

## Original Research Article

# Honesty in reporting suicidal ideations and behaviors in Alzheimer's disease, mild cognitive impairment, and dementias

Rinah T. Yamamoto\*, Susan M. Dallabrida

eResearch Technology, Boston, MA, USA

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### \*Correspondence:

Dr. Rinah T. Yamamoto,

E-mail: [rinah.yamamoto@ert.com](mailto:rinah.yamamoto@ert.com)

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## ABSTRACT

**Background:** Detection of patients' suicidal ideations and behaviors (SIB) is critical to patient safety. It is important to consider the needs, abilities and propensity for honesty in reporting SIB in populations with compromised cognitive abilities. We surveyed patients with compromised cognitive abilities to determine if they feel they would report SIB and the conditions under which they would be honest in reporting SIB?

**Methods:** Patients reporting diagnoses such as Alzheimer's disease (AD), mild cognitive impairment (MCI) or other dementias completed online surveys. Participants were asked their likelihood for honesty, preferences and comfort when answering questions on SIB in-person and using electronic self-report.

**Results:** 73 patients with AD, MCI or other dementias, 95% reported they were likely to report SIB honestly electronically and 92% would be honest with a health care provider (HCP). However, 96% would be honest in-person with an HCP they knew but less than 88% said they would be honest if they didn't know the HCP.

**Conclusions:** These data suggest that patients with cognitive conditions may be more likely to report SIB truthfully using electronic self-report than a clinical face to face interview but that either form of reporting is an effective methodology for obtaining honest responses about SIB. Taking the FDA guidance on suicidality and the potential for cognitive decrements in this population, multiple tools for assessing depression and SIB should be implemented when treating or working this population.

**Keywords:** Suicidal ideations and behaviors, Alzheimer's disease, Cognitive impairment

## INTRODUCTION

Suicide ranked 10th in the US as a leading cause of death in 2014. Prospective methods for identifying suicidality are important for reducing incidence of suicide. Alzheimer's disease (AD) has been moderately associated with suicide risk.<sup>1</sup> In 2013, the prevalence of Alzheimer's disease was over 5 million and rates were expected to double every 5 years in people over the age of 65.2 By 2050, 14 million people are expected to have the disease. Mild cognitive impairment can be an early sign of Alzheimer's disease, but it does not always develop into AD. Depression and apathy are common in

early AD.<sup>3,4</sup> As an example, Gruber-Baldini et al found a high prevalence of depression symptoms in patients with dementia in long-term care; depression was more than twice as common in patients with mild to moderate dementia compared to those without dementia.<sup>5</sup> In another study, Usman et al found that more than 75% of their Alzheimer's patients were suffering from depression, of those patients, 90% were women.<sup>6</sup>

Detection of patients' suicidal ideations and behaviors (SIB) is critical to patient safety. We previously reported that psychiatric patients are more likely to respond honestly to questions about SIB via electronic self-report

assessments, compared to in-person.<sup>7</sup> It is important to consider the needs, abilities and propensity for honesty in reporting SIB in populations with compromised cognitive abilities. The FDA’s draft guidance on suicidality recommends prospective assessment of SIB in clinical trials for patients with Alzheimer’s disease, dementias, or other mild cognitive impairments.<sup>8</sup> The guidance also indicates that the severity of the cognitive impairment should be considered when determining the method for assessing SIB.<sup>9</sup> It is also important to consider the conditions under which patients will be honest. Will patients with compromised cognitive abilities feel that they can be honest reporting suicidal ideations and behaviors using electronic self-report and/or face-to-face clinical interviews?

**METHODS**

This study employed an online survey research design.

An online survey was deployed through the website <https://www.clinicalconnection.com>, an online patient recruit resource.

Participants were asked about their likelihood for honesty, their preferences and comfort when answering questions on SIB in-person and using electronic self-report.

“If you were having thoughts of suicide or had acted on those thoughts, how likely would you be to honestly answer questions about those thoughts or acts, if a healthcare professional you have never met were asking you about this in a face-to-face interview?”

“If you were having thoughts of suicide or had acted on those thoughts, how likely would you be to honestly answer questions about those thoughts or acts, if a healthcare professional you have met were asking you about this in a face-to-face interview?”

