



Review of CALD dementia resources in Australia

Project Report

Nicky Hayward-Wright

Manager

Library & Information Service

Alzheimer's Australia NSW

Elizabeth McKenzie

Information Officer

Library & Information Service

Alzheimer's Australia NSW

On behalf of

Alzheimer's Australia

National Cross Cultural Dementia Network

© Alzheimer's Australia

14 November 2005

TABLE OF CONTENTS

1. BACKGROUND	3
2. AIM	3
3. PROJECT OUTCOMES	3
4. PROJECT METHODOLOGY	4
4 (i) Literature review	4
Consumer health information literature review	4
4 (ii) Selection criteria	5
4 (iii) Development of a resources database	5
4 (iv) Identifying, locating and obtaining resources	6
4 (v) Review and evaluation of resources against agreed selection criteria	8
4 (vi) CALD Resources Catalogue.....	9
5. MODELS OF INFORMATION DELIVERY	10
6. RECOMMENDATIONS.....	11
7. CONCLUSION	12
APPENDIX 1 : CONSUMER HEALTH INFORMATION LITERATURE REVIEW	13
APPENDIX 2 : SELECTION CRITERIA	17
APPENDIX 3 : STATISTICS.....	20
Table 1: Total number of resources by language.....	20
Table 2: Comparison of total number of resources by language against CALD population..	21
Table 3: Total number of resources by format	22
Table 4: Total number of dementia specific resources by subject area.....	23
Table 5: Total number of dementia specific resources by author	24
Table 6: Chinese dementia specific resources.....	25
Table 7: Italian dementia specific resources	26
Table 8: Greek dementia specific resources	27
Table 9: Arabic dementia specific resources	28
APPENDIX 4 : SUBJECT GATEWAYS	29

EXECUTIVE SUMMARY

The aim of this project has been to ascertain what dementia and dementia related resources (books, leaflets/pamphlets, videos, DVDs, audiotapes, multi-media kits) are currently available in Australia and would be suitable for use by people from Culturally and Linguistically Diverse (CALD) communities; specifically Arabic, Chinese, Croatian, Dutch, French, German, Greek, Hungarian, Italian, Latvian, Macedonian, Maltese, Polish, Russian, Serbian, Spanish, Tagalog / Filipino, Turkish and Vietnamese.

The main project activities undertaken include a literature review; development of selection criteria; development of a CALD resource database; identifying; locating and obtaining resources; and review and evaluation of resources against agreed selection criteria of authority, currency, accuracy, cultural sensitivity, appropriateness of translation, non-judgemental, of Australian context, parallel material in English and being freely available.

The outcome of these activities has been the production of a catalogue of CALD resources (separate from this report) and a database of all CALD resources which will be for internal Alzheimer's Australia use only. The production of a printed catalogue for external distribution is not recommended as it will become immediately out of date and does not include other language material that is available, such as Korean and Portuguese.

Whilst the main focus of this project has been the sourcing of dementia specific material such as information about dementia, its progression and treatment, other supporting topics such as managing behaviours of concern, coping with communication changes, promoting continence, legal issues, managing loss and grief, respite, day care and other community services, relinquishing care, palliative care, stress management and safety issues have also been sourced as these topics have been indicated as resources of interest to carers.

Key statistics¹:

Total number of resources	778
Major format available	Leaflets/pamphlets/help sheets (89%)
Language which has most coverage	Chinese (Mandarin, Cantonese, Script) Italian, Greek, Arabic
Total number of dementia specific resources	316
Number of dementia specific titles	67
Main author	Alzheimer's Australia (77%)

The major authors or producers include: Alzheimer's Australia (NSW, Vic, SA), Australian Department of Health and Ageing, NSW Multicultural Health Communication Service, NSW Department of Ageing, Disability and Home Care, Office of the Public Advocate (Vic.), Office of the Public Guardian (NSW), Palliative Care Australia, Transcultural Mental Health Centre (Diversity Health Institute).

¹ Statistics were calculated based on resources in database on 18/10/2005. Whilst statistics will vary with an increase in resources, the outcomes indicated appear to remain the same. Total number of CALD resources as of 30/11/2005 = 949.

Key Findings

The statistics indicate that there is a 'reasonable' coverage of dementia related material. However on closer examination, the level of dementia specific information is of a 'basic level', with the majority of material being produced in leaflet or pamphlet format (which includes help sheets).

It should also be noted that over 85% of material is now only available online. This has implications for the end user with regards to access to resources, the cost of printing to the end user or the intermediary who is supplying the material to the end user and the quality of the printed material.

Of the existing Australian CALD resources online databases (Multicultural Mental Health Australia Resource Database, Diversity Health Resources Clearinghouse, Health Translation Directory (Victorian Government), NSW Multicultural Health Communication Service) some information about resources is inaccurate and incomplete, and minimal updating has occurred. Additionally there is a large amount of duplication across these databases.

Whilst this project was only tasked with looking at what CALD resources are available, research and conclusions drawn have pointed to the need to look beyond translating material and material that is already translated, to the collection and distribution of these items.

Key Recommendations

- In order to be a leader in the development of quality consumer health information, best practice guidelines for the production of material by Alzheimer's Australia (and associations) should be developed based upon the section criteria and other key findings highlighted in this report.
- Collaboration between Alzheimer's associations worldwide should occur in the area of resource sharing of non-English material; and the development of parallel English material should be pursued. Consideration should also be given to the development of a 'select panel' of Alzheimer's Australia certified bilingual health professionals to assess (as per selection criteria) material developed overseas, which does not have parallel English material.
- Collaboration between the existing Australian CALD resources online database administrators should occur in order to develop one single entry point to multicultural resources; not only dementia specific, but additional support material required by people with dementia, carers, family members and health care workers.
- The production of a printed catalogue for external distribution is not recommended as it will become immediately out of date and does not include other language material that is available, such as Korean. The recommended action is the development of **one authoritative single web-based access point which is based upon a subject gateway model**; a single access point to a collection of information that is organised by subject and is developed, organised and maintained following established best practice guidelines.

Partnering with other organisations in the development of a single CALD resource database and web-based subject gateway will decrease duplication of effort, facilitate communities of practice and increase the availability of a broader range of accurate health information. Additional benefits of quality controlled accessible health information will include improved quality of care; better health outcomes; increased access to health services; better-informed clients and consumers; and greater client satisfaction.²

² Centre for Cultural Ethnicity & Health Centre for Culture, Ethnicity & Health. (2005). *How to: Reviewing existing translated materials checklist* (online), p. 5. <http://www.ceh.org.au/resources/resbyceh.html> [Accessed on 07/08/2005]

1. Background

As a result of discussion within the National Cross Cultural Dementia Network (NCCDN) and Alzheimer's Australia National Programs Manager it was determined that a project should be established to identify and review what dementia related resources are currently available to people from a culturally and linguistically diverse background.

