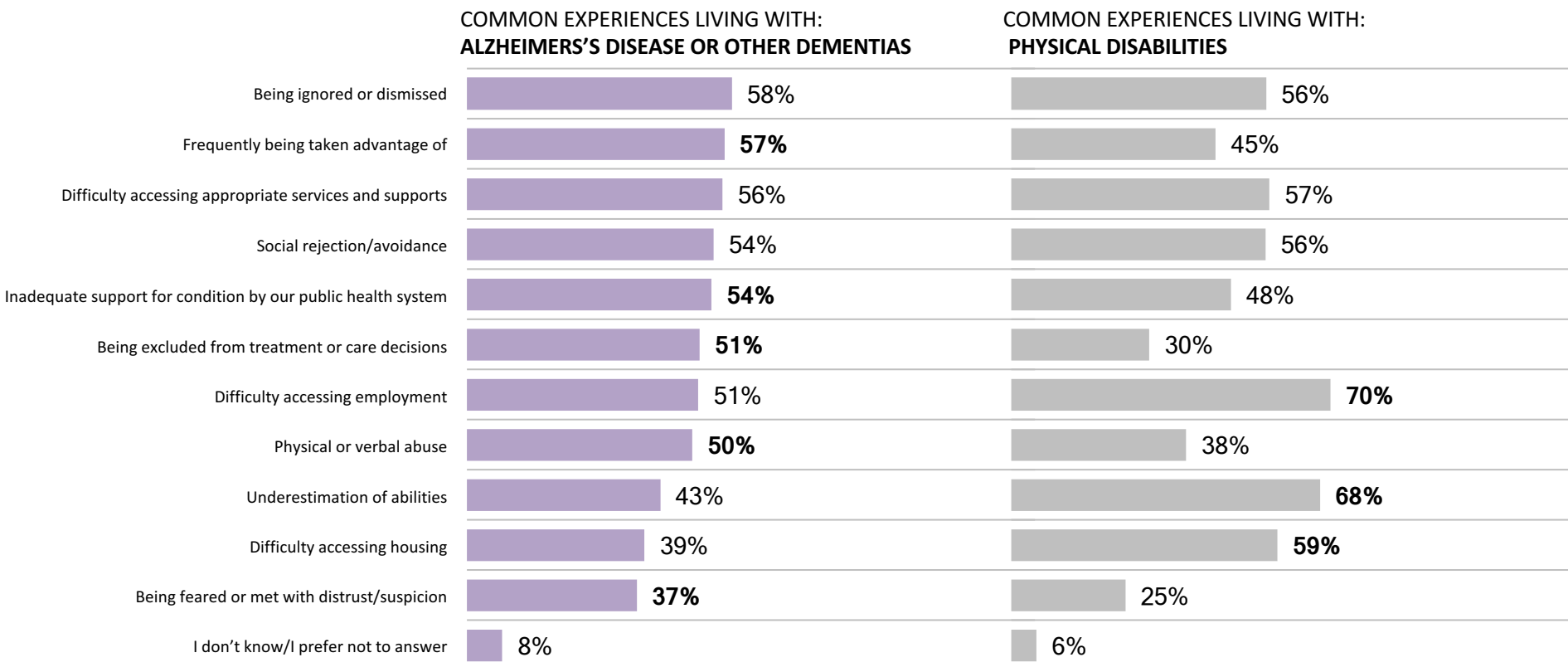
# THOSE LIVING WITH ALZHEIMER'S DISEASE / DEMENTIA HAVE IT WORSE, IN SOME INSTANCES

Relative to those living with mental health conditions (such as depression, anxiety, and addictions, among others), **respondents believe that those living with Alzheimer's disease (or another type of dementia) are *more likely* to be (a) taken advantage of and (b) excluded from their own treatment and care decisions, but *less likely* to be ignored, socially rejected/avoided, underestimated, or feared/distrusted.** Those living with Alzheimer's disease (or another type of dementia) are also *less likely* to experience inadequate support or difficulty accessing employment, according to respondents.



# THOSE LIVING WITH ALZHEIMER'S DISEASE / DEMENTIA HAVE IT WORSE, IN SOME INSTANCES

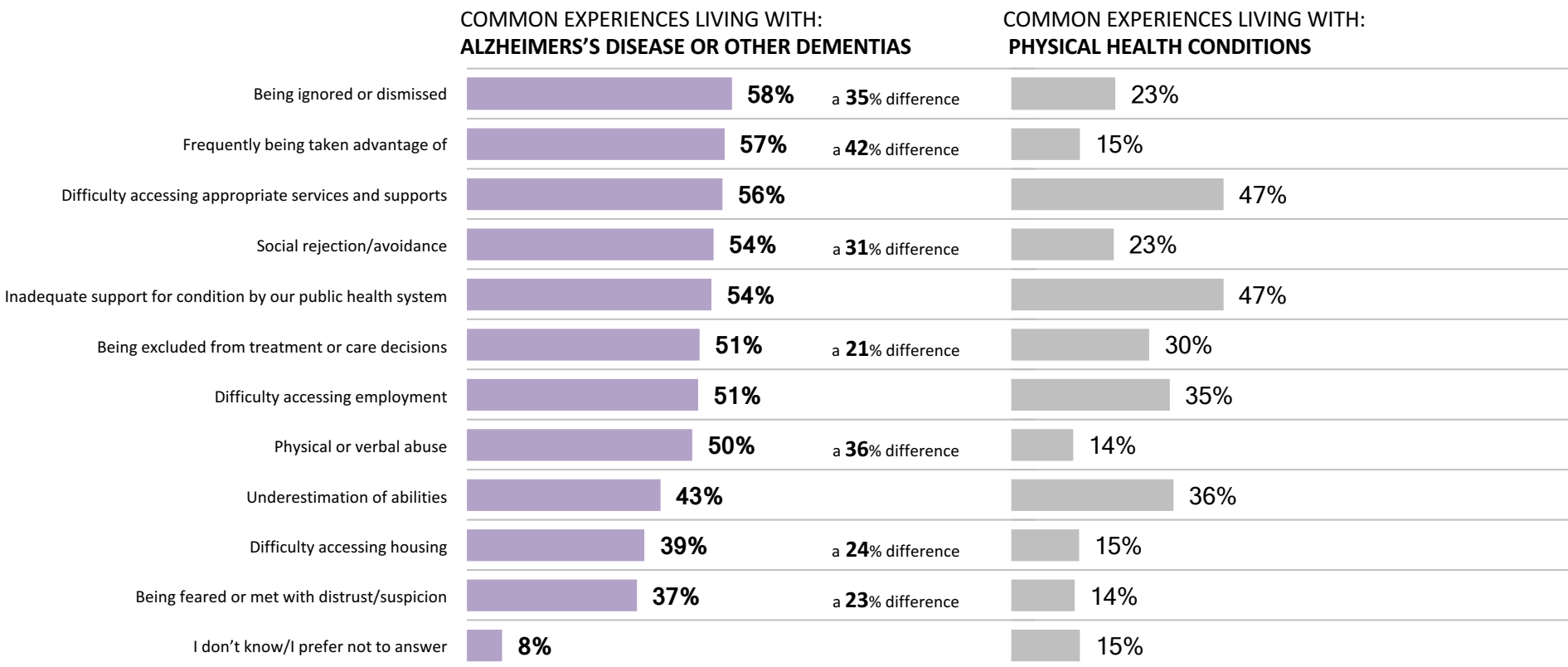
Relative to those living with physical disabilities (such as deafness, blindness, and/or having to use a wheelchair, for example), **respondents believe that those living with Alzheimer's disease (or another type of dementia) have a tougher time finding adequate support, and are *more likely* to be (a) taken advantage of, (b) excluded from their own treatment and care decisions, (c) targets of physical or verbal abuse, and (d) feared/distrusted. On the other hand, respondents believe that those living with Alzheimer's disease (or another type of dementia) are *less likely to be underestimated* (relative to those living with physical disabilities) and tend to have an easier time accessing employment and housing.**