“If you were having thoughts of suicide or had acted on those thoughts, how likely would you be to honestly answer questions about those thoughts or acts, if you were entering your responses directly into a computer system such as a tablet, smartphone, laptop or desktop and there was no healthcare professional present while you recorded your answer?”

**Statistical analysis**

Where appropriate, within subject comparisons will be assessed using the non-parametric, Cochran’s Q statistic.

**RESULTS**

73 patients reporting diagnoses such as AD, MCI or other dementias (ages 50 to >80, 52% female) completed online surveys (Table 1).

In patients with AD, MCI or other dementias, 95% reported they were likely to report SIB honestly electronically and 92% would be honest with a health care provider (HCP). When asked how likely they would be honest with an HCP they knew, 96% reported they would be honest in-person but if they did not know the HCP, less than 88% said they would be honest (electronic report compared to responding to either a known HCP and an unknown HCP; Cochran’s Q p=0.02) (Figure 1).

**Table 1: Demographics.**

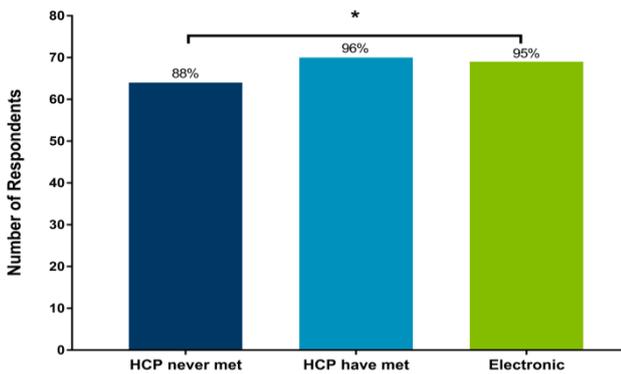
Diagnosis	N	Age mean (sd)	Years since diagnosis mean (sd)	Gender female/male	Living Situation (%)			
					Alone	Resident care	With spouse	With other family member
Alzheimer’s disease	16	69.71 (7.53)	3.63 (3.44)	8/8	9.1	13.6	72.7	4.6
MCI	42	70.20 (11.32)	2.55 (2.74)	24/18	25.9	3.7	63.0	7.4
Other dementia	4	64.78 (13.05)	3.90 (4.68)	2/9	18.2	0	72.7	9.1
Other unknown	11	60.33 (3.06)	9.00 (12.12)	4/0	25.0	0	25.0	50.0

If the patient had previously answered questions on SIB, 98% would be likely to report SIB honestly using electronic self-report assessments, 96% in-person, if they knew the HCP, and 91.5% if they didn’t know the HCP. These numbers did not change significantly when selecting only those patients with depression; 96% would be honest using electronic self-report, 96% in-person with an HCP they knew, 93% with an HCP they did not know (Figure 2).

82% of respondents reported that they were comfortable using technology. Only 6 (out of 87) respondents reported never using technology (Figure 3). Among those who were comfortable with technology 41% reported that they would prefer to answer questions on SIB electronically.

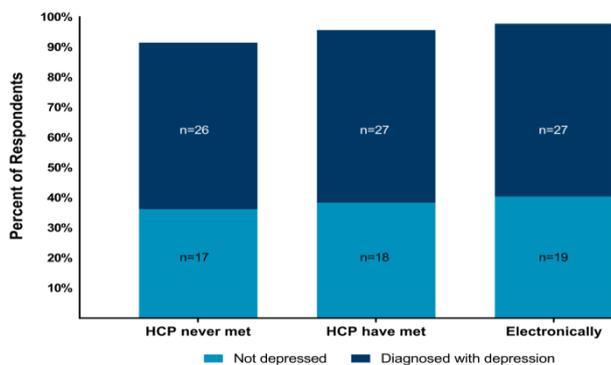
Most respondents felt they would be comfortable and truthful answering questions about having thoughts of suicide or self-harm; 67% electronically, 55% with a

healthcare professional. While many felt they would be uncomfortable, but would answer truthfully; 41% with a healthcare professional, 31% electronically (of the 30 who would be uncomfortable but truthful with a healthcare professional, 11 (37%) would be comfortable and truthful electronically) (Figure 4). There were no significant differences in preferences for reporting SIB electronically versus an HCP between men and women (Figure 5). In general, regardless of age group, most respondents indicated that they would be likely to report SIB under each of the conditions. In addition, when broken down by Alzheimer’s disease, Mild Cognitive Impairment or other Dementias, patients reported similar preferences for reporting SIB electronically and with a known HCP. However, while only 16 patients with Alzheimer’s Disease responded to the survey, the percent of those who would likely report SIB honestly either electronically or with a known HCP dropped from 94% to 81% when asked if they would report SIB honestly to an health care provider they did not know. Of the 42 patients with mild cognitive impairment, 98% indicated they were likely to be honest with a known HCP, but 90% were likely to be honest about SIB with an HCP they never met (Table 2).