The view held at the outset of the project was that there were minimal 'suitable' resources available. This assumption was based on personal observation of the NCCDN and also indicated by existing documentation produced by the NCCDN, NSW DADHC Office for Ageing Cross Cultural Dementia Working Group and the Catalogue of Dementia Materials in Community Languages produced by Alzheimer's Australia NSW (1999). There was however, no statistical evidence to base the assumption upon, despite its possible validity.

Following submissions of project proposals that were based on the briefing document prepared by David Turner, Alzheimer's Australia National Programs Manager (dated 28 April 2005), Alzheimer's Australia NSW was awarded the project in June 2005.

The project team consists of: Project Sponsor, David Tuner (National Program Manager, Alzheimer's Australia); Project Support Officer, Helena Kyriazopoulos (Multicultural Liaison Officer, Alzheimer's Australia SA; Convenor, National Cross Cultural Dementia Network); Project Manager, Nicky Hayward-Wright (Coordinator, Library & Information Service, Alzheimer's Australia NSW) and Information Officer, Elizabeth McKenzie (Library & Information Service, Alzheimer's Australia NSW).

2. Aim

The aim of this project is to identify if there is 'suitable' dementia related material available for people from Culturally and Linguistically Diverse (CALD) communities; specifically in Arabic, Chinese, Croatian, Dutch, French, German, Greek, Hungarian, Italian, Latvian, Macedonian, Maltese, Polish, Russian, Serbian, Spanish, Tagalog / Filipino, Turkish and Vietnamese.

The primary audience is the person with dementia, their carer and family members. The information therefore is consumer health orientated.

3. Project Outcomes

Further to identifying resources, the project has included the establishment of a resource database and the review of material following established selection criteria. The outcome of this has been the:

- a) Production of a catalogue of selected dementia related resources that have been identified as suitable for use by workers with people from CALD communities, specifically Arabic, Chinese (script, Cantonese and Mandarin), Croatian, Dutch, French, German, Greek, Hungarian, Italian, Latvian, Macedonian, Maltese, Polish, Russian, Serbian, Spanish, Tagalog / Filipino, Turkish and Vietnamese.
- b) The production of a second document that is not for external distribution, but which contains all material located during the project.

4. Project methodology

The main project activities undertaken include:

- Literature review.
- Development of selection criteria.
- Development of a CALD resource database.
- Identifying, locating and obtaining resources.
- Review and evaluation of resources against agreed selection criteria.
- Production of a catalogue of CALD resources that will be for external distribution and will only include materials that have met the selection criteria.
- Production of a catalogue of all CALD resources that have been located during the project, which is for internal Alzheimer's Australia use only.
- Production of a final report.

4 (i) Literature review

An initial literature review was conducted in order to provide a framework for undertaking other project activities. Four main areas were investigated:

- a) CALD communities and their consumer health information requirements.
- b) Protocols for translation of multicultural resources, with a focus on health information.
- c) Selection criteria for multicultural resources, which focus on consumer health information.
- d) Web-based models for the storage and retrieval of information embedded in the project database.

Consumer health information literature review

A brief review of consumer health information, including CALD communities' information needs was undertaken and is available in the Appendix 1. In summary the review identified the following:

- There is a high demand for quality consumer health information.
- This information needs to be filtered information; i.e. authoritative and selected.
- Core topics of interest to carers of people with dementia include not only information about dementia its progression and treatment; but also supporting topics such as managing behaviours of concern, coping with communication changes, promoting continence, legal issues, managing loss and grief, respite, day care and other community services, relinquishing care, stress management and safety issues.
- Knowledge of the different culturally distinct beliefs and behaviours relating to health and health care of the various CALD communities is important in the provision of appropriate health information and health care services.
- Culture, language and literacy are also key factors that can affect a person's understanding of health information as well as being barriers to accessing it.

4 (ii) Selection criteria

From a review of the literature, selection criteria were developed and used to evaluate resources. For details pertaining to the following selection criteria see the Appendix 2.

- Authority
- Currency
- Accuracy of content
- Audience
- Cultural sensitivity
- Translation
- Language
- Non-judgemental
- Australian Context
- Availability
- Visual appearance and characteristics (*Secondary selection criteria*)

Initially the selection criteria for “translation” and “cultural sensitivity” were based upon the checklist for the review of existing translated materials developed by the Centre for Culture, Ethnicity & Health.³ However, in the process of identifying and verifying resources it was established that in the majority of cases the authors of material (mainly government and health departments or agencies, and government funded bodies) had developed strict guidelines for the translation process based upon a seminal text produced by Multicultural Mental Health Australia; “Guidelines and protocols for translated mental health resources”.⁴ As a result it was decided that these two selection criteria would be based upon whether they could be verified through the translation and cultural sensitivity guidelines developed and adhered to by the authors/translators.

4 (iii) Development of a resources database

In order to organise, store and retrieve information about resources that were identified during the project, it was determined that a database should be developed. A major consideration was that the database or the data contained within the database should be transferable. Microsoft Access was used as the database platform. Key fields were identified based upon resource discovery and metadata (resource description standards).

Problems encountered

As the requirements for the database grew, it was decided to seek assistance with its development.

Because of the resultant database structure, the database is not as easy to use as first anticipated. It is recommended that if this project is to continue the database be redeveloped.

³ Centre for Cultural Ethnicity & Health Centre for Culture, Ethnicity & Health. (2005). *How to: Reviewing existing translated materials checklist* (online), p. 5. <http://www.ceh.org.au/resources/resbyceh.html> [accessed 07/08/2005]

⁴ Bastian, K. et. al. (200?). *Guidelines and protocols for translated mental health resources*. West Australian Transcultural Mental Health Centre (online). <http://www.mmha.org.au/watmhc/CriteriaForTranslatedResources.pdf> [accessed 07/08/2005]

The time and delay with the database development has meant a time delay in data input, which has had a knock on effect in other project areas; in particular the extraction of statistics. With regards to data entry it is noted that there are inconsistencies due to more than one person doing the entry; in particular with relation to the allocation of main subject and additional subjects. It is recommended that in future project work a set of guidelines be developed for the selection of subject headings. The current thesaurus should be further developed to assist in the process of subject heading selection. Additionally, a short description for each format would be useful as this would also aid in consistent data entry.

