

## Readability of advance directive forms and health literacy in Canada: missing the mark

Alby Richard<sup>1</sup>, Wendy Johnston<sup>2</sup> & Janis Miyasaki<sup>2</sup>

<sup>1</sup>Montreal Neurological Institute, McGill University & <sup>2</sup>University of Alberta Department of Neurology

Medical language is frequently not understood by the public. *Health literacy* broadly refers to the degree to which individuals have the capacity to process and understand basic health information in order to make appropriate health decisions. In Canada, health literacy depends on a number of factors including place of birth, education level, socioeconomic status, language spoken (English versus French), and geographical location (1). Low health literacy is associated with fewer health-promoting behaviors, poorer health status, and higher rates of hospitalization and health care costs (2). Health literacy is an important prerequisite for patient autonomy. Once information is received and internalized, the person must be able to articulate individual preferences and goals for healthcare interventions. Perhaps the most crucial time for comprehension of medical information and assurance of patient autonomy occurs at the time of completion of an advance directive. This process is essential in order to document an individual's wishes in the event that they are not able to speak for themselves. The most commonly used types of ADs in Canada are provincially or territorially mandated forms. While institutional templates and individually drafted forms are also used, at the present time there is no federally prescribed AD documentation available.

Many of the same factors that influence health literacy also affect the completion of ADs. Pertinent among these is education level (3), with the highest rates of AD completion seen in those that have completed high school (4). Moreover, people who rate their health as fair or poor have the lowest levels of language proficiency and general health literacy (5). To put this further into context, it is known that the average reading level, comparable in the United States (US) and Canada, is in the range of 8<sup>th</sup> grade or lower (9). Considering this, it is perhaps not surprising that many studies demonstrate that patient materials (including informed consent forms, educational materials, and AD forms) are virtually incomprehensible for the majority of adults (6; 7). The Canadian Council on Learning (CCL) reports that "60% of adults in Canada lack the capacity to obtain, understand and act upon health information and services and to make appropriate health decisions on their own" (8).

Based on these findings, the National Work Group on Literacy and Health in the US recommended that health care documentation be written at a 5<sup>th</sup> grade reading level (9). However, a large portion of health information materials are written at a level that exceeds the reading skills of the average high school graduate (10). This discrepancy is especially

1  
2  
3 concerning in the context of ADs for several reasons. First, it is increasingly recognized that  
4 the shifting demographic profile in Canada (by 2056, 25-30% of Canada's population will be  
5 above 65 years of age) is contributing to increased health services demands (11). For  
6 instance, as the population ages, upwards of 75% of men and women will suffer from at least  
7 one chronic condition (12). It is therefore of paramount importance to identify and correct  
8 any barriers that may prevent ailing individuals from being able to communicate their wishes in  
9 a timely and unambiguous manner. Ensuring proper access to understandable policy and  
10 documentation regarding personal health is essential for effective health care delivery, and  
11 also constitutes an important feature of patient autonomy. A recent analysis of government-  
12 sponsored AD forms in the US reported an alarming discrepancy between their readability  
13 and the average literacy level of adults (9). In Canada, to our knowledge, no such analysis  
14 has been performed for available AD documentation across all provinces and territories.

15  
16 We therefore compiled all available documentation from provincial and territorial  
17 websites regarding ADs, in addition to palliative care and hospice websites with provincial  
18 resources<sup>1</sup>. In total 13 such documents were identified, varying in format between standard  
19 goals of care forms to fillable personal directives and brochures on how to make an AD. Each  
20 form was subjected to readability analysis using the Flesch-Kincaid scale, which is widely  
21 used and has proven reliability (7). This scale identifies a reading level between 0 and 19 for  
22 the text analyzed, where the score is inversely proportional to reading ease. For example, a  
23 score of 7 on the Flesch-Kincaid scale indicates that the text is written at a 7<sup>th</sup> grade reading  
24 level. One-sample *t* tests were used to compare mean readability scores using the Flesch-  
25 Kincaid scale with the average reading skill level of US adults, as in Mueller et al. (2010).  
26 The readability scores for all provincial and territorial forms analyzed are displayed in Figure  
27 1 (median: 9.40 [range 8.0-12.0]; mean: 9.62 [SD 1.45]). The average readability score of the  
28 AD documentation was significantly higher than both the recommended grade level [ $t(12) =$   
29 4.03,  $p=0.002$ ] and average reading level [ $t(12) = 11.47$ ,  $p<0.001$ ], with CI (8.74, 10.50).