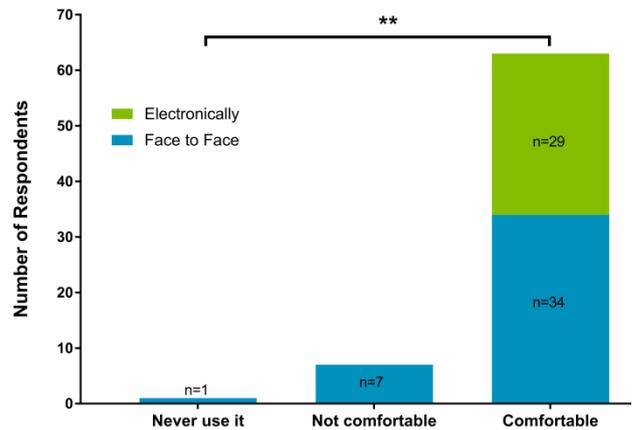
**Figure 1: The number of respondents who would honestly report their SIB.**

HCP=Healthcare provider; Cochran,  $Q_2=7.8$ ; \* $p=0.02$ ;  $N=73$ .



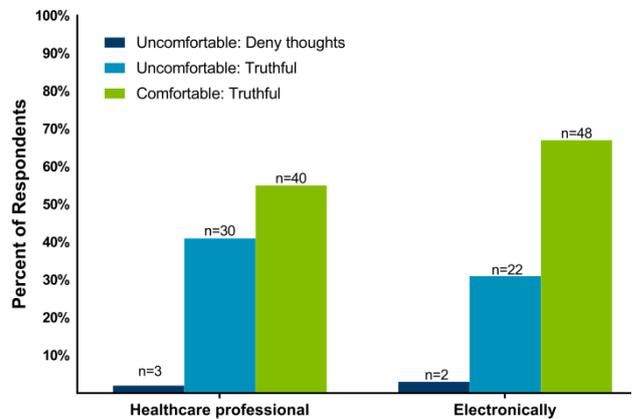
**Figure 2: The percent of respondents who had previously answered questions on SIB who would be likely to report SIB honestly; comparison of respondents diagnosed with depression and those without depression.**

No significant differences.



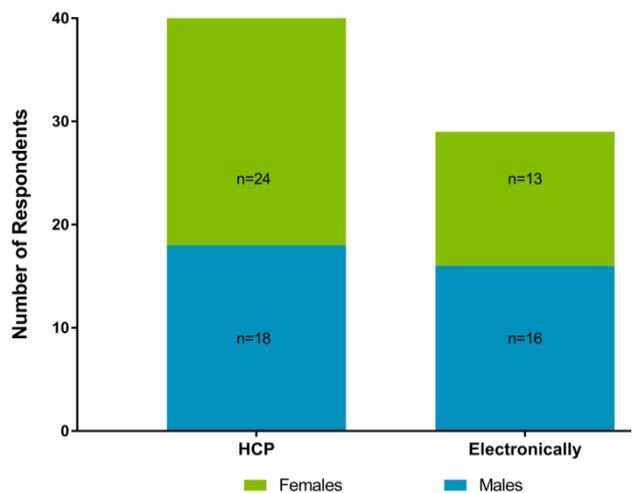
**Figure 3: Comfort using technology by those who would report SIB electronically compared with face to face with an HCP.**

$\chi^2_2=91.5$ ; \*\* $p<0.001$ ;  $n=72$ .



**Figure 4: The percent of respondents who would be comfortable and would answer questions about SIB honestly with and an HCP or electronically.**

No significant differences.



**Figure 5: Preference for responding to questions on SIB by gender.**

No significant differences.