4 (iv) Identifying, locating and obtaining resources

The two key steps taken in identifying and locating obtaining resources have been:

- establishing what content will be obtained for review, and
- identifying possible resource producers at a state, local and federal level.

Content for review

Whilst the core content was indicated as ‘dementia specific’, during the initial investigation additional resources were located that would be relevant and support people with dementia and their carers and families. These additional topics include:

- legal: wills, capacity, consent, medical treatment, power of attorney
- health, ageing and memory
- residential and respite services
- activities
- stress management / relaxation
- incontinence

The focus has been to collect dementia specific material such as what is dementia, behaviours of concern and dementia services. The above dementia related topics have been included, because they are indicated in the literature review of consumer health information as being of interest to the carer and supporting their information needs.

Identification of authors or producers/ publishers/ suppliers

The initial project scope indicated that contact with Alzheimer’s Australia associations, state based dementia networks, local government area health services, state and federal health / aged care services, community and state based organisations which service ethnic communities and ethnic radio and TV would be made. Also it was suggested that an audit of resources held by a selection of organisations which would include Alzheimer’s Australia associations’ library services / resource centres, public libraries, health libraries and organisations indicated as suppliers should be undertaken.

Soon after commencing the resource discovery, it was clear that the above was too complex for the time constraints of this project. Particular concerns related to:

- the multitude of community based organisations,
- government department’s changing their name, and
- information being buried in websites.

In discussion with the project team it was determined that the community based organisations, ethnic radio and TV stations would not be included in the investigation of possible producers. Additionally, the project would focus on the producers / authors (federal and state government departments, and national, state or local organisations that specifically deal with multicultural health and aged care) of resources and not suppliers or service points (such as libraries).

Whilst it is noted that several overseas Alzheimer's associations produce material in other languages, due to time constraints these resources have not been added to the database. It is recommended that a future project should focus on web-based resources produced by overseas organisations. Alzheimer's Disease International recently updated (25 May 2005) their web page "Information In Other Languages" <<http://www.alz.co.uk/alzheimers/languages.html>> that provides a list of associations which produce material in languages other than English. Only the following associations have parallel material available in English:

Chinese - Alzheimer's Association - <http://www.alz.org/Resources/Diversity/Chinese.asp>

French - Alzheimer's Society of Canada - <http://www.alzheimer.ca/>

Spanish - Alzheimer's Association - <http://www.alz.org/Resources/Diversity/HispanicLatino.asp>

It is recommended that the above resources be reviewed, evaluated and added to the catalogue of CALD resources. Additionally it is recommended that collaboration between Alzheimer's associations worldwide occur in the area of resource sharing of non-English material and the development of parallel English material.

Consideration should also be given to the development of a 'select panel' of Alzheimer's Australia certified bilingual health professionals to assess (as per selection criteria) material developed overseas, which does not have parallel English material.

Key Findings

A major finding of this phase is that over 85% of material is now only available online. This has implications for the end user with regards to access to resources, and the cost of printing to the end user or the intermediary who is supplying the material to the end user. Additionally, many of the resources are a direct conversion of a glossy hard copy that are not specifically designed to be printed from the web and read, the result being that some online resources lack visual clarity and are difficult to read when printed.

The major authors or producers (in most cases the publisher is the same as the author or producer) include:

- Alzheimer's Australia (and its associations)
- Australian Department of Health and Ageing
- NSW Multicultural Health Communication Service
- NSW Department of Ageing, Disability and Home Care
- Office of the Public Advocate (Vic.)
- Office of the Public Guardian (NSW)
- Palliative Care Australia
- Transcultural Mental Health Centre (Diversity Health Institute)

Problems Identified

Main obstacles that have been encountered in this phase of the project include:

- Publications being listed on multiple web sites (duplication).
- Web based lists or databases not being maintained or updated.
- Online databases not listing correct bibliographic information for resources (eg. the distributor being indicated as the author).
- Finding resources through online databases or publications is sometimes difficult.
- Difficulty in verifying resource details with the author or producer.
- Material not being available because of copyright.
- Delays in obtaining resources or verifying resource details as the people who handle this area, in the majority of cases, only work part-time.

4 (v) *Review and evaluation of resources against agreed selection criteria*

A matrix of the selection criteria was developed and used as a tool when evaluating resources. 'Y' (yes) and 'N' (no) were used to indicate meeting of criteria. Notes were made against criteria as required, in particular for 'availability' and 'Australian context'.

For items that did not have an English equivalent the authority or credibility of the author was verified and the uniqueness of the material was ascertained.

Key Findings

A key finding of this phase relates to updating of materials. The first example relates to the translation of materials. It was noted that some non-English resources carry a 'verification stamp', which is of a different date to the English publication. For example: a non-English item carried a verification stamp from the translator dated 2004, however the English version was published by NSW Health in 1999 (author Alzheimer's Association NSW) and no known updates.

The second example relates to audio material where the slipcover carries the date, which relates to updating of the slipcover and no other date is included which indicates the date of publication.

In both cases the dates indicated on the items are misleading. It is recommended that in future additional guidelines be developed for the collection and verification of bibliographic details, in particular information pertaining to publication date, copyright date, date of modification and translation date. Additionally the use of 'verification update' by translation bodies needs to be clarified.

It is recommended that attention be paid to the use of standard practice in the Cataloguing in Publication (CIP) of resources, in particular in relation to the date an item is modified or updated and the date a translation is undertaken or verified (as distinct from the resource creation date). Collaboration between the main authors and translators should occur in order to achieve standardisation. Alzheimer's Australia should lead the way by developing and adhering to best practice guidelines for the production of material which can be based upon the section criteria and other key findings highlighted in this report.

In the process of locating material, other languages, in particular Korean and Portuguese were found. In future, other languages other than those requested for this project should be included in the database. With regards to what information should be translated future research should be undertaken to ensure that the selection of languages keeps pace with the changing multicultural face of Australia.

Statistics

Total number of resources (excluding English)	778 (as of 18/10/2005) ⁵
Major format available	Leaflets/pamphlets/help sheets (89%)
Language which has most coverage	Chinese (Mandarin, Cantonese, Script) Italian, Greek, Arabic
Total number of dementia specific resources	316
Number of dementia specific titles	67
Main author	Alzheimer's Australia (77%)

More detailed statistics are available in the Appendix 3.

