

Final Report
2016

Consumer Satisfaction with Aging & Disability Resource Connection of Oregon: Round 5

Part 6. Confusion and Memory Loss: The ADRC Experience

Submitted to
Oregon State Unit on Aging, Department of Human Services



Diana L. White, PhD
Sheryl Elliott, MUS



Consumer Satisfaction with Aging & Disability Resource Connection (ADRC) Services: Round 5

Diana White and Sheryl Elliott
 Portland State University Institute on Aging
 April 2016

Part 6 of the ADRC consumer satisfaction survey report focuses specifically on comparisons between participants who indicated they or a family member had an issue with confusion or memory loss (CML) and those who did not. This focus was added in Round 4. Although CML has been listed as a possible reason for contacting the ADRC in all rounds of data collection, participants were asked explicitly in 2014 (Round 4) if they, or their family member, had experienced more or worse confusion or memory loss during the past 12 months. If they said yes, they were asked if they or the family member they were calling about had a diagnosis of dementia. In this report, we compare responses between those with and those without issues related to confusion and memory loss across Rounds 4 and 5.

Table 6.1. Participants reporting Confusion or Memory Loss (CML)

	CML – reason for contacting ADRC <u>and/or</u> CML increased over 12 months	CML as reason for contacting the ADRC ^a	CML happening more ^a	Alzheimer’s or related dementia diagnosis	CML, but cause unknown
2014	n=123; 41% of all participants	n=64 (52% of CML group)	n=108 (88% of CML group; 35% of total sample)	n=26 (21%)	n=97 (79%)
2015	n=138; 44% of all participants	n=78 (56% of CML group; 25% total sample) 17 said yes to this, but not to CML happening more	n=121 (88% of CML group; 38% of total sample) 60 said yes to happening more, but not need	n=35 (30% of CML group) 11% of total sample	n=83 (70% of those with need or observed)

As shown in Table 6.1¹, the percentages responding “yes” to either or both questions related to CML were slightly higher in 2015 (41% in 2014; 44% in 2015). As described in Part 1, about 25% of the total sample indicated CML was a reason for contacting the ADRC, a consistent response over time. A higher percentage of participants overall reported that confusion or memory loss was experienced more or was getting worse over the past 12 months; 35% in 2014 and 38% in 2015. Sixty-one participants answered “yes” to both questions. Of those describing worsening CML, 35 participants (25% of those with CML and 11% of the total sample) reported a diagnosis of Alzheimer’s disease; which is a greater percentage

¹All tables presenting Round 5 data are in Appendix B.

than was found in 2014. It is possible that rates of diagnoses is increasing; however, these rates will need to be followed over time in order to establish a trend. As in 2014, the causes of CML for most of the 2015 participants is unknown.

Participant Characteristics

As displayed in Table 6.2, the CML and no-CML samples were similar in terms of age and gender, although participants in the no-CML sample were slightly older and more likely to be women. Median education and income levels fell within the same range across the two groups and participants were predominantly White.

As in 2014, family members were much more likely to report concerns about CML than consumers were to describe themselves having CML issues. The percentage of family members with CML concerns increased from 61% to 68% in 2015. It is important to note, however, that there were fewer family members in the 2015 CML group than consumers.

Table 6.2. Sample Characteristics Related to Confusion or Memory Loss – 2015

Circumstances	Total Sample (n=314) ^a			
	Confusion or Memory Loss (n=138)		No Confusion or Memory Loss (n=176)	
	Consumer	Family	Consumer	Family
Number	80	58	149	27
Women	51 (64%)	39 (67%)	103 (69%)	19 (70%)
Mean Age ^b	61 years	61 years	63	56
Age Range	19-87	29-89	16-95	16-74
Median Education	Some college or post-secondary education	Associates or technical degree	Some college or post-secondary education	Associates or technical degree
Median Income	\$10,000 - \$20,000	\$40,000 - \$50,000	\$10,000 - \$20,000	\$40,000 - \$50,000
Number/Percent White	67 (84%)	52 (90%)	132 (89%)	24 (89%)

^a14 participants from the total sample did not answer the two questions related to memory loss and are not included in these analyses.