**Table 2: Number of respondents likely to report SIB honestly.**

Diagnosis	HCP Never Met	HCP Have Met	Electronically
Alzheimer's disease	13/16	15/16	15/16
MCI	38/42	41/42	40/42
Other Dementia	9/11	10/11	10/11
Other Unknown	4/4	4/4	4/4

Of 9 patients who indicated that they were unlikely to honestly report SIB to an HCP they did not know, 7 indicated they would honestly report SIB to an HCP they know and 5 would electronically. Only 3 patients indicated they were unlikely to honestly report SIB to an HCP they do know, of those, 1 would be honest electronically. Only 2 patients indicated that they would not be honest under any of the 3 conditions, 2 who were not likely in electronic format or with an unknown HCP would be honest about SIB with a known HCP. And 1 patient felt that while they were not likely to be honest with a known HCP, they would be honest about SIB electronically or with a healthcare provider they never met.

## DISCUSSION

These data suggest that patients with cognitive conditions including Alzheimer's disease, mild cognitive impairment, and other dementias may be slightly more likely to truthfully report SIB using electronic self-report compared to a healthcare professional. Most were comfortable and they are similarly likely to report SIB using electronic self-report or in a clinical face to face interview with a known healthcare provider. However, significantly fewer would report SIB to a healthcare provider they had never met. This should be a consideration in clinical trial situations, where patients are interacting with healthcare providers who are unknown to them. It is important to note that, Luoma et al reported that on average 75% of those who do commit suicide had contact with their physician and 32% had contact with a mental health professional in the year prior to their suicide.<sup>10</sup> However, physicians often fail to ask their patients about suicide. Feldman et al designed a study to examine the roles of physician characteristics, patients' symptoms and patients' behaviors that impact whether physicians ask about suicidality during clinical visits.<sup>11</sup> They found that when not prompted, physicians asked about suicide less than 30% of the time. And, these same physicians asked about suicide in less than half of patients who had endorsed depression. Physicians may avoid asking about suicidality for a number of reasons; for example, they are afraid it will offend the patient, they are afraid they may increase the suicidal feelings by asking, or they may feel uncomfortable asking about a subject that has been considered "sinful" or a crime.<sup>11,12</sup>

Patients with cognitive conditions will honestly report their SIB if asked. However, if healthcare providers fail to ask about suicidality, patients may not volunteer that information. Electronic self-report of SIB is a strong and valid alternative method for identifying patients at risk for suicide.

Haw et al found a higher risk for suicide in patients with forms of dementia, such as Alzheimer's disease, shortly after diagnosis.<sup>13</sup> They identified risk factors for suicide that included depression, hopelessness, mild cognitive impairment, preserved insight, younger age and failure to respond to anti-dementia drugs. Taking into consideration the FDA guidance on suicidality and the potential for cognitive decrements in this population in conjunction with the increased risk for depression and suicidality, assessing depression and SIB should be a priority when treating or working with this population. Patients with Alzheimer's disease, MCI or other dementias should be assessed for SIB regularly. Assessment of SIB, whether by direct questioning from a healthcare provider or through electronic assessment is critical in these patients. While the ability to eliciting honest reports of SIB in cognitively compromised patients using electronic format and through direct inquiry from a clinician are both effective, electronic self-report has a number of advantages. Electronic self-report offers the advantage of a simple method for addressing potential suicidality in a manner that is a low burden on the patient, additionally, reducing the burden of assessment for health care professionals in clinical use and for sites in clinical trials that need to monitor treatment emergent suicidality.<sup>14</sup> Previously, we have shown that tools such as the electronic Columbia Suicide Severity Rating Scale (e-CSSRS) are not just sensitive and reliable, but may increase patient candor regarding SIB and allows for immediate follow-up through an active alert system.<sup>7,14</sup>

## CONCLUSION

Results of this current study demonstrate that people with Alzheimer's disease, mild cognitive impairment and other dementias are likely to report suicidality truthfully, regardless of whether they are reporting face to face with a clinician or through electronic self-report. However, if the clinician does not ask about SIB during an exam, the patient may not volunteer that information and any suicidal thoughts or behaviors could easily be missed. Use of an electronic self-report assessment for SIB could alleviate the burden of inquiry for clinicians. Additionally, prospective monitoring of SIB symptoms in cognitively compromised patients using an electronic self-report system could help identify and track patients at risk for suicide and potentially prevent suicide attempts.

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