# THOSE LIVING WITH ALZHEIMER'S DISEASE / DEMENTIA ARE WORSE OFF. PERIOD.

Relative to those living with physical health conditions (such as cancer, heart disease, stroke, or diabetes, for example), **respondents believe that those living with Alzheimer's disease (or another type of dementia) have a tougher time with everything – especially with respect to being: taken advantage of, targets of abuse, feared/distrusted, ignored, socially rejected/avoided, and being excluded from their own treatment or care decisions. Respondents also believe those living with Alzheimer's disease (or another type of dementia) have a tougher time accessing housing** (relative to those living with physical health conditions).



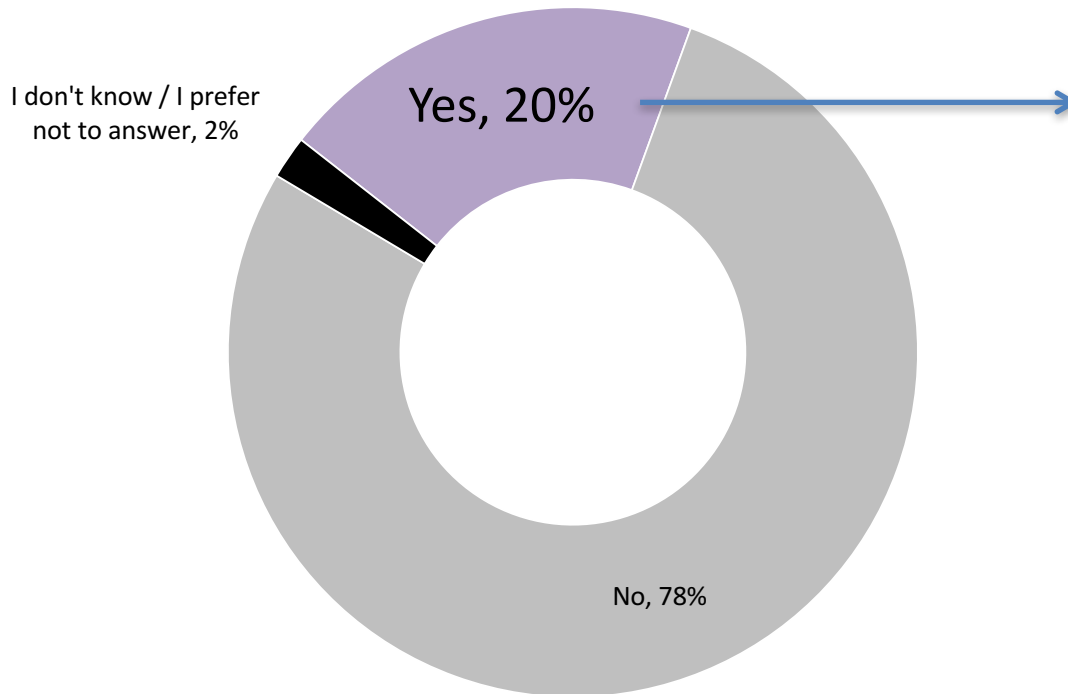
# DETAILED RESULTS

1. DESCRIBING DEMENTIA
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3. KNOWLEDGE  
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COMFORT LEVELS
4. PERCEIVED COMMON EXPERIENCES
5. **CAREGIVERS' EXPERIENCES**
6. UNEXPERIENCED PERCEPTIONS

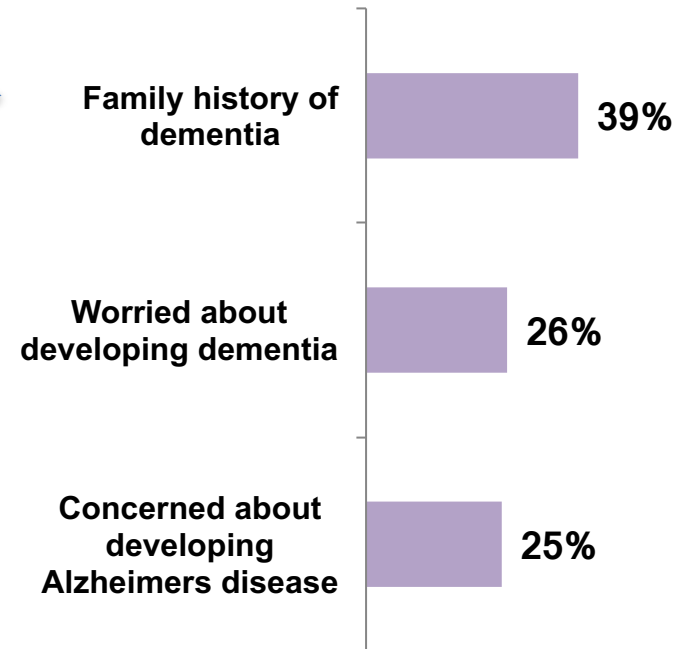
# ONE-IN-FIVE HAVE CARED FOR SOMEONE WITH DEMENTIA

**One in five (20%) Canadians indicate that they have cared for, or currently care for, someone with dementia.** There is a linkage between exposure to this disease and worry or concern about developing it at some point in their lifetime.