Consumers with CML were significantly more likely to report receiving options counseling (OC) with a home visit (30%) than consumers without CML (19%; Table 6.3). In 2014 these percentages were 34% and 32% respectively. No statistical differences in use of OC were noted for family members of those with and without CML. About half of those with an Alzheimer’s or dementia diagnosis received OC services (with or without home visits) and another 21% reported having a home visit. About 30% of consumers and family members reporting CML did not receive OC or home visits at the time of the survey. Conversely, most consumers (52%) and a large segment of family members (42%) in the no-CML group received Call Center services only. Note that the total numbers in Table 6.3 do not match the total

numbers in Table 1.4 (see Appendix B) because not all participants answered questions about CML. The distribution of responses, however, is almost the same.

Table 6.3. Sample by Options Counseling and Home Visit Categories - 2015

	Confusion, Memory Loss		No Confusion, Memory Loss		Total
	Consumer (n=79)	Family (n=58)	Consumer (n=149)	Family (n=26)	
Options Counseling, home visit	24 (30%)	23 (40%)	28 (19%)	9 (35%)	84 (27%)
Options Counseling, no home visit	16 (20%)	8 (14%)	22 (15%)	2 (8%)	48 (15%)
Call Center consumer, home visit	16 (20%)	9 (16%)	22 (15%)	4 (15%)	51 (16%)
Call Center consumer, no home visit	23 (29%)	18 (31%)	77 (52%)	11 (42%)	129 (41%)
Total	79 (99%)	58 (101%)	149 (101%)	26 (100%)	312

Note: Percentages do not add to 100% due to rounding. Consumers with CML significantly more likely to receive options counseling ($p < .05$).

Needs. Sixteen reasons for contacting the ADRC were identified from open-ended questions during the first round of interviewing in 2011-2012; these are listed in Table 6.4 and have continued to provide an indicator of need in subsequent survey years. In 2015, participants in the CML sample reported a significantly larger number of needs (average = 5.81) than those without CML (average = 4.20), a pattern similar to 2014. In Round 5, most of these differences were explained by consumer responses rather than family responses. Consumers with concerns about CML were more likely than those without to contact the ADRC about physical health needs, personal care, getting help at home, getting shopping and errands done, and help moving into residential care.

In 2014, family members with concerns about CML were significantly more likely than consumers with CML issues to contact the ADRC for general information and for help with caregiver respite. However, in 2015, both family members and consumers with CML concerns were significantly more likely to contact the ADRCs for these services.

In contrast to 2014, family members with CML concerns in 2015 were no more likely than those without CML concerns to contact the ADRC about needs related to physical health, personal care, or for assistance moving a family member into residential care. This may be due to the overall physical frailty of consumers supported by family members in 2015.

In 2015, family members with CML concerns were more likely to have contacted the ADRC about the need for food stamps than those without CML concerns. This is somewhat curious and is different than previous report findings. No differences were noted in the need for food stamps and energy assistance among consumers reporting CML concerns or no CML concerns.

It appears the 2015 sample of family members were supporting those with more needs overall than in previous samples. This finding may reflect the higher proportion of OC consumers in the Round 5 sample, and the service needs of the rapidly increasing aging population.

Table 6.4. Reasons (Needs) for Contacting the ADRC

Service Type	2014		2015	
	Confusion, Memory Loss (n=123)	No Confusion, Memory Loss (n=174)	Confusion, Memory Loss (n=138)	No Confusion, Memory Loss (n=171)
General information/advice ^a	92 (75%)	117 (68%)	109 (80%)	103 (59%)
Physical health needs ^b	81 (66%)	99 (57%)	40 (29%)	76 (43%)
Help at home (making meals, housekeeping, laundry, yard work) ^c	68 (55%)	72 (41%)	73 (53%)	65 (37%)
Help getting food stamps ^d	29 (24%)	58 (34%)	28 (20%)	62 (36%)
Help with Medicaid or paying for medical care	50 (41%)	64 (37%)	58 (43%)	59 (34%)
Help with personal care ^b	62 (50%)	56 (32%)	65 (47%)	47 (27%)
Help with transportation	56 (45%)	56 (32%)	54 (39%)	58 (33%)
Help with medications	20 (27%)	38 (27%)	36 (26%)	35 (20%)
Help paying for energy bills	23 (19%)	34 (20%)	15 (11%)	41 (24%)
Help getting caregiver respite ^a	28 (23%)	24 (14%)	43 (32%)	14 (8%)
Dental care	25 (20%)	28 (16%)	18 (13%)	29 (16%)
Help getting shopping and errands done ^c	52 (42%)	50 (29%)	49 (36%)	43 (25%)
Help with housing: home modification	20 (16%)	18 (10%)	21 (15%)	21 (12%)
Help with housing: Finding subsidized housing ^c	17 (14%)	19 (11%)	28 (20%)	27 (15%)
Help moving into residential care ^b	21 (17%)	11 (6%)	30 (22%)	15 (9%)
Total number of needs (average) ^e	5.94	4.48	5.81 (SD 2.83)	4.20 (SD 2.40)

^a All participants with CML concerns were significantly more likely to report these needs than those without CML in 2015; this was true for family members but not consumers in 2014.