The statistics indicate that there is a 'reasonable' coverage of dementia related material. However on closer examination, the level of dementia specific information is of a 'basic level', with the majority of material being produced in leaflet or pamphlet format (which includes help sheets). It should also be noted that with the exclusion of some material, for example help sheets produced by Alzheimer's Australia NSW and Alzheimer's Australia SA, the number of 'selected' dementia specific titles decreases.

The literature indicates that in the early stages of diagnosis the person seeking information is usually content with a more general level of information, however as the condition progresses, the level of detail of information required becomes greater and more complex.⁶

In order to support the ongoing information needs of the consumer, it is recommended that a review of the information requirements of the consumer should occur in order to ascertain what new material should be developed and at what depth or level of coverage.

4 (vi) CALD Resources Catalogue

The identified outcome of the project was the production of two catalogues (a) CALD resources that that will be for external distribution and will only include materials that have met the selection criteria (b) all CALD resources that have been located during the project, which is for internal Alzheimer's Australia use only. A summary report of audited resources is separate to this report.

Whilst the project outcome requested the production of a printed catalogue for external distribution, this format of delivery is not recommended as it will become immediately out of date, currently does not include other language material that is available, such as Korean, and will be costly to update, reprint and distribute.

⁵ Whilst statistics will vary with an increase in resources, the outcomes indicated appear to remain the same. Total number of resources as of 30/11/2005 = 949.

⁶ Carers NSW. (2005). *Carer life course framework : an evidence-based approach to effective carer support and education*. NSW Health: Sydney, pp. 52-57.

In the process of discovering what resources are available, it was noted that multicultural resource databases already exist. The main databases identified are:

- Diversity Health Resources Clearinghouse
<http://www.dhi.gov.au/clearinghouse/Resources.htm>
- Multicultural Mental Health Australia Resource Database
<http://www.mmha.org.au/ResourceDatabase/>
- NSW Multicultural Health Communication Service
<http://www.health.nsw.gov.au/health-public-affairs/mhcs/>
- Health Translation Directory (Victorian Government)
<http://www.healthtranslations.vic.gov.au/>

It is recommended that collaboration with these organisations should occur in order to develop one single entry point to multicultural resources on the Internet.

Such an integrated database could therefore provide access to multiple resources, not only dementia specific but additional support material required by people with dementia, carers, family members and health care workers. The benefits from making accessible, accurate health information include improved quality of care; better health outcomes; increased access to health services; better-informed clients and consumers; and greater client satisfaction.⁷ Additionally, partnering with other organisations in the development of a common database will facilitate a growth of networks of common interest and practice, and decrease duplication of effort.

5. Models of information delivery

Whilst a database is the platform that allows information capture, there are different models for how and what information is stored and made available electronically. The two main models are clearinghouse and subject gateway, although these two terms are quite often used interchangeably. For the purpose of this report the following definitions apply:

A **clearinghouse** is a single access point to a collection of information. Usually there is limited data verification prior to input and minimal updating. In this description the clearinghouse is merely a repository.

A **subject gateway** is a single access point to a collection of information that is organised by subject or discipline and selected for inclusion following a published set of quality criteria.

The main function of both the clearinghouse and subject gateway is to facilitate information access and retrieval for users. However, the distinguishing factor is that subject gateways only include quality, evaluated resources. Additional characteristics of a subject gateway include the use of controlled vocabularies (thesaurus) and metadata; resource description such as the addition of annotations, either descriptive or evaluative; and collection maintenance including verifying, updating, weeding and link checking.

⁷ Centre for Cultural Ethnicity & Health Centre for Culture, Ethnicity & Health. (2005). *How to: Reviewing existing translated materials checklist* (online), p. 5. <http://www.ceh.org.au/resources/resbyceh.html> [Accessed on 07/08/2005]

The literature indicates that a distinction can be made between a subject gateway and a “quality controlled or selective subject gateway” where:

- a) a subject gateway has minimal description and shallow subject structure, and
- b) a **selective subject gateway** has high standards of quality control and rich resource description and structure.⁸

From the above definitions and characteristics, the previously listed CALD databases would align more closely to the clearinghouse model because of their lack of quality control.

It is recommended that any future development of a CALD database by Alzheimer’s Australia should be based on the quality controlled, selective subject gateway model.

With regards to collaborative partnerships in the development of a subject gateway, three models are indicated in the literature:

- a) **proprietary** model: operated by a single body,
- b) **consortium** model: collaboratively operated by a group of organisations, and
- c) **hybrid consortium** model: operations of the consortia are the responsibility of one body.⁹

Currently the previously listed CALD databases are using the proprietary model.

It is recommended that a consortium or hybrid consortium option be adopted as the preferred models of partnership. These models would promote cooperation among participating organisations and help ensure that the interests of each partner are met.

6. Recommendations

- **A selective, quality controlled subject gateway model for the capture and retrieval of resources be used in any future development of a CALD resources database.**
- The consortium model for collaboration partnerships is recommended for the development of subject gateway.
- International resources which have an English equivalent, in particular resources from the Alzheimer’s Association (Chinese, Spanish) and Alzheimer’s Association of Canada (French) be reviewed, evaluated and added to the catalogue of CALD resources.
- Collaboration between Alzheimer’s associations worldwide should occur in the area of resource sharing of non-English material and the development of parallel English material.
- Consideration should be given to the development of a ‘select panel’ of Alzheimer’s Australia certified bilingual health professionals to assess (as per selection criteria) material developed overseas, which does not have parallel English material.
- Diversity Health Resources Clearinghouse, Multicultural Mental Health Australia Resource Database, NSW Multicultural Health Communication Service and Health Translation Directory (Victorian Government) be pursued as collaborative partners in the development of a single entry point to multicultural resources on the Internet.

⁸ Koch, T. (2000). Quality-controlled subject gateways: definitions, typologies, empirical overview. *Online Information Review*, 24(1). <http://www.lub.lu.se/~traugott/OIR-SBIG.txt> [accessed 25/09/2005]

⁹ Reilly, B. (2003). *Developing print repositories: models for shared preservation and access*. Council on Libraries and Information Resources: Washington. <http://www.clir.org/pubs/reports/pub117/contents.html> [accessed 30/09/2005]

- If the existing Alzheimer's Australia CALD resources database continues to be used, guidelines and standards should be developed (eg. thesaurus, formats, etc.), the structure should be modified, and additional information such as content description or an annotation should be added to each resource.
- In order to be a leader in the development of quality consumer health information, best practice guidelines for the production of material by Alzheimer's Australia (and associations) should be developed based upon the section criteria and other key findings highlighted in this report.
- Whilst there appears to be a 'reasonable' coverage of a basic level of dementia related material, a review of the information needs of the consumer should occur in order to ascertain what type of information and what depth of coverage is required which will support their 'ongoing' information requirements.