## Currently or have cared for someone with dementia?

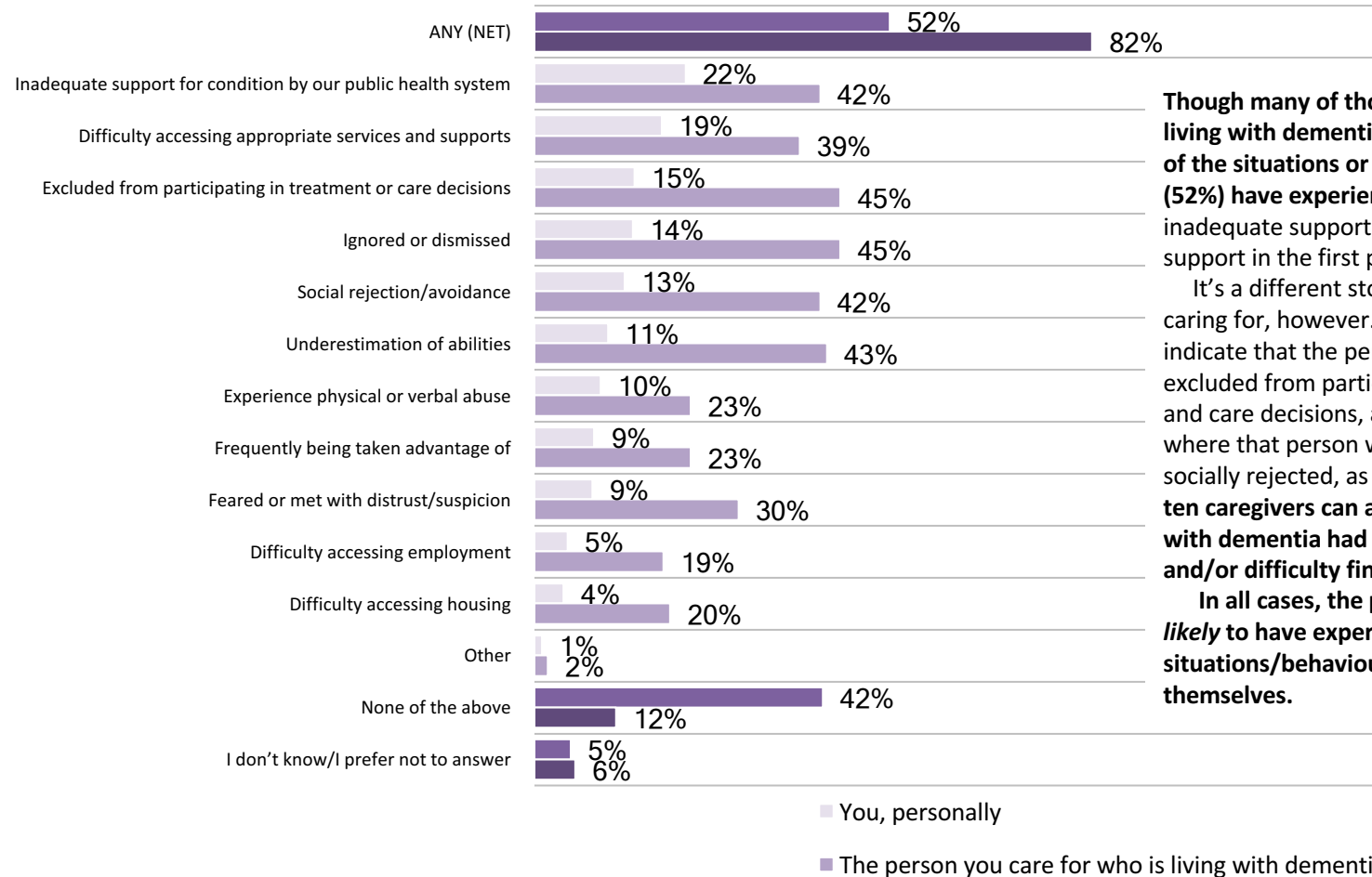


## Most experienced



# MANY CAREGIVERS HAVE HAD TROUBLE FINDING ADEQUATE SUPPORT FOR THE PERSON THEY CARE FOR

## EXPERIENCES



Though many of those who have cared for someone living with dementia (42%) haven't experienced any of the situations or behaviours listed below, half (52%) have experienced at least one, such as inadequate support (22%) and/or difficulty finding support in the first place (19%).

It's a different story for the person they're actually caring for, however. About half (45%), for example, indicate that the person they care for has been excluded from participating in their own treatment and care decisions, and many can recall situations where that person was ignored, dismissed, and/or socially rejected, as well as underestimated. **Four-in-ten caregivers can also recall a time the person living with dementia had trouble with inadequate support and/or difficulty finding support in the first place.**

In all cases, the person they care for is ***much more likely*** to have experienced each of the situations/behaviours listed, relative to caregivers themselves.

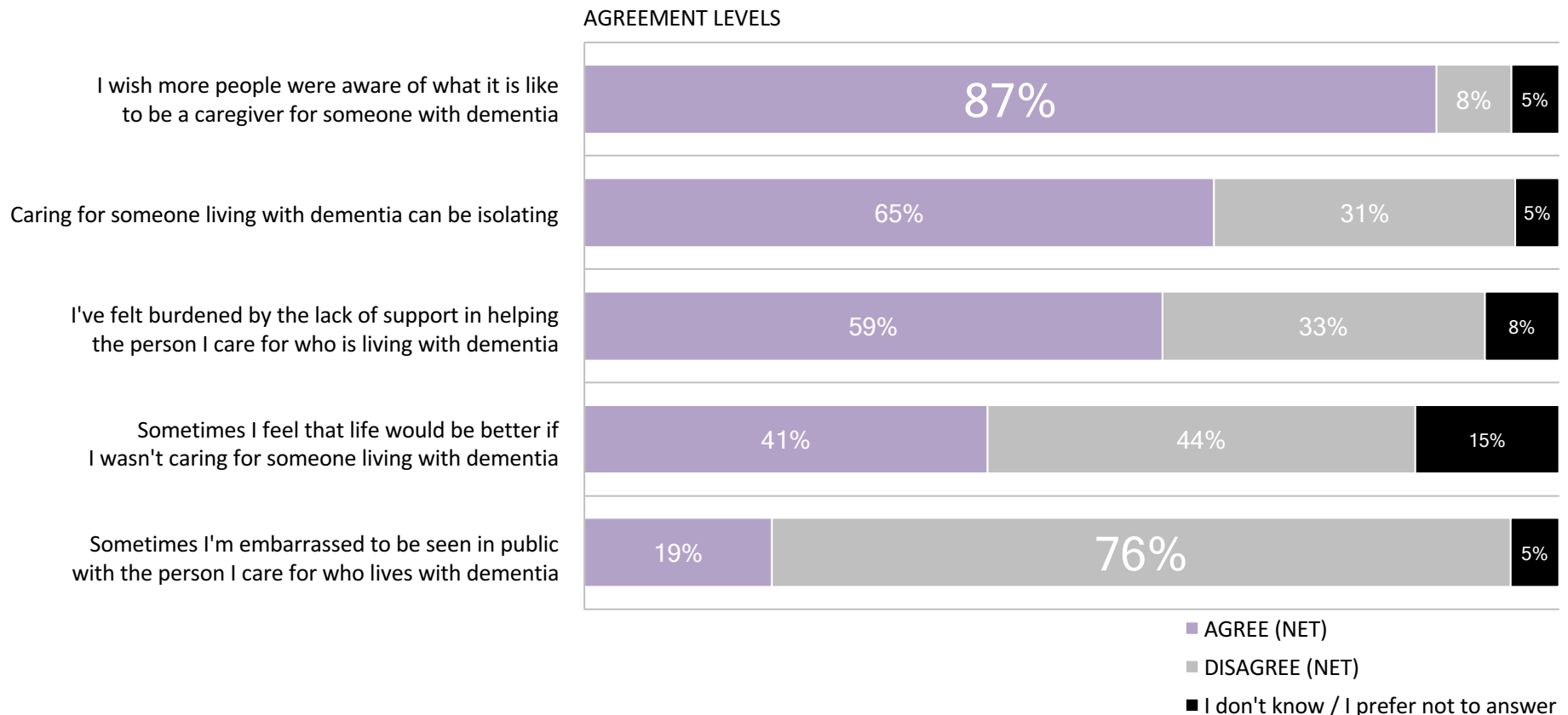
Q14 As a person who has cared for somebody living with dementia, have you or the person with dementia that you care for experienced any of the following situations or behaviours?

