

# Nutrition Education Needs and Resources for Dementia Care in the Community

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Nutrition problems and specifically weight loss are common in older adults with dementia living in the community. Study 1 involved interviews with 14 formal providers to identify the range of nutrition concerns they had experienced. In study 2, 74 Canadian Alzheimer Society chapters were surveyed by e-mail (23% participation rate) to determine nutrition concerns and education resources provided to clients. In all, 26 of these nutrition pamphlets or handouts were rated on content and format by 2 independent researchers using a standardized rating system. Common nutrition concerns identified in older adults with dementia living in the community include

safety, weight loss, forgetting or refusing to eat, appetite, dysphagia, and unfavorable eating behaviors. Most resources provided to clients were considered low quality and did not match the nutrition concerns expressed by formal providers. Currently, there is a considerable knowledge translation gap around nutrition and dementia, and this study provides a basis for the future development of nutrition education resources.

**Keywords:** nutrition; education; community; dementia; caregivers

**M**alnutrition is a common problem in older adults with dementia<sup>1,2</sup>; weight loss predominates and occurs throughout the disease process.<sup>3-5</sup> Malnutrition and specifically being underweight or losing weight are associated with death and institutionalization<sup>6,7</sup> and increased informal caregiver stress.<sup>8,9</sup> Malnutrition is thus a relevant issue, and its management is important to the health and quality of life of persons with dementia.

Although the exact cause for weight loss is difficult to pinpoint,<sup>3-5</sup> appetite, food preferences, sensory

changes, swallowing difficulties, and challenges with self-feeding difficulties have been shown to lead to compromised nutritional status in persons with Alzheimer disease and related dementias (ADRD).<sup>2,10-14</sup> As the disease progresses, food intake is influenced by the occurrence of unfavorable feeding behaviors such as resisting eating (eg, throws food, turns head away from spoon), dyspraxia (eg, loss of ability to perform coordinated movements), use of fingers instead of utensils, eating nonedibles, and wandering away from table.<sup>8</sup> The occurrence and progression of these feeding behaviors are related to increased caregiver burden.<sup>8</sup> As the prevalence of ADRD increases, it is imperative to address these nutrition issues for persons with dementia and their family partners to maintain independence, optimal health, and quality of life for as long as possible.

Although education of informal caregivers has been identified as an important aspect of addressing care needs of older adults with dementia,<sup>15</sup> nutrition education research in persons and families experiencing dementia is scarce. Silver and Wellman<sup>16</sup>

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identified that informal caregivers (not specific to dementia) had poor nutrition knowledge and could only recognize signs of gross malnutrition in the person for whom they were caring. Wackerbath and Johnson<sup>17</sup> interviewed 28 families of persons with dementia to better understand their support and educational needs. They found that the most common source of information for these families was the Alzheimer Association, followed by health care workers, social workers, family members, day program workers, friends, siblings, clergy, and support groups. A recent randomized control trial<sup>18</sup> identified that informal caregivers and their family members with dementia benefited from a nutrition education intervention. In all, 9 nutritional sessions of 1 hour each over a 1-year period were provided by a dietitian or other health professional.<sup>18</sup> This intervention promoted weight maintenance or increases in weight, prevented depression, and reduced caregivers' stress. In addition, caregivers reported being more relaxed when dealing with behavioral problems, especially feeding problems.<sup>18</sup> This limited research suggests that nutrition education is needed and that high-quality education can benefit informal caregivers and persons with dementia.

The mandate of Alzheimer Societies and Associations includes the education of the public and persons with dementia and their family partners in care. Education is focused on the disease process and issues associated with caring for someone with dementia. Much of the material provided by these societies is in print form, available in hard copy, or available on the internet. Currently, it is unknown what nutrition education resources are needed and are being provided by these societies to meet the nutritional needs of their clients. Additionally, it is unknown if print materials follow adult education and literacy principles that promote understanding and knowledge transfer. This study was designed with the following purposes: (a) to explore the range of nutrition concerns and thus education needs of informal and formal care providers of persons with dementia and (b) to evaluate print resources currently provided to informal caregivers in Canada by Alzheimer Society chapters.

## Methods

In all, 2 separate data collections were completed to address the research purposes. Study 1 involved

semistructured interviews with formal providers to elicit their perceptions of informal and formal care partner nutrition education needs. The primary objective of this study was to identify the types and range of concerns. Study 2 identified (a) frequency of nutrition queries and types of nutrition queries posed and (b) the print resources commonly provided to informal caregivers by Alzheimer chapters in Canada. These resources were rated on design quality and style, which could influence use of the resource. Gaps in nutrition education materials based on the known nutrition concerns with this group were identified.