^b Consumers with CML concerns were significantly more likely to report these needs than those without CML concerns; this was opposite in 2014 when family members of those with CML concerns were more likely to report this need.

^c Consumers with CML concerns were significantly more likely to report these needs than those without CML concerns; no differences were noted in 2014.

^d Family members without CML concerns in 2015 were significantly more likely to report this need than those without; these needs are generally identified more often by consumers without CML.

^e Overall, those with CML concerns reported significantly more needs than those without CML, consistent with 2014.

Pathways to the ADRC

Contact with the ADRC. As in 2014, no significant differences were found between CML and no-CML samples with respect to how they learned about the ADRC (see Table 6.5). However, within the CML sample (n=124), participants were most likely to have learned about the ADRC through a referral from another agency (39% for consumers and 29% for family). This finding represents an increase from 2014 (32% of consumers and 21% of family members), and may be an indicator of increasing referrals to the ADRC from other agencies' staff who have concerns about people with CML.

Table 6.5. How did you first learn about the ADRC?

	2014		2015	
	Confusion, Memory Loss (n=116)	No Confusion, Memory Loss (n=160)	Confusion, Memory Loss (n=124)	No Confusion, Memory Loss (n=164)
Referral from another agency ^a	32 (28%)	35 (22%)	43 (35%)	60 (37%)
Friend	12 (10%)	24 (15%)	11 (9%)	20 (12%)
Hospital/clinic/doctor/nurse	12 (10%)	20 (12%)	10 (8%)	15 (9%)
Family ^b	14 (12%)	18 (11%)	19 (15%)	13 (8%)
Nursing home/assisted living	3 (37%)	3 (2%)	-	-
Phone book	--	3 (2%)	2 (2%)	6 (4%)
Recommendation/word of mouth	2 (2%)	2 (2%)	11 (9%)	17 (10%)
Brochure/flyer	6 (5%)	5 (3%)	5 (4%)	3 (2%)
Media/newspaper/TV/radio	1 (1%)	4 (2.5%)	1 (<1%)	5 (3%)
Internet	9 (3%)	7 (4%)	8 (6%)	11 (7%)

Both those with and without CML were most likely to have their first contact with the ADRC by telephone. In contrast to 2014, however, the percentage of those without CML having first contact by phone was somewhat higher for both consumers and family members than for those with CML (Table 6.6). Family members (66%) in 2015 were more likely than consumers (54%) to report first contact to be by telephone, but the difference was not as great as in 2014, when 81% and 56% respectively contacted the ADRC this way. In 2015, both Consumers with CML (20%) and family members reporting CML (26%) went to the ADRC office as the first contact, an increase from 2014 when percentages were 16% and 4% respectively. As in 2014, consumers with CML were more likely to report that the ADRC first contacted them: 19% of consumers compared to 5% of family members in 2015. The percentages for consumers who reported that the ADRC contacted them was the same in both years, but was lower for family members in 2015.

Table 6.6. How did you first come in contact with the ADRC?

	2014		2015	
	Confusion, Memory Loss	No Confusion, Memory Loss	Confusion, Memory Loss	No Confusion, Memory Loss
By telephone ^a	77 (66%)	97 (56%)	80 (59%)	109 (63%)
Went to the office, in person ^b	13 (11%)	31 (19%)	31 (23%)	40 (23%)
They called me ^c	18 (15%)	16 (10%)	18 (13%)	16 (9%)
Through the website	1 (<1%)	1 (1%)	2 (2%)	3 (2%)
Other (please specify)	8 (7%)	20 (12%)	4 (3%)	4 (2%)

^aFamily in the no-CML group in 2015 were more likely to report first contact was by phone.

^bFamily members and consumers with CML in 2015 went to the ADRC office as a first contact than those without CML

^cConsumers in 2015 were more likely to report that someone from the ADRC called them.

No statistically significant differences were found with respect to the phone being answered by a person among those with or without CML. Regarding a return call, consumers with CML were more likely to report a longer wait for a call back, but the difference was not statistically significant. No differences were found between groups with respect to ever going to the ADRC building or ease of finding it.