Base: Caregivers (n=304).

# 87% WISH MORE PEOPLE WERE AWARE OF WHAT IT'S LIKE TO CARE FOR SOMEONE WITH DEMENTIA

Caring for someone living with dementia can be hard. Six-in-ten, for example, state that it can be isolating and that, at times, they've felt burdened by a lack of support. Furthermore, many (41%) admit that, sometimes, they feel life would be better if they weren't caring for someone with dementia.

While relatively few (19%) are embarrassed to be seen in public with the person they care for (given the other percentages of agreement listed), the vast majority (87%) wishes more people were aware of what it's like to be a caregiver for someone with dementia.

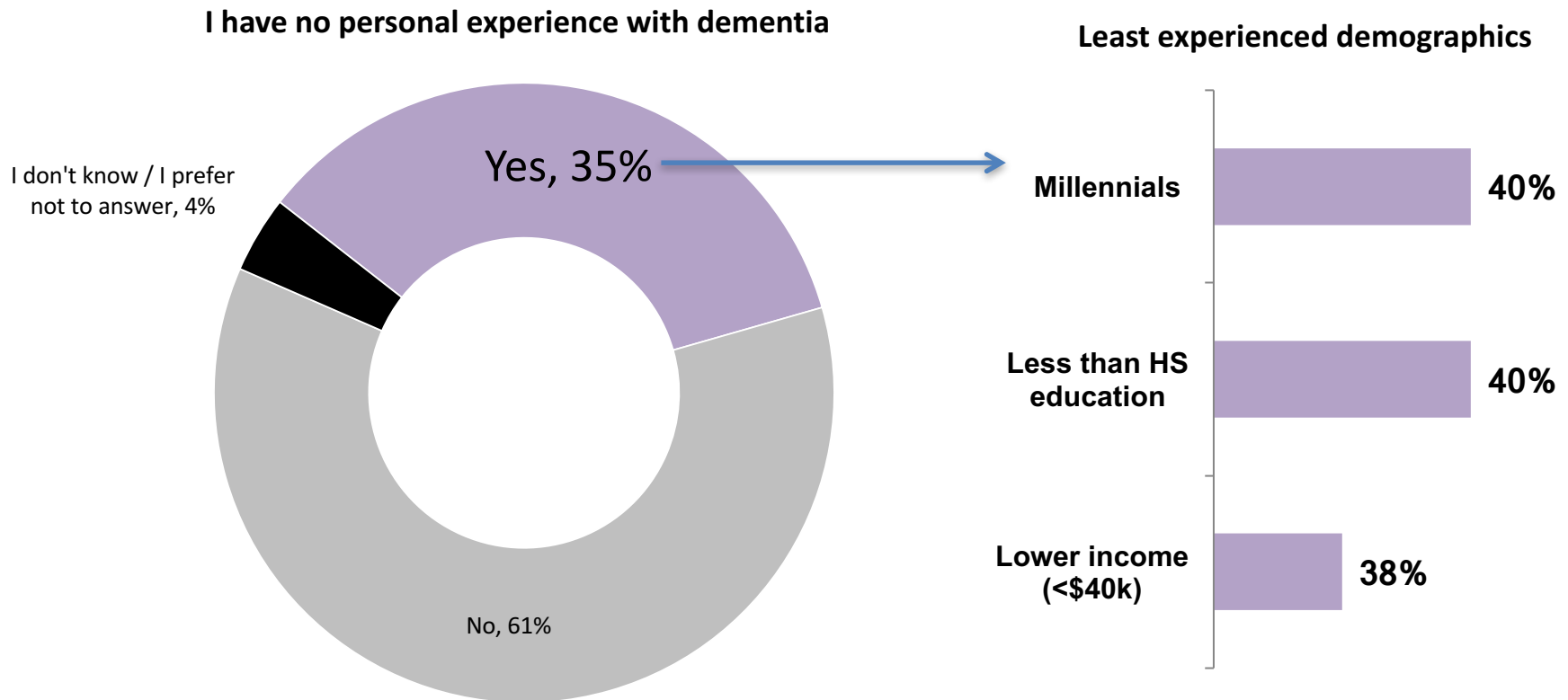


# DETAILED RESULTS

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COMFORT LEVELS
4. PERCEIVED COMMON EXPERIENCES
5. CAREGIVERS' EXPERIENCES
6. **UNEXPERIENCED PERCEPTIONS**