7. Conclusion

The literature indicates that in the provision of information to people from a CALD background, consideration has to be given to this group's distinct beliefs and cultural behaviours. Additionally, whilst there is a demand for quality consumer health information, attention must be paid to the distribution of this information and how it can be more easily accessed.

Currently Diversity Health, Multicultural Mental Health Australia, NSW Multicultural Health Communication Service and Health Translation Directory have online CALD resource databases, however the following issues have been identified:

- Duplication - publications are being listed on multiple web sites
- Regular maintenance does not occur - information is not updated, out of date resources are not deleted
- Data verification does not occur
 - incorrect bibliographic information for resources is listed, eg. the distributor being indicated as the author
 - material that is not available for distribution because of copyright is listed
- No single collection of information – need to visit multiple sites to locate material

If Alzheimer's Australia NSW is to continue with the development of a print based catalogue it must be pointed out that it will become immediately out of date, currently does not include other language material that is available, such as Korean, and will be costly to update, reprint and distribute.

Therefore, it is recommended that Alzheimer's Australia should move away from the concept of developing and distributing a print based catalogue of CALD resource and look at the development of one single authoritative online catalogue in collaboration with the key CALD online database administrators (listed above).

As each of the above organisations is using different models of information storage and delivery **the concept of a subject gateway should be adopted because it is a single access point to a collection of information, which is arranged by subject and is developed, organised and maintained following established best practice guidelines.**

APPENDIX 1 : Consumer Health Information Literature Review

Research, studies and surveys point to the following:

Need for public education and access to dementia resources are likely to become increasingly important as the population of elderly people continues to grow.¹

Caregivers rated information needs more important than support needs in early stages of dementia.² The type of information required by carers will change depending on the phase of the disease.³

Earlier studies among other disease groups show that a person's stage of disease, age, socio-economic status and education level can influence their need for information.⁴

Regarding WHAT information – caregivers need information about health plan coverage and best available care. This is reflected in the two categories of information considered most important: legal / financial and diagnosis / treatment. Caregivers rated support for the care receivers as most important.⁵

Carers of people with a mental illness / mental disorder wanted a roadmap to services (eg. how do you access services, what is the referral process, information about residential, respite, intervention and bereavement services) along with information about mental illness (eg. how is diagnosis made, causes, course of the disease, how decisions are made about treatment, medication and treatment approaches, managing challenging situations or behaviours); legal / judicial issues (eg. guardianship, carer rights); financial issues (sources of financial assistance, insurance, protection of financial assets, estate planning); formal support services (eg. what support services are available, such as educational programs, support groups and counselling) and the experience of being a carer (grief and loss; positive coping strategies; impact on the family; reassurance that what the carer is experiencing is the norm; how to cope with the end of active caring role).⁶

Carers want good quality, realistic information about topics related to dementia: what is dementia, coping with challenging behaviour, coping with communication changes, promoting continence, legal issues. Include both evidence and experienced-based knowledge.⁷

Whilst information needs of carers from CALD backgrounds will vary, core content is similar across the majority of communities: understanding dementia and brain function; treatments and medications; managing behaviours of concern; promoting continence; legal and financial issues; managing emotional responses of loss, change, stress, grief and anxiety; respite, day care and other community services; relinquishing care, and safety issues.⁸

Low education and being a spouse were the most important vulnerability factors associated with poor knowledge about Alzheimer's disease and dementia.⁹

Carers who were more knowledgeable about the causes, symptoms and epidemiology of dementia reported significantly lower levels of depression but also higher rates of anxiety than those who were less well informed. This raises issues about how carers use and apply information.¹⁰

How carers respond to information depends on individual coping style. Carers characterised by monitoring [monitors] or blunting coping style [blunters]. Monitors: positive association with coping knowledge and service knowledge but not biomedical knowledge (epidemiology and aetiology of dementia) seek information in order to try and control their situation. Thus they are more aware of how they are coping than blunters. Blunters are positive association with service knowledge but not for coping or biomedical knowledge.¹¹

Regarding WHO needs which information, gender, rural residence and years of care giving experience were key predictors. Women caregivers, rural caregivers and long-time caregivers of a family member considered support for care receiver more important to them than other caregivers.¹²

Written patient information is often medico-centred and distributed as a one-way flow from doctor to patient. Whereas a patient-centred model of patient information aims to meet the patient's expressed needs for information and reflects a growing demand for patient participation in health-care decisions.¹³

“Health information literacy” is the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyse, understand, and use the information to make good health decisions. Studies have shown that people from all ages, cultures, income and education levels are challenged by this problem.¹⁴

Health-care information should be evidence-based, patient-centred and address the information needs and concerns as experienced by the patients themselves.¹⁵

There is a need to produce health information which is easy to read, culturally and contextually relevant, and accessible.¹⁶

The Internet may have improved the accessibility of information, but problems of relevance and reliability remain.¹⁷

Whilst the Internet is being increasingly used to seek health information, the developers of web based health information and web sites need to take into consideration the needs of the target audience in relation to information literacy, health information literacy and cultural perspectives.¹⁸

Public need and desire convenient anonymous access to critical information about this sensitive topic.¹⁹

People seeking health information are less embarrassed and more self-disclosing when interacting with a computer than with another person.²⁰

Barriers that prevent an individual from accessing or making use of health-care information include: doctor's lack of time and failure to elicit the needs and concerns of their patients, lack of communication skills, attitudes to patients with the disease and the use of medical jargon.²¹

Cultural norms (in particular regarding disability and mental health) language and literacy difficulties, the acceptability of assistance from outside the family and expectations of who should adopt a carer role are also key factors that can affect a person's understanding of health information, as well as being barriers to accessing it.^{22 23 24 25}

Dementia and mental health issues have a cultural and societal stigmatism attached to them, which is a barrier to accessing health services.²⁶

Providers of an information service need to acknowledge that individuals may have different levels of information needs, and that information should be presented at different levels of complexity.²⁷