### Study 1

Qualitative research methods were used to identify perception of education needs of informal and formal care providers of persons with dementia.<sup>19,20</sup> Formal providers were interviewed as they have extensive experience interacting with and hearing nutrition concerns of many families. Such providers can be accurate reporters of the needs of a specific client group.<sup>21</sup> Participants (n = 14) were recruited through e-mails and cold calls to Alzheimer Society chapters, senior day programs, and other various contacts in the community in southwestern Ontario. A diverse group of participants was specifically recruited as families experiencing dementia solicit informational support from various sources. Purposive sampling was used to identify professional groups working in the area of dementia. Sampling and data collection continued until no new information was being identified in the interviews. Data on education background, experience, and extent of dementia practice were collected. The key informants had been working with clients with dementia for various lengths of time, ranging from 1.5 to 27 years, with a median of 15.2 years. The professional positions of the care providers also varied from Executive Director of an Alzheimer Society chapter (n = 1), Public Education or Resource Coordinators at chapters (n = 4), day program staff (n = 3), registered dietitian (n = 1), social worker or counselor (n = 2), clinical resource worker (n = 2), and family support worker (n = 1). Each participant saw an average of 40 clients with dementia per month.

Interviews were conducted by a single researcher. A semistructured interview guide was developed and used during the interviews, which lasted approximately 30 minutes. Questions focused on nutrition and eating issues (Appendix A) that formal caregivers

had experienced in helping families manage dementia. Prompts were provided specific to the question on types of nutrition concerns of informal and formal care partners. The focus of this question was on the range of nutrition concerns, which may indicate an educational need, rather than the frequency or intensity of requests for this information. A total of 12 interviews were conducted via telephone and 2 were done in-person. Detailed notes were taken during the interviews by the interviewer. Audio taping and transcription of interviews were not considered necessary due to the focused nature of the questions and the use of basic content analysis to identify common nutrition concerns and education gaps. Thematic analysis focused on identifying key concerns or issues and key words.<sup>22</sup>

## Study 2

A questionnaire was developed and faxed or e-mailed to Alzheimer Society chapters in 9 provinces to determine frequency of nutrition questions posed to staff, content of these questions, and resource use; Quebec was not included in the survey due to language barriers. Contact information was solicited from provincial offices by directly telephoning the chapter and by searching Web sites. Some provinces (eg, British Columbia) lacked contact information for some chapters, and many provinces had only a few chapters available for recruitment. In total, 74 chapters were mailed a questionnaire (British Columbia = 15, Alberta = 8, Saskatchewan = 2, Manitoba = 5, Ontario = 39, Prince Edward Island = 1, Nova Scotia = 1, Newfoundland = 1, New Brunswick = 2).

The questionnaire consisted of open-ended and closed-ended questions. The questions determined the scope of service (eg, number of employees, number served per month, region covered) for the chapter, frequency and topic of nutrition questions directed to the chapter from people affected by ADRD, as well as asked the respondents to list the current nutrition resources provided to clients. Respondents were asked to report how many general and nutrition questions were asked per month (open-ended response). Using a checklist, content of these nutrition queries was attained. There was no attempt to determine the frequency of queries on a specific nutrition topics but rather to get the range of topics that society staff address with families. Respondent details were also collected. The questionnaire was pilot tested on 2 chapters, which assisted with question wording

and format. It was e-mailed or faxed ( $n = 6$ ) to the 74 chapters. After 2 weeks, a reminder e-mail or fax was sent to all chapters asking that they complete the questionnaire. Another copy of the consent or information form and questionnaire were attached. After 4 weeks from initial e-mail or fax, a final letter was sent asking for their help and thanking those who had already responded. Another consent or information form and questionnaire were attached to this final mail.