# OVER A THIRD OF CANADIANS HAVE HAD NO PERSONAL EXPERIENCE WITH DEMENTIA

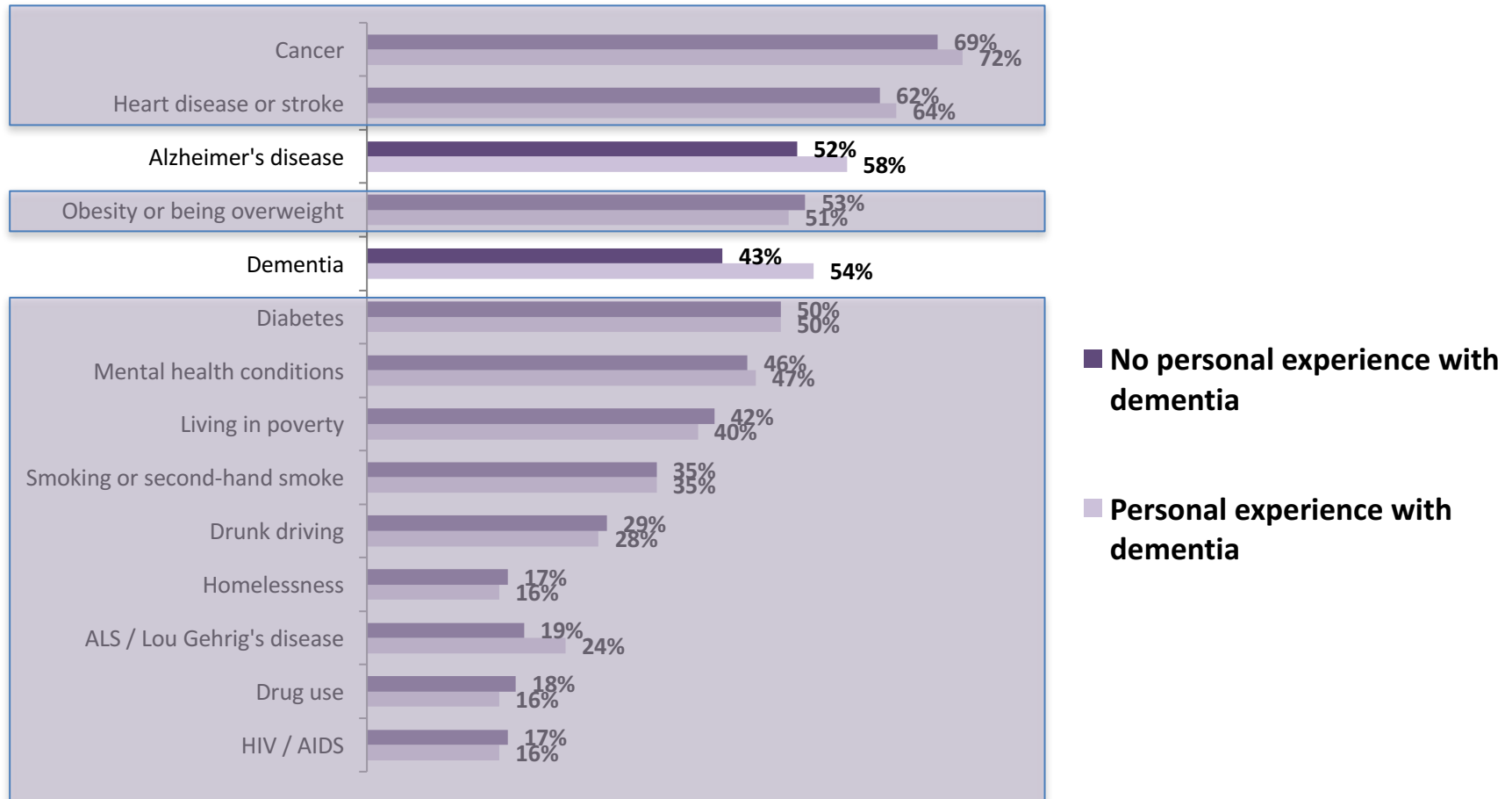
Among this group, those least experienced with dementia coincides with being younger.