Knowledge of the different culturally distinct beliefs and behaviours relating to health and health care of the various CALD communities is important in the provision of appropriate health information and health care services.^{28 29 30 31 32}

Endnotes

-
- ¹ J. Mundt, Meeting the need for public education about dementia. *Alzheimer's Disease and Associated Disorders*. 2001, **15** (1) pp. 26 – 30.
 - ² S. Wackerbarth and M. Johnson, Essential information and support needs of family caregivers. *Patient Education and Counseling*, 2002, **47**, pp. 95 – 100.
 - ³ Carers NSW. (2005). *Carer life course framework : an evidence-based approach to effective carer support and education*. NSW Health: Sydney, pp. 52-57.
 - ⁴ P. Werner. Correlates of family caregiver's knowledge about Alzheimer's disease. *International Journal of Geriatric Psychiatry*. 2001, **16** (1) pp. 32 – 38.
 - ⁵ S. Wackerbarth, op. cit.
 - ⁶ Carers NSW, op. cit.
 - ⁷ S. Wackerbarth, op.cit.
 - ⁸ Kate Barnett and Associates. *Cross cultural training needs analysis: Alzheimer's Australia*. Sydney workshops report. October 11, 2004, p. 3.
 - ⁹ P. Werner, op .cit.
 - ¹⁰ C . Simon, Who cares for the carers? The district nurse perspective. *Family Practice*, 2002,**19** (1) pp. 29 – 35. Simon, op. cit.
 - ¹¹ R. Proctor, When a little knowledge is a dangerous thing...a study of carer's knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry*. 2002, **17** (12) pp. 1133 – 1139.
 - ¹² S. Wackerbarth, op. cit.
 - ¹³ C. Glenton, Developing patient-centre information for back pain sufferers. *Health Expectations*. 2002, **5**, pp. 319 – 329.
 - ¹⁴ MLANET. Health Information Literacy. (online) July 23, 2003. <<http://www.mlanet.org/resources/healthlit/define.html>> [accessed 10 October 2005].
 - ¹⁵ C. Glenton, op. cit.
 - ¹⁶ H. Sandstrom. Watch your language. In Consumer health issues, trends and research; part 1. Strategic strides toward a better future. *Library Trends*, 2004, **53** (2)pp. 329 - 335.

- ¹⁷ C. Glenton, op. cit.
- ¹⁸ E. Detlefsen. Where am I to go? Use of the internet for consumer health information by two vulnerable communities. *In Consumer health issues, trends and research; part 1. Strategic strides toward a better future. Library Trends*, 2004, **53** (2)pp. 283 – 300.
- ¹⁹ T. Cosgrove, Planetree health information services: public access to the health information people want. *Bulletin of the Medical Library Association*. 1994, **82** (1) pp. 57 – 63.
- ²⁰ J. Mundt, op. cit.
- ²¹ C. Simon, op. cit.
- ²² K. Alpi and B. Bibel. Meeting the health information needs of diverse populations. *In Consumer health issues, trends and research; part 1. Strategic strides toward a better future. Library Trends*, 2004, **53** (2) pp. 268 – 282.
- ²³ M. Allen, S. Matthew and M.J. Boland. Working with immigrant and refugee populations: Issues and Hmong case study. *In Consumer health issues, trends and research; part 1. Strategic strides toward a better future. Library Trends*, 2004, **53** (2) pp. 301 – 328.
- ²⁴ Multicultural Mental Health Australia and Carers NSW. (2004). *In their own rights. Assessing the needs of carers in diverse communities*. MMHA: Parramatta; p. 5.
- ²⁵ National Ethnic Disability Alliance. (2001). *Personal support program*. (online) <http://www.neda.org.au/files/Personal_Support.doc> [accessed 10 October 2005].
- ²⁶ Multicultural Mental Health Australia, National Ethnic Disability Alliance, Australian Mental Health Consumer Network. (2004). *Reality check. Culturally diverse mental health consumers speak out*. MMHA: Parramatta.
- ²⁷ C. Glenton, op. cit.
- ²⁸ M. Allen, S. Matthew and M.J. Boland. Working with immigrant and refugee populations: Issues and Hmong case study. *In Consumer health issues, trends and research; part 1. Strategic strides toward a better future. Library Trends*, 2004, **53** (2) pp. 301 – 328.
- ²⁹ F. Barron, A. Hunter, R. Mayo and D. Willoughby D. .Acculturation and adherence: issues for health care providers working with clients of Mexican origin. *Journal of Transcultural Nursing*. 2004, **15** (4), pp. 331-337.
- ³⁰ J. Campinha-Bacote. The Process of Cultural Competence in the Delivery of Healthcare Services: a model of care. *Journal of Transcultural Nursing*, 2002, **13** (3), pp. 181-184.
- ³¹ A. Craig. Mental health nursing and cultural diversity. *Australian and New Zealand Journal of Mental Health Nursing*, 1999, **8** (3), pp. 93-99.
- ³² J.A.Erlen. Culture, ethics, and respect: the bottom line is understanding. *Orthopaedic Nursing*, 1998, **17** (6), pp. 79-82.

APPENDIX 2 : Selection Criteria

- Authority
 - Can the reputation of author / organisation be verified?
 - Is the information presented by authors credible, i.e.; information is peer reviewed?
- Currency
 - Has the resource been produced within the last 5 years (2000+)?
 - If > 5 years is the information still current in relation to subject and context?
- Accuracy of content
 - Is the information clinically correct?
 - Is the information factually correct?
- Audience
 - Is the information aimed at the primary audience, who are carers and people with dementia?
 - Can the material be used by the secondary audience; health care workers to support their work with their clients? (*Secondary consideration*)
- Cultural sensitivity
 - Has appropriate language been used for that culture?
 - Does the language show an understanding of cultural based view of mental health and dementia?
- Translation
 - Has the material been translated by an accredited translator?
- Language
 - What is the readability of this resource?
 - Is the material of a consumer health focus?
- Non-judgemental
 - Does the material show an unbiased representation of people living with dementia?
 - Does the material avoid the negative stereotype of people living with dementia?
- Australian Context
 - Is information relating to services, legal, social and financial systems, drugs, etc., relevant to Australia?
 - If the material is from overseas, does the majority of the content meet the other selection criteria?
- Parallel material in English
 - Is the translated title available in English?
 - *If not is the author credible (apply authority criteria)?*
- Availability
 - Is the material readily available in Australia?
 - Is the material free of charge?
- Visual appearance and characteristics (*Secondary selection criteria*)
 - Does the layout allow for ease of readability?
 - For video material is the quality of picture and sound good?
 - For audio material is the quality of sound good?
 - For video and audio material is packaging appropriate?