## Educational Resource Evaluation

To identify the quality of print materials currently provided to clients of Alzheimer chapters, 2 resource review checklists were developed based on basic principles of plain language and criteria regarding effective formatting and style for print material that promotes uptake of information.<sup>23-30</sup> Adult learning theory guided the focus of the evaluation as it describes how older adults learn. Older adults prefer to use their own experience and expertise and to learn about topics that are relevant to their own lives.<sup>31-32</sup> In the dementia and nutrition context, it is important that the resource builds on the older adults' experiences by including information from various cultures and foods common to the older adult generation.<sup>31-32</sup> Information should be specific to the disease (eg, nutrition issues experienced by people with dementia and their family partners in care) and be solution focused. Practical tips and limiting extraneous material are also consistent with this theory. A prior study rating print materials had developed checklists to standardize this process.<sup>33</sup> Using this as a basis,<sup>23-33</sup> 2 checklists were developed focusing on nutrition topics covered and adherence to plain language and adult learning principles (eg, depth of information, use of technical terms, clarity of words, use of concrete examples). Accuracy of content was not specifically reviewed as this was not the focus of this evaluation. However, expertise in authorship was used in the checklist as a proxy for credibility of the resource. The second checklist focused on writing style, organization, design, appearance, and comprehension components, consistent with plain language principles.<sup>23-30</sup> Writing style consists of components such as language, readability, and length of sentences. Organization examines flow, purpose, objectives, and overall clarity. The design and appearance looks at the font size, white space, and attractiveness of the document. Quality

**Table 1.** Comparison of Nutrition Concerns Between Family/Clients and Formal Providers (n = 14) (Study 1)<sup>a</sup>

	% of providers reporting family or clients had this concern	% of formal provider participants with this concern
Appetite	100	—
Safety with stove or with other cooking utensils	100	—
Weight changes	93	7
Food preferences	93	—
Refusing to eat or getting enough food	86	57
Food safety	86	—
Understanding nutritional needs	86	—
Unfavorable eating behavior	79	—
Swallowing problems	79	7
Overeating	79	—
Eating nonedibles	64	7
Difficulty with self-feeding	64	—
Fluid requirements	64	7
Coughing or choking issues	57	7
Vitamins	36	—
Supplements	36	7
Access to food	—	21
Meal preparation	—	14
Caregiver stress	—	36
Inadequate resources	—	7
Diabetes	—	7
Maintaining independence	—	21
Quality-of-life issues	—	7

<sup>a</sup> Semistructured interview question “What sorts of problems or questions arise from family care providers and seniors with dementia in the area of eating and nutrition?” was asked with standard prompts eliciting the nutrition areas.

design points on the checklists were not weighted in any manner; rather those who used the checklists used a star-rating system (Appendix B) to give an overall rating to the resource. Checklists were designed and evaluated for content with the research team but did not undergo external review for content validity.

Resources included in the evaluation had to meet the following criteria: (a) print material targeted at caregivers or persons with dementia, (b) an accessible, stand-alone resource (eg, pamphlet), and (c) focused on food intake or nutrition. Journal and paper articles, excerpts from books, and entire books were reported by Alzheimer chapters as relevant resources and were provided to families, but these were not included in

this review as their primary purpose was not education of the caregiver on a specific nutrition issue.

## Data Analysis

Closed-ended survey questions were analyzed using descriptive statistics such as simple counts of each category, percentages, medians, ranges, and standard deviation (SD) as required. Qualitative answers were described with basic content analysis (eg, number of times a common issue was identified or a common resource was recommended, suggestions for nutrition education). Materials that met inclusion criteria for review were obtained from local chapters. If a chapter had created the resource themselves, it was forwarded to the research team for review. A 5-star rating system was devised for overall rating the resources (Appendix C). Two researchers independently rated each selected resource, and intraclass correlation was calculated to determine the agreement on the 5-star rating.<sup>34</sup> Readability was analyzed using the simple measure of gobbledygook (SMOG) readability test.<sup>35</sup>

## Results

### Study 1

Several formal providers were concerned with inadequate and unbalanced food intake of clients (n = 8). Specifically, they were concerned that their clients have adequate access to food (n = 3) and were able to maintain independence with feeding (n = 3) and meal preparation (n = 2; Table 1). Participants identified that numerous nutrition issues prompted by the interviewer were the questions raised by their contact families. In decreasing order, these concerns were: decreased appetite and stove safety issues (n = 14), food preferences (n = 13), refusal to eat (n = 12), food safety (n = 12); understanding their nutritional needs (n = 12), unfavorable eating behaviors (n = 11; eg, turning away from food, resisting assistance, agitation), overeating (n = 11), swallowing problems (n = 11), eating nonedible objects (n = 9), difficulty with self-feeding (n = 9), and achieving adequate fluid requirements (n = 9). Family or clients were reported to have fewer concerns with coughing or choking issues (n = 8) and questions about vitamins (n = 5) and supplements (n = 5; Table 1).