Information and Referral/Assistance (I&R/A)

Participants were asked whether the person they worked with at the ADRC spent enough time with them to understand their concerns. As reported in Part 3 of this report, the vast majority answered affirmatively. In 2015, consumers with CML concerns were significantly less likely than those without CML concerns to agree that the ADRC person spent enough time with them, 85% compared to 93%. No differences were noted by family members with or without CML concerns.

Similarly, both groups reported receiving written materials relevant to their concerns at similar rates. Ratings of staff attributes also were similar, including those for being knowledgeable and respectful.

Options Counseling (OC) or Home Visit Recipients

Ninety-six (71%) of the survey participants in the CML sample received options counseling and/or a home visit (Table 6.3). This percentage was significantly greater than those reporting no CML (30%). The difference in the 2015 sample was greater than in 2014 (67% and 50% respectively) and is accounted for mostly by differences in consumer responses. As in 2014, those with a diagnosis of Alzheimer’s disease were no more likely to receive OC or home visits than those without.

Those who received options counseling or reporting that they had received a home visit were asked questions specific to home visits, their understanding about services, decision support, and perceived outcomes.

Home visits. As in 2014, those in the 2015 CML sample were significantly more likely to receive a home visit than those in the no-CML sample. Over half of participants in the CML sample, including both consumers and family members, reported a home visit. In contrast, a greater percentage (50%) of family members in the no-CML sample reported home visits compared to 34% of consumers in the no-CML sample.

Consumer reports on length of time from talking with someone in the ADRC to having a home visit were similar for both those in the no-CML and CML groups. Family members did report significant differences, with 68% of family members of those with dementia waiting 3 or more days for a home visit, compared to 27% of the no-CML group waiting that long. Family members in the CML group were significantly more likely than family members in the no-CML group to indicate that a family member was present during the home visit. No significant differences were found in either family or consumer groups between the no-CML and the CML group assessments concerning whether the wait was prompt, reasonable, or too long. Similarly, no differences were found regarding helpfulness of the home visit, or whether the person who did the home visit identified additional needs.

Decision Support and Outcomes.

Few differences were found between those with and without CML with respect to decision support. Both groups found staff to be helpful in listening to their needs, providing information needed to make decisions, helping to explore options, and supporting decisions made by the consumer. Not surprisingly, however, significant differences were found with respect to control over the decision making process. Those with CML reported that they had less control in actually making decisions than those without CML concerns.

Similarly, no significant differences were found in participant-reported outcomes between the two groups (Table 6.7). Although mean scores were typically lower for the CML versus the no-CML group, none reached statistical significance. This finding is different than was reported in Round 4 when differences between the no-CML group and those reporting CML concerns did show some significant differences.

Public Programs and Assistance

Those with and without CML received similar numbers of, and types of services. They also had similar responses with respect to the overall timeliness and helpfulness of services.

Table 6.7. Outcome measures

	2014		2015	
	Confusion, Memory Loss (Mean, SD)	No Confusion, Memory Loss (Mean, SD)	Confusion, Memory Loss (Mean, SD)	No Confusion, Memory Loss (Mean, SD)
The services or information received have allowed me to live in the place I most desire.	3.04 (.916)	3.20 (.741)	3.17 (.862)	3.14 (.807)
I am receiving enough support to meet my needs and preferences	2.72 (.974)	2.97 (.738)	2.90 (.954)	2.94 (.842)
I believe I am more independent as a result of the information and services I received	2.67 (.928)	3.04 (.752)	2.95 (.917).	3.03 (.772)
I believe I am safer in my home as a result of the information and services I received	3.03 (.903)	2.97 (.694)	3.08 (.884)	3.04 (.835)
The services or information received have allowed me to expand or maintain activities outside of my home	2.57 (.947)	2.73 (.775)	2.75 (.940)	2.87 (.767)
The services or information received have helped me make the most of personal money and resources	2.76 (.806)	2.73 (.725)	2.75 (.898)	2.77 (.826)
I was eventually able to find help that I could afford	2.85 (.923)	2.91 (.771)	2.77 (.72)	2.83 (.904)
Total Outcome Score	2.51 (.825)	2.71 (.696)	2.53 (.904)	2.58 (.832)

Note: 1=strongly disagree, 2=disagree, 3=agree, 4 = strongly agree; unlike in 2014, no significant differences were found on these measures between participants who reported CML and those who did not.

Circumstances without the ADRC

For the most part, the pattern of responses to the question “What would your circumstances be without the ADRC?” did not differ significantly by CML status (Table 6.8). Across the CML and no-CML groups, two-thirds reported that they would be worse. A higher percentage of those with CML issues did indicate they would be worse financially without the ADRC than those with no CML issues. They were also even less likely to report a negative experience with the ADRC.