Sample from Selection Matrix

TITLE	COVERAGE	Authority	Currency	Accuracy of content	Audience	Cultural sensitivity	Translation	Language	Non-judgemental	Australian Context	Parallel in English	Availability	Visual
Mind Your Memory	DEM	Y	Y	Y	Y	Y	Y	Y	Y	Com +	Y	Y	Y
MEDIMATE	support service	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Fees & charges	support service	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Useful contact numbers	support service	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Aged care complaints resolution	support service	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Incontinence Series 1/2/3/4/5/6/7/8/9/10/11/12	dem	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Carers Victoria	SERVICE	Y	Y	Y	Y	Y	Y	Y	Y	VIC or	Y	pdf	Y
A service for independent living HACC	support service	Y	Y	Y	Y	Y	Y	Y	Y	NSW	Y	Y	Y
What does the Guardianship Tribunal do (NSW)	support service	Y	Y	Y	Y	Y	Y	Y	Y	NSW	Y	Y	Y
Opening doors	HP	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	COST	Y
Help at home (North Sydney)	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	nsw - I	Y	Y	Y
Directory of Multicultural Services	HP	useful directory for health professionals. Multicultural officer in council for directory											
Eat and drink safely	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	check	Y
About dementia	dem	Y	Y	Y	Y	Y	Y	Y	Y	Vic	Y	Y	Y
Our Services (Alz Vic)	Dem Services	Y	Y	Y	Y	Y	Y	Y	Y	Vic	Y	Y	Y
Sharing dementia Care (Alz Vic)	Dem Services	Y	Y	Y	Y	Y	Y	Y	Y	Vic	Check	Y	Y
What you can expect when you use (Alz Vic)	Dem Services	Y	Y	Y	Y	Y	Y	Y	Y	Vic	Y	Y	Y
Getting Help (Alz Vic)	Dem Services	Y	Y	Y	Y	Y	Y	Y	Y	Vic	Y	Y	Y
Carer support kit	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Support for carers in their caring role	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Caring for a person with dementia (audio)	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Palliative care	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Loss and grief	dem/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Postcards	check to see if new helpline number will be printed												
Palliative care relief comfort support	DEM/2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

References for Selection Criteria

Translation:

Bastian, K. et. al. (200?). *Guidelines and protocols for translated mental health resources*. West Australian Transcultural Mental Health Centre (online).

<http://www.mmha.org.au/watmhc/CriteriaForTranslatedResources.pdf> [accessed 07/08/2005]

Centre for Culture, Ethnicity & Health. (2005). *How to: Reviewing existing translated materials checklist* (online).

<http://www.ceh.org.au/resources/resbyceh.html> [accessed 07/08/2005]

Centre for Culture, Ethnicity & Health. (2005). *How to: Translating health promotion materials into community languages* (online).

<http://www.ceh.org.au/resources/resbyceh.html> [accessed 07/08/2005]

Centre for Culture, Ethnicity & Health. (2005). *Language Services: Good practice in the Victorian Health and Community Sector* (online).

<http://www.ceh.org.au/resources/resbyceh.html> [accessed 07/08/2005]

Multicultural Communication. (1999). *Seven steps: Guidelines for health staff checking translations* (online). <http://mhcs.health.nsw.gov.au/health-publicaffairs/mhcs/images/pdfs/steps.pdf>

[accessed 07/08/2005]

Multicultural Communication. (2000). *Guidelines for health staff producing multilingual information* (online).

<http://mhcs.health.nsw.gov.au/health-publicaffairs/mhcs/images/pdfs/guidelines.pdf>

[accessed 07/08/2005]

Evaluation Criteria (selected references):

Cornell University. (2004) *Critically analysing information sources*. Modified 6 October 2004

<http://www.library.cornell.edu/olinuris/ref/research/skill26.htm> [accessed 16/08/2005]

Evans, G.E. (2000). *Developing library and information center collections*. 4th ed. Libraries unlimited: Colorado.

HON Foundation (2005). *HON code of conduct for medical and health websites: Principles*.

modified 7 September 2005. <http://www.hon.ch/HONcode/Conduct.html> [accessed 16/08/2005]

Lieberman, J. (2000). *Evaluating health websites*. Modified 1 March 2004 (online).

<http://nnlm.gov/scri/conhlth/evalsite.htm> [accessed 16/08/2005]

State Library of NSW. (2004). *Quality assurance guidelines for health information on the Internet*.

Modified 31 August 2004 (online). <http://www.sl.nsw.gov.au/services/health/eval.cfm> [accessed 16/08/2005]

APPENDIX 3 : Statistics

All statistics and tables in Appendix 3 are based on resources in database on 18/10/2005.

Table 1: Total number of resources by language

Language	Total no. of Resources	% of Resources	% rank
Chinese	100	13.12%	1
Italian	95	12.47%	2
Greek	86	11.29%	3
Arabic	70	9.19%	4
Polish	61	8.01%	5
Vietnamese	58	7.61%	7
Croatian	56	7.35%	6
Spanish	45	5.91%	8
Maltese	32	4.20%	9
Macedonian	32	4.20%	10
Serbian	30	3.94%	11
Turkish	30	3.94%	12
Russian	20	2.62%	13
German	18	2.36%	14
Dutch	13	1.71%	15
Hungarian	11	1.44%	16
Filipino/Tagalog	5	0.66%	17
French	0	0.00%	18
Latvian	0	0.00%	19
Total	762		