The majority ( $n = 11$ ; 79%) of formal care providers used some form of written resource or information sheet to support the counseling interventions they provided to clients. Written resources used by participants included general handouts on mealtimes created by the Alzheimer Society of Canada, handouts on dining out, Canada's Food Guide to Healthy Eating, and handouts on simplified cooking. A few reported using the internet as a resource ( $n = 3$ ) and writing down specific tips or information for families and clients ( $n = 2$ ). When asked about what types of nutrition education resources participants would like to have available for families, the received answers were divided into 2 categories: comments referring to the format of resources and comments referring to the content of resources. In terms of the format, resources needed to be written for persons with dementia living alone and for family partners in care. Booklets that were concise and simply written with practical tips were considered most useful. Various potential nutrition topics were suggested, although only a few were offered by more than 1 participant. Topics included resources that address food preparation and mealtime preparation, the social and cultural aspects of eating, tips for maintaining quality of life, creative strategies for getting people to eat, the importance of the mealtime or dining experience, basic nutrition for seniors, food selection in the context of diabetes, swallowing disorders, food safety, and vitamin supplementation. Individual formal care providers reported various nutrition topics, which they personally wanted to learn. There was minimal consistency identified in the education needs expressed; however, all informants expressed a need for more information on nutrition and dementia. Additionally, they suggested that front-line staff required more nutrition education than that was currently provided.

## Study 2

The response rate for the e-mailed or faxed survey was 23% ( $n = 17$ ). The majority of respondents were from Ontario chapters (82%), followed by Alberta, Manitoba, and Newfoundland/Labrador (5.8% each). Respondents, primarily women (94.1%), had a University degree (47.1%) or postgraduate degree (17.6%), and had worked at their current chapter for 1 to 10 years (median 3 years). More than two-thirds of respondents (64.7%) had been in the field of

dementia for less than 10 years and almost a third (29.4%) for less than 4 years. Education disciplines included gerontology (29.4%), nursing (23.5%), and social work (17.6%). Chapter characteristics are not provided due to the low response rate to the survey and the large differences in resources between Ontario and the other provinces that responded.

There was considerable variance in the number of educational contacts provided by staff members from the 17 participating chapters, and readers are cautioned from drawing conclusions from these data. The number of clients who telephoned or visited the society to ask general questions of the staff in a month was a median of 50 (SD = 77.8) and 20 (SD = 21.3), respectively. Chapters noted a median of 10 (SD = 16.7) people per month visit the society to pickup educational material. Nutrition questions were relatively rare at a median of 1.5 (SD = 3.8) per month for these 17 chapters. Nutrition questions asked of staff by families centered around cooking safety, forgetting or refusing to eat, weight changes, appetite, vitamins and supplements, swallowing problems, fluid requirements, food preferences, and unfavorable eating behaviors including difficulty with self-feeding (Table 2). Almost three-quarters of chapters (70.6%) turned to reference books and journal articles when faced with a specific nutrition concern.

Of the resources reported to be provided to clients, 46.4% ( $n = 26$ ) met inclusion criteria and were reviewed by the 2 raters. Of these 26 resources reviewed, 50% were rated 3 stars or lower out of 5 and only 4 were rated at 4.5 stars. The agreement between raters was good (intraclass correlation = 0.58);<sup>34</sup> 8 of the resources were rated exactly at the same level and 16 within a 0.5 rating with the star system. Top resources were *Food for Thought: Practical tips about eating, feeding and nutrition for people with AD* (A. Watson, Toronto, 2002); *Managing Nutrition in Dementia Care: A supportive approach for caregivers* (Alzheimer Association, Western New York Chapter, 2001); *Food, Drink and Dementia* (H. Crawley, University of Stirling, Stirling, Scotland, 2002); and *Caregiver's Guide to Nutrition and Feeding: A supportive approach for caregivers of individuals with AD and related disorders* (Alzheimer Association, Western New York Chapter, 1989). Although these resources met almost all of the checklist criteria, they included too much detail and were generally long (13 pages to 30 pages).