# LACK OF EXPERIENCE MEANS ALZHEIMER'S AND DEMENTIA ARE A LESSER CONCERN

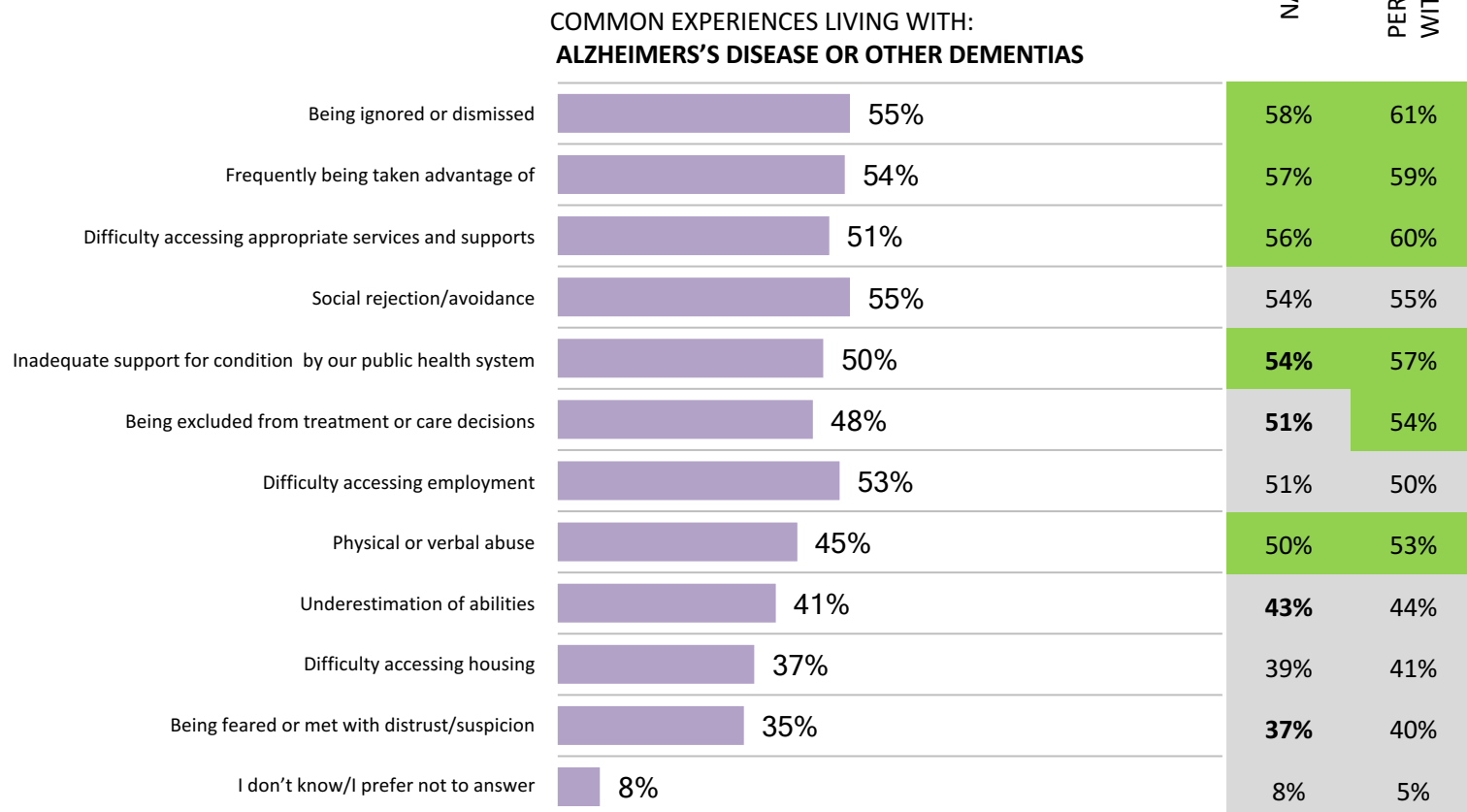
LEVELS OF CONCERN



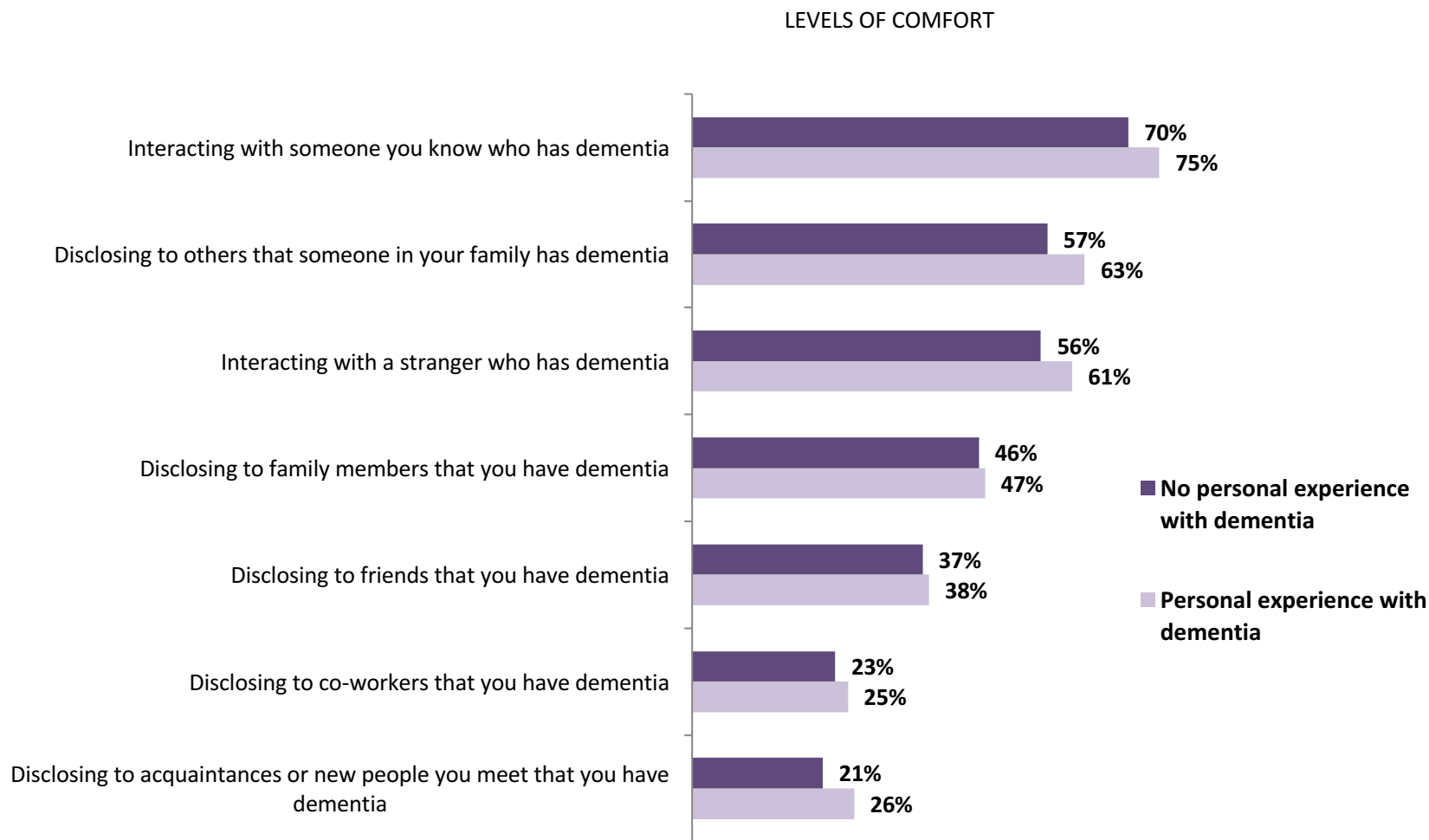
# LACK OF EXPERIENCE TRANSLATES TO LESS UNDERSTANDING OF EXPERIENCE ON SOME FRONTS, BUT NO DRASTIC DIFFERENCES

Compared to those *with* personal experience of dementia, those with *no personal experience* are significantly less likely to think that people with dementia commonly experience:

- being ignored or dismissed;
- being taken advantage of; and
- having difficulty accessing appropriate services and supports, among others.