Table 6.8. What do you think your circumstances would be now if you had not received information or services through the ADRC?

	2014		2015	
	Confusion, Memory Loss	No Confusion, Memory Loss	Confusion, Memory Loss	No Confusion, Memory Loss
Worse	65%	61%	68%	68%
Worse emotionally	7%	11%	8%	10%
More difficulty with basic needs	28%	16%	17%	19%

Worse physically	11%	7%	8%	9%
Worse financially	9%	17%	24%	17%
A lot worse: general	4%	11%	7%	8%
A lot worse: would be homeless	2%	3%	2%	3%
Neutral, no difference	21%	33%	23%	26%
Negative ADRC experience; things worse	<1%	8%	2%	6%

Consumer Recommendations and Overall Satisfaction

No significant differences were found between the CML and no-CML groups with respect to ratings of overall helpfulness of the ADRC or in identifying concerns that had not been addressed. Although only 22 people (7%) of the total sample indicated that they would not recommend the ADRC to a friend or family member, two-thirds of these participants were in the CML group.

Conclusions and Recommendations

In 2015, more consumers and family members reported an issue with confusion or memory loss (CML) than participants did in 2014. This may be explained by the greater proportion of participants who were receiving OC services (42% in 2015, compared to 34% in 2014). This may also be a result of extensive outreach efforts to support this population in recent years. Those with CML were more likely to have OC services with home visits. Thirty-five of those in the CML group (30%) had received a diagnosis for Alzheimer’s disease, an increase over 2014. We do not know whether others without a diagnosis had been assessed for cognitive impairment. Presence of a diagnosis of Alzheimer’s disease was not related to service use.

As in 2014, family members were more likely to report a CML issue than consumers; 2/3 of family members surveyed indicated they contacted the ADRC because of CML and/or that they had observed increasing difficulties with CML over the past year, compared to about 1/3 of the consumers. The greatest numbers of those reporting CML issues came from the consumer group. This is not surprising given that almost 75% of the total sample was composed of consumers.

The CML group, especially consumers, identified more needs overall than the no-CML group. The CML group also called the ADRC to get general information and caregiver respite at higher rates than the no-CML group. This was true for both family and consumers. Most differences between CML and no-CML responses, however, were accounted for by consumers. For example, consumers (but not family members) in the CML group were more likely to be calling about physical health, personal care, or for assistance moving into residential care. They

were also more likely to report learning about the ADRC from another agency or that someone from the ADRC contacted them first. This likely reflects high levels of physical and cognitive impairment in the people family members were supporting. Consumers in the CML group were significantly less likely to feel they were in total control of their decisions, but they were more likely to report that someone from the ADRC helped them develop a plan listing their own goals and next steps.

In spite of these differences, the two groups had more similarities than differences. With the exception of OC, the numbers and types of services actually received reported by participants was similar for the CML and no-CML groups. The two groups gave similar ratings with respect to the timeliness of receiving services and the helpfulness of those services. Most responses to questions about staff attributes, decision support, and outcomes (including assessments of what their circumstances would be without the ADRC), and overall satisfaction were also similar.

Recommendations

- Be prepared to talk with consumers and especially family members about confusion and memory loss.
- When those calling the ADRC have specific questions about confusion and memory loss, encourage them to obtain a complete medical checkup.
- Be knowledgeable about person-centered support services for people with dementia.
- Incorporate questions about confusion and memory loss into conversations with those who contact the ADRC. Ask if there has been a diagnosis of Alzheimer's disease (AD) or a related disorder and encourage those who haven't to talk with a healthcare provider about their confusion and memory loss.
- Prioritize options counseling for those who report CML (include both consumers and their family caregivers), especially if they have a diagnosis of AD or a related disorder.
- Explore reasons why those with CML generally, and those with a diagnosis of AD specifically, are not getting more services than those without CML. Many needs identified were for ADL, IADL, caregiver respite, and assistance with transition to residential care settings. Identify gaps in services that need to be addressed to assure that those with CML get those services in a timely way.
- Maintain and enhance efforts to develop action plans and follow up with those with CML. Continue to help those with CML to complete paper work for services. Consider additional resources which simply and clearly provide information and direction to those with CML so that they know what they can do to get help if needed.
- Continue to listen, provide person-centered decision support, and share knowledge with this population regardless of their cognitive status.