**Table 2.** Comparison of Nutrition Concerns Between Family or Clients and Reviewed Print Resources Provided by Formal Caregivers (Study 2)

Topic	% of Alzheimer Society Chapters Reporting Topics Based on Client Concerns (n = 17)	Number of Resources Reviewed That Discussed This Topic (n = 26)
Safety with stove and other cooking utensils	94	1
Forgetting to eat	88	2
Weight changes	82	4
Refusing to eat	82	4
Appetite	76	6
Long-term care	71	0
Specific nutrients (vitamins)	71	4
Swallowing problems	65	11
Supplements	65	0
Food preferences	59	2
Unfavorable eating behaviors	53	6
Food safety	53	1
Difficulty with self feeding	47	0
Understanding nutritional needs	47	1
Fluid requirements	47	4
Coughing or choking	35	6
Overeating	29	1
Eating nonedibles	18	0

Many resources were missing common criteria that are essential for resources meant for a lay audience. Specific concerns can be generalized into content, language, and design issues. The primary drawback of the content was that it was very detailed; resources typically included information that was unnecessary for care and confused the main point of the resource. Several resources were not practical, providing few examples and giving unattainable suggestions. Most resources were not dated, and no author or references were given. The main language concern was the lack of use of plain language techniques, and the SMOG test indicated that all 26 resources were written above the recommended grade 4 to 6 levels. Polysyllable words were common, and an active voice and friendly, positive tone were not consistently used. Common problems with the design of resources included lack of visual cuing devices (eg, boxes, arrows), inadequate white space, and lackluster titles, and cover page. Finally, the content

of reviewed materials was not consistent with the reported questions arising from families approaching the chapters for guidance (Table 2). The most common topic addressed in the resources reviewed was regarding swallowing problems. The largest difference in questions asked and resources available were seen on topics such as safety with stove and other cooking utensils, forgetting to eat, appetite, weight changes, and refusing to eat.

## Discussion

Results of Study 1 and 2 on the nutrition concerns and resource needs of clients and formal providers were quite consistent and many of the nutrition issues have been previously reported in the literature. Changes in appetite, altered food preferences (specifically sweets), and changes in eating patterns including refusal to eat are thoroughly documented in dementia care.<sup>2,11,12,36-38</sup> However, concerns specific to persons with dementia living in the community are less well-documented due to the lack of research in this area. Specifically, difficulties with stove and cooking safety were reported by participants, but this issue is unaddressed in the education literature.

Hard copy print resources were identified in both studies as a preferred method to deliver information to clients and is consistent with previous education research with older adults.<sup>39,40</sup> The nutrition information being distributed to clients must be effective and appropriate for a lay audience. This analysis has identified gaps between what is needed and what print resources are available, and the quality of current resources to meet nutrition education needs.

Generally, there were few high quality, brief print resources that met the style criteria set out in this analysis. More than half of the resources provided to clients by participants in Study 2 did not meet inclusion criteria for review, indicating that there is a need for development of good resources. Additionally, most rated resources had significant flaws that would make them less effective knowledge-translation tools. Even the best rated resources in this analysis were long and were written above a grade 6 level. This could result in confusion and could overwhelm the reader. Caregiver stress and feelings of being overwhelmed are documented in

several studies,<sup>17,41</sup> and previous studies have identified these flaws with other health education resources.<sup>25,32,42</sup> It is apparent that further study is required to develop high quality–nutrition education resources to meet the information needs of families and formal providers.

These studies are not without limitations that influence interpretation and must be considered in light of developing new resources, which is a costly and time-consuming endeavor. First, Study 1 was based on a relatively small, geographically convenient sample in southwestern Ontario. Literature supports most of the recognized problems in this study, suggesting that bias did not limit detection of pertinent nutrition issues. However, we only obtained information from formal care providers in this study, and these participants were heterogeneous, influencing findings. Specifically, they had varied experiences and length of experience in providing or being asked about nutrition issues by informal care partners and persons with dementia. This exploratory data collection did not attain information specifically on the frequency or intensity of specific nutrition issues, and interview questions were not focused on the urgency of nutrition education needs for family, persons with dementia, or formal providers. The relative importance of nutrition issues in light of other caring issues for these care partners is not known from Study 1. What is clear from Study 1 is that informal and formal care partners recognize nutrition to be an issue in care of persons with dementia and that easy to read, practical information in print form is valued. Future research is needed, which examines the nutrition and eating issues and information needs of persons with dementia and their family partners in care from their perspectives.