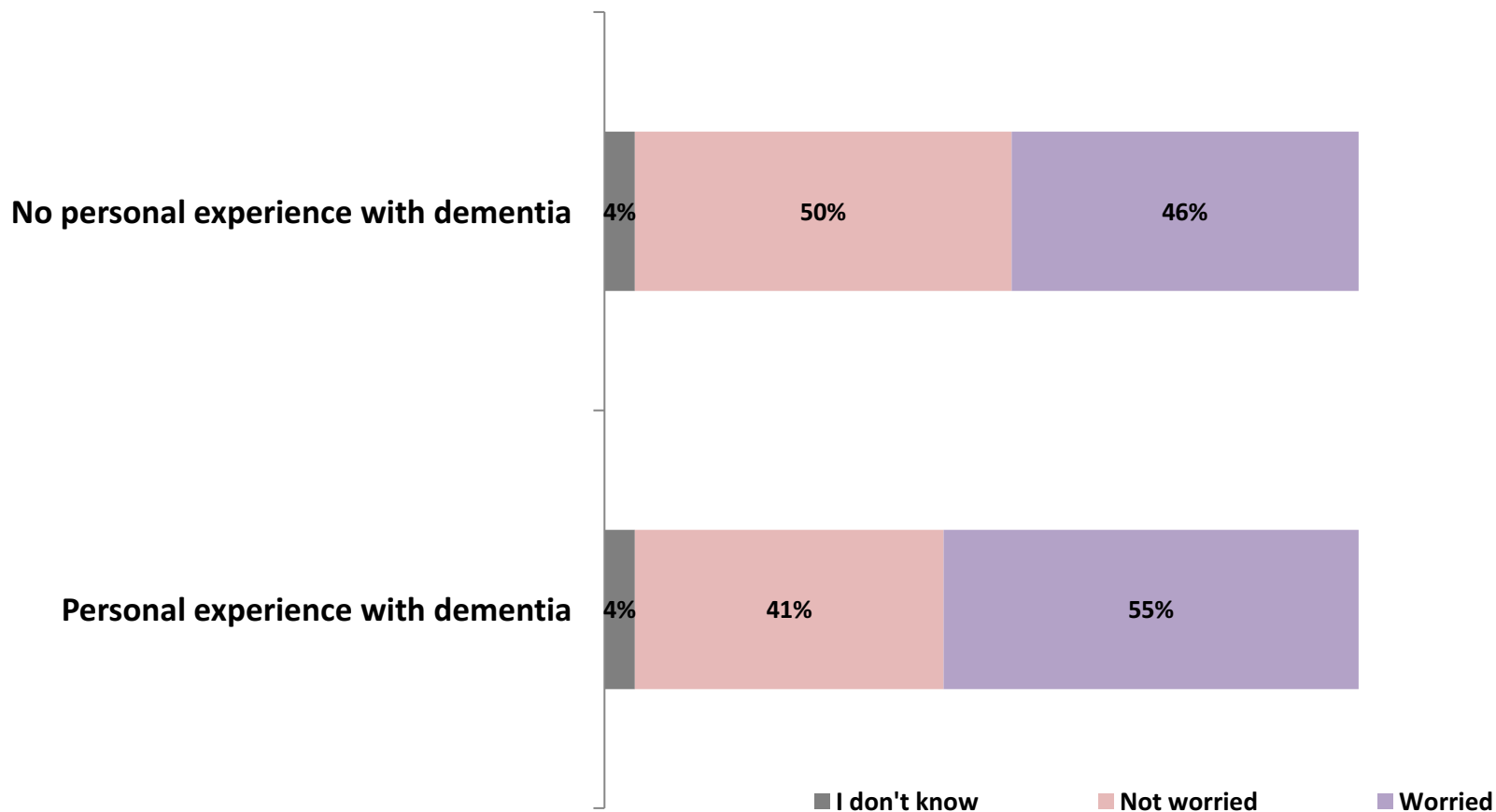


# COMFORT LEVELS, REGARDLESS OF PERSONAL EXPERIENCE WITH DEMENTIA, ARE FAIRLY CLOSE

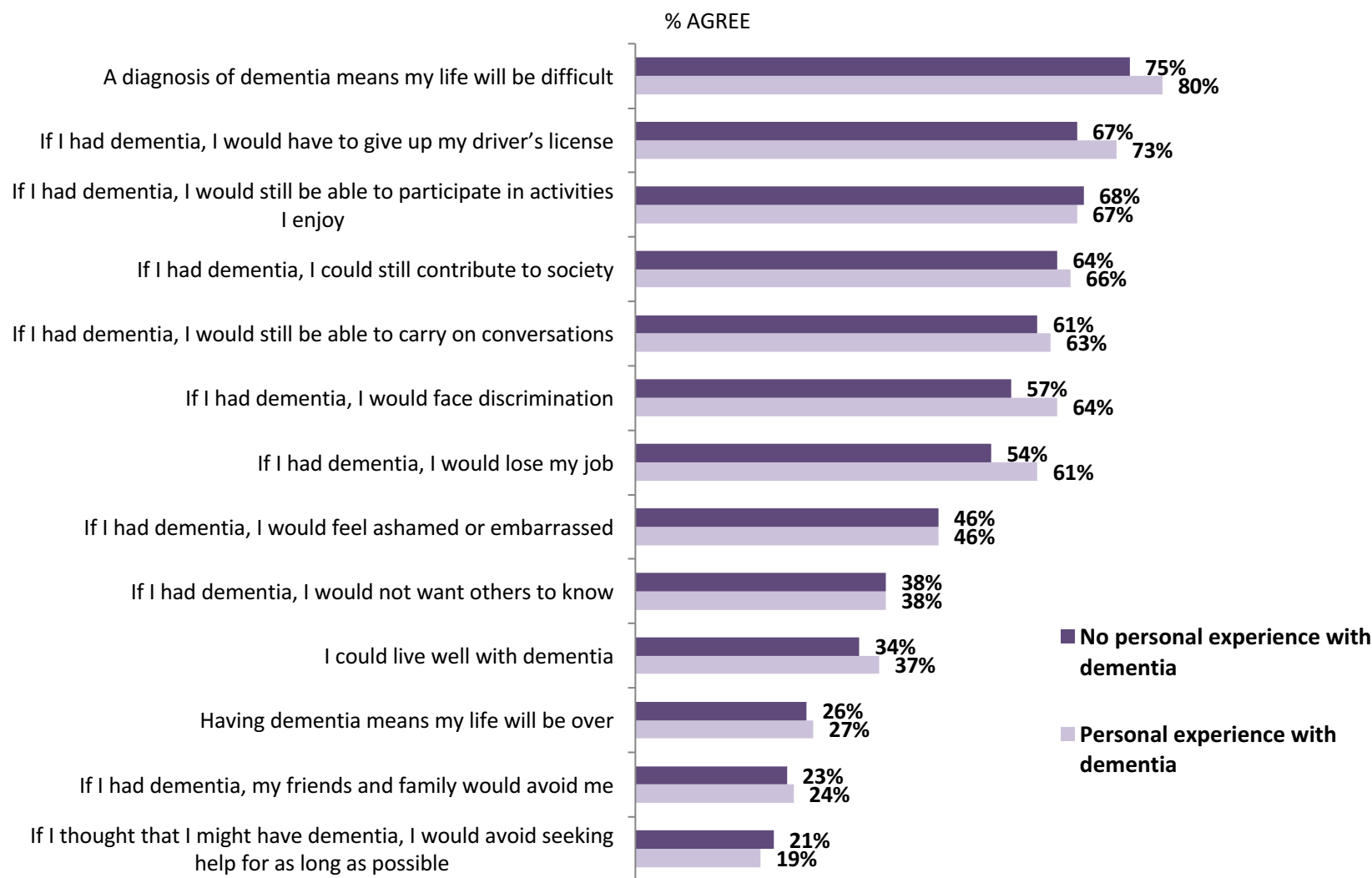


# LESS EXPOSURE LEADS TO LESS WORRY

LEVELS OF WORRY



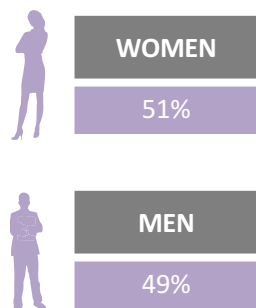
# STIGMA-RELEVANT PERCEPTIONS BARELY DIFFER BETWEEN THOSE WITH AND THOSE WITHOUT PERSONAL EXPERIENCE OF THE DISEASE