30  
31 In agreement with a previous American study (9), these findings demonstrate that, on  
32 average, Canadian AD forms exceeded the recommended readability level of the National  
33 Work Group on Literacy and Health, and the average reading skill of adults in the US and  
34 Canada. These results are important because incomprehensible AD forms undermine patient  
35 autonomy by limiting their ability to express their goals and preferences for future care.

---

36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
<sup>1</sup> The Google search engine was used with such keywords as *advance directive*, *living will*, and *power of attorney* for health care were used, along with the province's name. The websites identified by the search engine were examined, and AD forms that met the legal criteria for the respective jurisdictions were used.

1  
2  
3 Health care in Canada is provincially/territorially adjudicated, and governments fall short of  
4 their fiduciary responsibilities when they fail to provide comprehensible AD forms for  
5 citizens. This problem is tractable however, and the provision of forms that are in line with  
6 the reading level of the population is likely to not only increase engagement, but also promote  
7 health literacy at the same time.  
8  
9  
10

11  
12 *Words: 964/1000*  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Confidential

## References

1. Rootman I, Gordon-El-Bihbety D (2008). *A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy*. Ottawa : Canadian Public Health Association.
2. Committee on Health Literacy, Board on Neuroscience and Behavioral Health. *Health Literacy: A Prescription to End Confusion*. [ed.] Panzer AM, Kindig DA: Institute of Medicine in the National Academies Nielsen- Bohlman L. Washington: National Academies Press, 2004.
3. Hanson LC, Rodgman E (1996). *The use of living wills at the end of life: a national study.*, Arch Intern Med, Vol. 156, pp. 1018-1022.
4. Nishimura A, Mueller PS, Evenson LK, Downer LL, Bowron CT, Thieke MP, Wroblewski DM, Crowley ME (2007). *Patients who complete advance directives and what they prefer*. Mayo Clin Proc, Vol. 82, pp. 1480-1486.
5. Murray MD, Young J, Hoke S, Tu W, Weiner M, Morrow D, Stroupe KT, Wu J, Clark D, Smith F, Gradus-Pizlo I, Weinberger M, Brater DC (2007). *Pharmacist intervention to improve medication adherence in heart failure: a randomized trial*. Ann Intern Med, Vol. 146, pp. 714-725.
6. Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR (2005). *The prevalence of limited health literacy*. J Gen Intern Med, Vol. 20, pp. 175-184.
7. Paasche-Orlow MK, Taylor HA, Brancati FL (2003). *Readability standards for informed-consent forms as compared with actual readability*. N Engl J Med, Vol. 348, pp. 721-726.
8. Canadian Council on Learning (2008). *Health Literacy in Canada: A Healthy Understanding*. Ottawa : s.n., 2008.
9. Mueller LA, Reid KI, Mueller PS (2010). *Readability of state-sponsored advance directive forms in the United States: a cross sectional study BMC Medical Ethics*, BMC Medical Ethics, Vol. 11, p. 6.
10. Rudd, R., Kirsch, I, Yamamoto, K (2004). *Literacy and Health in America: A Policy Information Report*. Princeton, NJ : Educational Testing Service.
11. Statistics Canada (2009). Life expectancy, abridged life table, at birth and at age 65, by sex, Canada, provinces and territories, annual (years). CANSIM Table.
12. Schultz SE, Kopec JA (2003). *Impact of chronic conditions*. Statistics Canada. Ottawa: Health Reports, Vol. 14, No. 4, 2003. pp. 41-53.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