For Study 2, the response rate of 23% (n = 17) is typical of e-mailed surveys; previous questionnaires provided through the internet to physicians, academics, policy makers, and practitioners ranged in response from 19.3% to 32.0%.<sup>43,44</sup> The limited response may have stemmed from lack of personal e-mail addresses, time of year (prior to a major fund raising event), or lack of interest in nutrition among the chapter staff. Responses were mainly from Ontario (82.3%) as 52.7% of the chapters contacted were in this province, and consequent generalization of findings on common concerns and gaps is cautioned at this time. Due to the extensive nature of

potential educational material, we decided to limit review of materials that were specifically written for informal partners in care. Future study should consider evaluation of other education formats such as videos and Web pages, although some of the documents used in this review were available via the internet. As for the checklists, these were primarily focused on style and presentation of material rather than accuracy of content, and individual quality items, were not weighted. A proxy indicator of quality in content was authorship of the material. Future ratings of educational resources should consider accuracy of content by expert review. As some of these design components are likely to be more relevant to users (eg, positive tone vs catchy title) weighting of checklists is recommended for future study. Despite these limitations, the primary finding is still relevant; current education resources provided to client groups lack quality and topic coverage (Table 2).

## Conclusion

The area of nutrition and eating issues in persons living with dementia in the community is fairly new, and research and education developments are currently being made. The need for nutrition education resources will rise as more and more formal and informal caregivers support persons living with dementia in the community. These caregivers require education to help them understand and to strategize around eating changes that occur with dementia. This research has identified that currently there are gaps between the resources being provided and the quality of these resources. Good resources get used. Some of the top resources identified in this research were internationally developed, and the internet is a good vehicle for worldwide dissemination. Internet sites are commonly used for education about dementia, and authors need to be cognizant of some of the principles of adult learning theory and the need for high quality, well-designed material when posting information for consumers. A specialist in plain language and resource design, as well as someone with a strong background in nutrition and dementia, is crucial for the composition of quality resources. Those involved in providing education materials are urged to consider these findings when selecting and developing resources.

## Appendix A

### Study 1: Semistructured Interview Questions

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What sorts of problems or questions arise from family careproviders and seniors with dementia in the area of eating and nutrition? (standard prompts provided see Table 1).

What are your nutrition/food concerns for families experiencing dementia in the community? (standard prompts provided see Table 1).

How do you address the nutrition concerns of these families? (eg, write down tips, provide with a pamphlet, refer to another health professional etc).

1. (If use a specific pamphlet/resource) Why do you use these resources?
2. (If provide oral/handwritten material for family) Why do you choose to educate the families this way?
3. Are you aware of other resources on nutrition and eating for seniors with dementia that you are currently not using? Prompts: print form, video, Web sites, presentations, other.
4. Why do you choose to not use these resources with families?

What types of education resources specific to nutrition would you like to have available for family caregivers?

What are your educational needs in the area of nutrition and eating with dementia?

What are the educational needs of front-line staff who have frequent contact with these families (eg, MOW drivers, personal support workers, homemakers etc)?

What are the service needs of families managing nutrition problems in the person they care for in the community?

Any other suggestions or comments you'd like to make on nutrition education needs of informal or formal caregivers?

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## Appendix B

### Study 2: Checklist of Content, Topics Covered

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Main topic of resource (eg, forgetting to eat, appetite, supplements etc).

Coverage of topic—general, overwhelming, unnecessary information.

Purpose stated clearly.

Main points stated concisely.

Repetition of important points.

Use of concrete examples.

Options/alternatives provided when referring to solutions.

Resource information provided (authorship, publisher).

Resource dated.

Author credibility.

Type of references.

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## Appendix C

### Checklist for Design Quality of Resource

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#### Writing Style/Language

Conversational, friendly tone, uses first or second person (eg, "I", "we," "us," "you").

Positive tone used.

Language appropriate (uses common terms and simple words).

Any new/medical terms are defined.

All acronyms or short-forms defined.

Short sentences (<20 words).

Active voice used in majority of document.

Verbs used whenever possible (not nouns).

Not written in past tense

According to SMOG, the document is written at a grade 4 to 6 reading level.

All tables, charts or graphs are clear and contain only one main point.

#### Organization

Logical flow.

Point form/bullet style.

Clear topic headings.

#### Design and Appearance

Appealing cover.

Catchy title.

Dark print on light background.

Matte finish paper.

At least 12-pt font.

Plain, clear typeface (serif fonts).

One type of font used.

Sections not written in all italics.

Sections not written in all caps locks.

Text lined left and ragged on right.