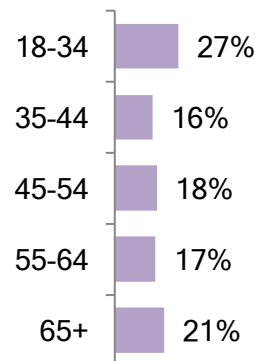
# RESPONDENT PROFILE

# RESPONDENT PROFILE

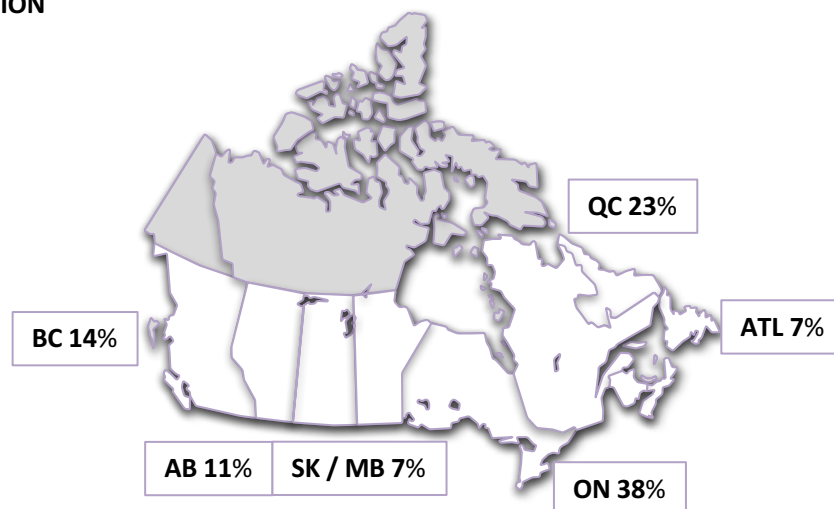
## GENDER



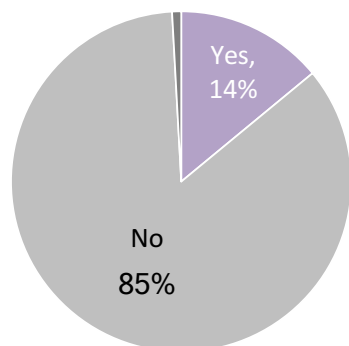
## AGE



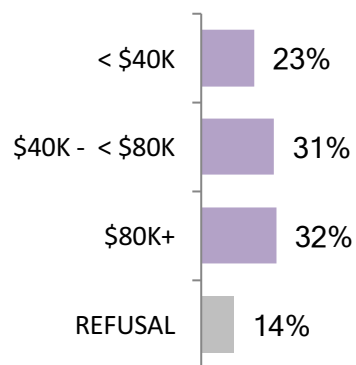
## REGION



## WORK(ED) IN HEALTHCARE?



## HH INCOME



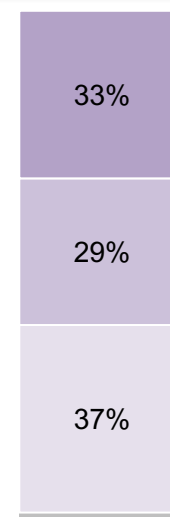
## EDUCATION

UNIVERSITY

SOME COLLEGE / COLLEGE

HIGH SCHOOL OR LESS

REFUSAL

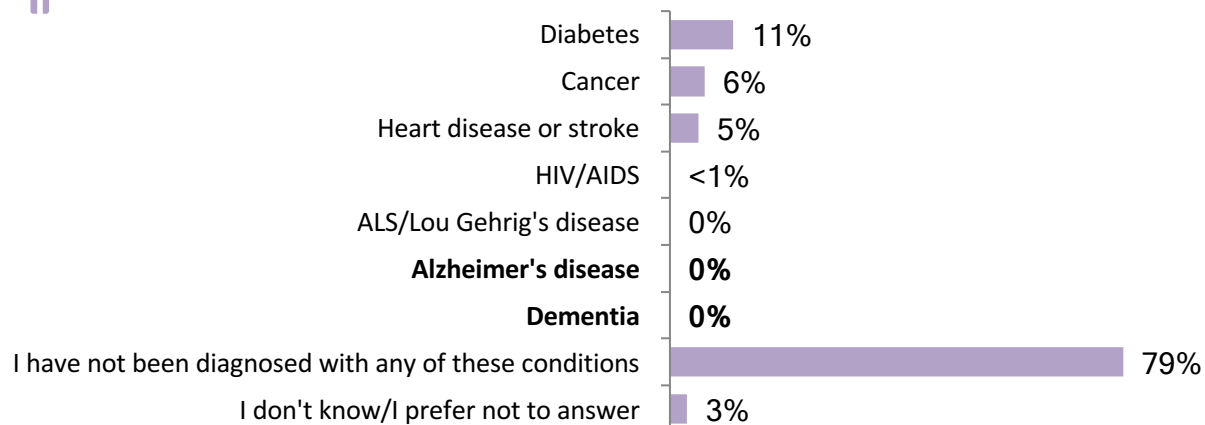




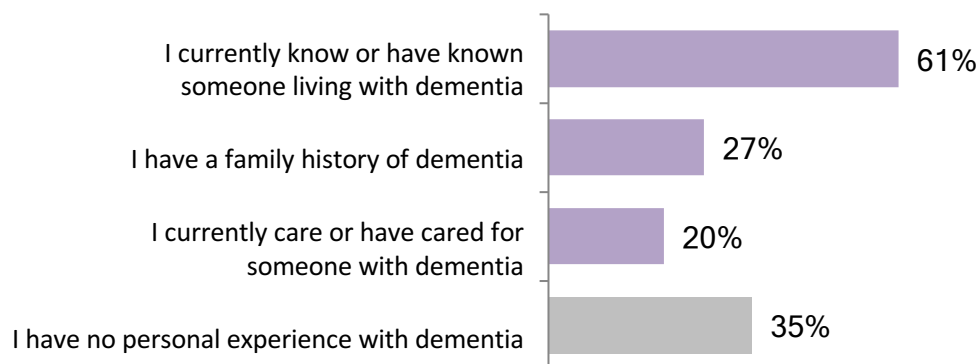
# RESPONDENT PROFILE



## EVER BEEN DIAGNOSED WITH ANY OF THE FOLLOWING?



## EXPERIENCE WITH DEMENTIA





THE RESEARCH INTELLIGENCE GROUP

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