Visual cuing devices used (boxes, arrows, underlining).

At least 1 margins.

White space between paragraphs.

Simple, appropriate illustrations.

#### Comprehension

Defines behavioural objectives.

Instructions written in the order they should be performed.

Document covers only 3-5 main points.

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## Star Rating System

No. of Stars	Criteria
1 Star	very few to none, language, design or content components fulfilled
2 Stars	basic writing principles not followed, no plain language; few content and design components met
3 Stars	some basic writing principles used, some plain language used; some content and design components satisfied
4 Stars	most basic writing principles and plain language followed; most content and design components fulfilled
5 Stars	basic writing principles and plain language used, all content and design components satisfied

## References

1. Cronin-Stubbs D, Beckett LA, Scherr PA, et al. Weight loss in people with Alzheimer disease: a prospective population based analysis. *Br Med J*. 1997;314:178.
2. White H, Pieper C, Schmader K, Fillenbaum G. Weight change in Alzheimer's disease. *J Am Geriatr Soc*. 1996;44:265-272.
3. Gregorio G, Diaz R, Casado R, Demenu Group. Dementia and nutrition. Intervention study in institutionalized patients with Alzheimer Disease. *J Nutr Health Aging*. 2003;7:304-308.
4. Suominen M, Laine A, Routasalo P, Pitkala K, Rasanen L. Nutrient content of served food, nutrient intake and nutritional status of residents with dementia in a Finnish nursing home. *J Nutr Health Aging*. 2004;8:234-238.
5. VanWymelbeke V, Guedon A, Maniere D, Manckoundia P, Pfitzenmeyer P. A 6-month follow-up of nutritional status in institutionalized patients with Alzheimer's disease. *J Nutr Health Aging*. 2004;8:505-508.
6. Andrieu S, Reynish W, Nourhashemi F, et al. Nutritional risk factors for institutionalization placement in Alzheimer's disease after one-year follow-up. *J Nutr Health Aging*. 2001;5:113-117.
7. Faxen-Irving G, Basun H, Cederholm T. Nutritional and cognitive relationships and long-term mortality in patients with various dementia disorders. *Age Ageing*. 2005;34:136-141.
8. Riviere S, Gillette-Guyonnet S, Andrieu S, et al. Cognitive function and caregiver burden: predictive factors for eating behaviour disorders in Alzheimer's disease. *Int J Geriatr Psychiatry*. 2002;17:950-955.
9. Guyonnet S, Nourhashemi F, Andrieu S, et al. A prospective study of changes in the nutritional status of Alzheimer's patients. *Arch Gerontol Geriatr*. 1998;6 (suppl):255-262.
10. Amella EJ. Resistance at mealtimes for persons with dementia. *J Nutr Health Aging*. 2002;6:117-122.
11. Cullen P, Abid F, Patel A, Coope B, Ballard CG. Eating disorders in dementia. *Int J Geriatr Psychiatry*. 1997;12:559-562.
12. Ikeda M, Brown J, Holland AJ, Fukuhara R, Hodges JR. Changes in appetite, food preference, and eating habits in frontotemporal dementia and Alzheimer's disease. *J Neurol Neurosurg Psychiatry*. 2002;73:371-375.
13. Morris CH, Hope RA, Fairburn CG. Eating habits in dementia: a descriptive study. *Br J Psychiatry*. 1989;154:801-806.
14. Wolf-Klein GP, Silverstone FA, Levy AP. Nutritional patterns and weight change in Alzheimer's patients. *Int Psychogeriatr*. 1992;4:103-118.
15. Chambers LW, Hendriks A, Hall HL, Raina P, McDowell I. Research on Alzheimer's caregiving in Canada: current status and future directions. *Chron Dis Can*. 2004;25:108-118.
16. Silver HJ, Wellman NS. Nutrition education may reduce burden in family caregivers of older adults. *J Nutr Educ Behav*. 2002;34:S53-S58.
17. Wackerbath SB, Johnson M. Essential information and support need of family caregivers. *Patient Educ Couns*. 2002;47:95-100.
18. Riviere S, Gillette-Guyonnet S, Voisin T, et al. A nutritional education program could prevent weight loss and slow cognitive decline in Alzheimer's disease. *J Nutr Health Aging*. 2001;5:295-299.
19. Giacomini MK, Cook DJ. Users' guide to the medical literature XXIII. Qualitative research in health care A. Are the results of the study valid? *J Am Med Assoc*. 2000;284:357-362.
20. Miles MD, Huberman AM. *Qualitative data analysis: An expanded sourcebook*. 2nd ed. Thousand Oaks, CA: Sage; 1994.
21. Kempson KM, Palmer Keenan D, Sadani PS, Ridlen S, Scotto Rosato N. Food management practices used by people with limited resources to maintain food sufficiency as reported by nutrition educators. *J Am Diet Assoc*. 2002;102:1795-1799.
22. Weber RP. *Basic Content Analysis*. 2nd ed. Thousand Oaks, CA: Sage; 1990.
23. National Literacy and Health Program & Canadian Public Health Association. *Working with low-literacy seniors. Practical strategies for health providers*. Ottawa, ON: Canadian Public Health Association; 1998.
24. National Literacy and Health Program & Canadian Public Health Association. *Directory of Plain Language Health Information*. Ottawa, ON: Canadian Public Health Association; 1999.
25. Myers RE, Shepard-White F. Evaluation of adequacy of reading level and readability of psychotropic medication handouts. *J Am Psychiatr Nurses Assoc*. 2004;10:55-59.

26. Tools for effective communications. <http://www.ific.org/tools/intro.cfm>. Accessed September 9, 2005.
27. Clear writing. [http://uuhsc.utah.edu/pated/authors/clear\\_writing.html](http://uuhsc.utah.edu/pated/authors/clear_writing.html). Accessed September 9, 2005.
28. Clark KL, AbuSabha R, von Eye A, Achterberg C. Text and graphics: manipulating nutrition brochures to maximize recall. *Health Educ Res.* 1999;14:555-564.
29. Coulter A, Entwistle V, Gilbert D. Sharing Decisions with patients: is the information good enough. *Br Med J.* 1999;318:318-322.
30. Betterley C, Dobson B. Guide to evaluating written nutrition education materials. <http://www.extension.iastate.edu/Publications/SP119.pdf>. Accessed September 11, 2005.
31. Anderson RM, Funnell MM. Theory is the cart, vision is the horse: reflections on research in diabetes patient education. *Diabetes Educ.* 1999;25 (suppl 6):43-50.
32. Hayes K. Designing written medication instructions. Effective ways to help older adults self-medicate. *J Gerontol Nurs.* 2005;31:5-10.
33. Harwood A, Harrison JE. How readable are orthodontic patient information leaflets? *J Orthod.* 2004;31:210-219.
34. Donker DK, Hasman A, Van Geijn HP. Interpretation of low kappa values. *Int J Biomed Comput.* 1993;33:55-64.
35. The SMOG Readability Formula. <http://uuhsc.utah.edu/pated/authors/readability.html>. Accessed March 14, 2007.
36. Bozeat S, Gregory CA, Lambon R, et al. Which neuropsychiatric and behavioral features distinguish frontal and temporal variants of frontotemporal dementia from Alzheimer's disease? *J Neurol Neurosurg Psychiatry.* 2000;69:178-186.
37. Gillette-Guyonnet S, Nourhashemi F, Andrieu S, et al. Weight loss in Alzheimer disease. *Am J Clin Nutr.* 2000;71(suppl): 637S-642S.
38. Duerr L. Assessing nutrition education wants and needs of older adults through focus group. *J Nutr Elder.* 2003;23:77-91.
39. Stewart PL, Brochetti D, Cox RH, Clarke MP. Low-income elderly adults' needs and preferences for nutrition education. *J Nutr Elder.* 1998;18:1-20.
40. Commissaris CJAM, Jolles J, Verhey FRJ, Kok GK. Problems of caregiving spouse of patients with dementia. *Patient Educ Couns.* 1995;25:143-149.
41. Dollahite J, Thompson C, McNew R. Readability of printed sources of diet and health information. *Patient Educ Couns.* 1996;27:123-134.
42. Burbridge B, Douglas D, Kriegler S. Chest x-ray ordering related to varied clinical scenarios: a survey of Saskatchewan physicians. *Can Assoc Radiol J.* 2005;56:219-224.
43. Davenport C, Mathers J, Parry J. Use of health impact assessment in incorporating health considerations in decision making. *J Epidemiol Community Health.* 2006;60:196-201.
44. Burbridge B, Douglas D, Kriegler S. Chest X-ray ordering related to varied clinical scenarios: a survey of Saskatchewan physicians. *Can Assoc Radiol J.* 2005;56: 219-224.