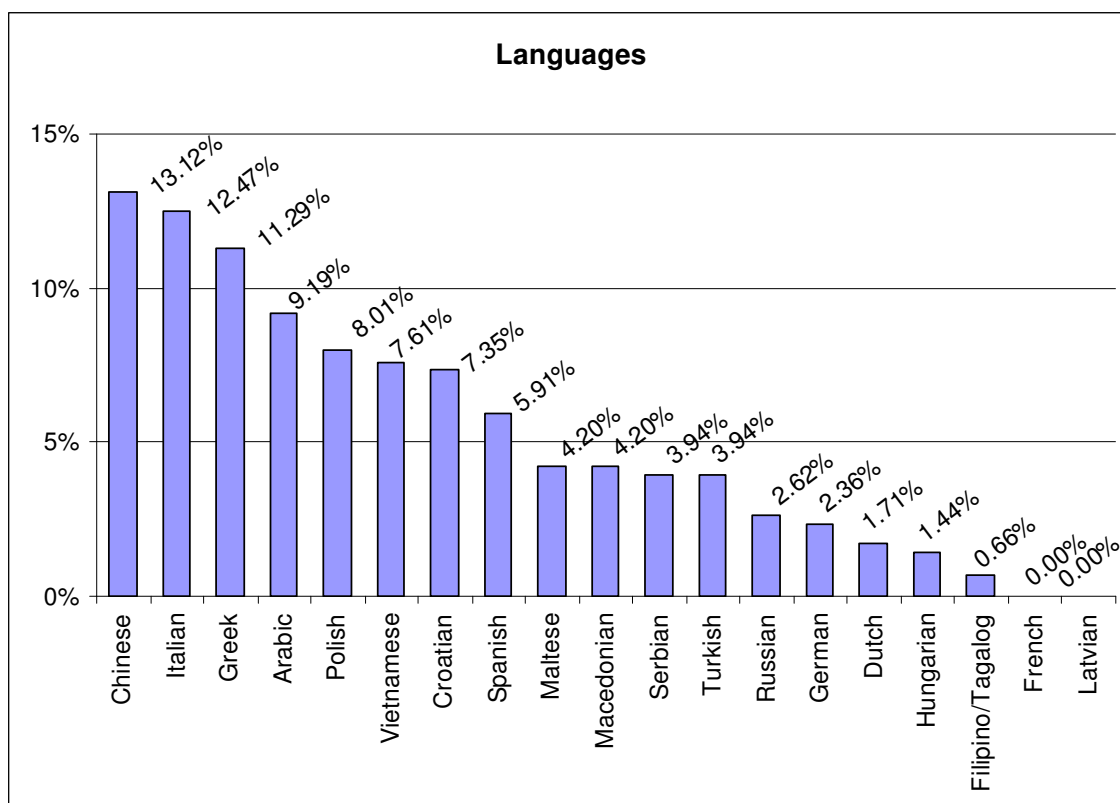


Table 2: Comparison of total number of resources by language against CALD population

Language	Total no. of Resources	% of Resources	% rank	CALD* Population	% of CALD Population
Chinese	45	6.36%	1	38690	8.98%
Italian	95	13.44%	2	111124	25.80%
Greek	86	12.16%	3	73951	17.17%
Arabic	70	9.90%	4	18961	4.40%
Polish	61	8.63%	5	12761	2.96%
Vietnamese	58	8.20%	7	16722	3.88%
Croatian	56	7.92%	6	19021	4.42%
Spanish	45	6.36%	8	16722	3.88%
Maltese	32	4.53%	9	14348	3.33%
Macedonian	32	4.53%	10	13655	3.17%
Serbian	30	4.24%	11	7703	1.79%
Turkish	30	4.24%	12	4940	1.15%
Russian	20	2.83%	13	7754	1.80%
German	18	2.55%	14	33788	7.85%
Dutch	13	1.84%	15	15709	3.65%
Hungarian	11	1.56%	16	8558	1.99%
Filipino/Tagalog	5	0.71%	17	8204	1.91%
French	0	0.00%	18	8028	1.86%
Latvian	0	0.00%	19		
Total	707			430639	

* Persons aged 65+, main language spoken at home 2011 projection (AIHW (2003). Projection of Older Immigrants, p. 24)

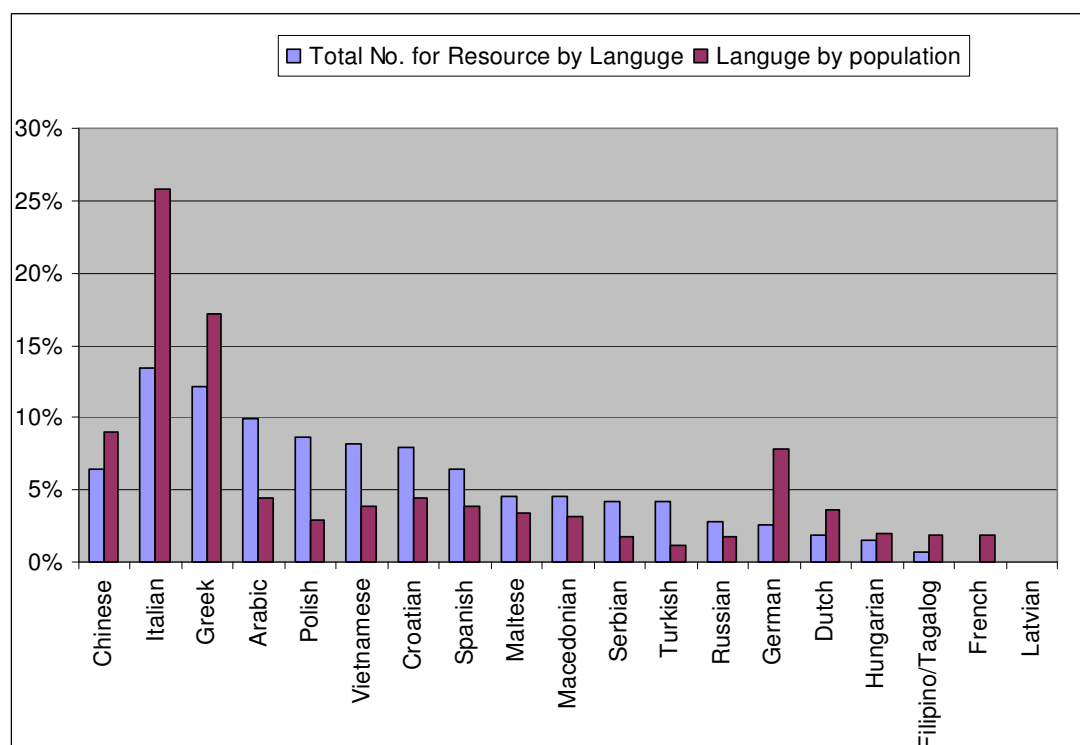


Table 3: Total number of resources by format

Language	Total no. of Resources	% of Resources	% rank
Pamphlet	346	44.47%	1
Leaflet	312	40.10%	2
Book	37	4.76%	3
Booklet	37	4.76%	4
Audio cassette	16	2.06%	5
Video	10	1.29%	6
Promotional	8	1.03%	7
Cards	4	0.51%	8
Kit	4	0.51%	9
Book	3	0.39%	10
DVD	1	0.13%	11
Total	778		

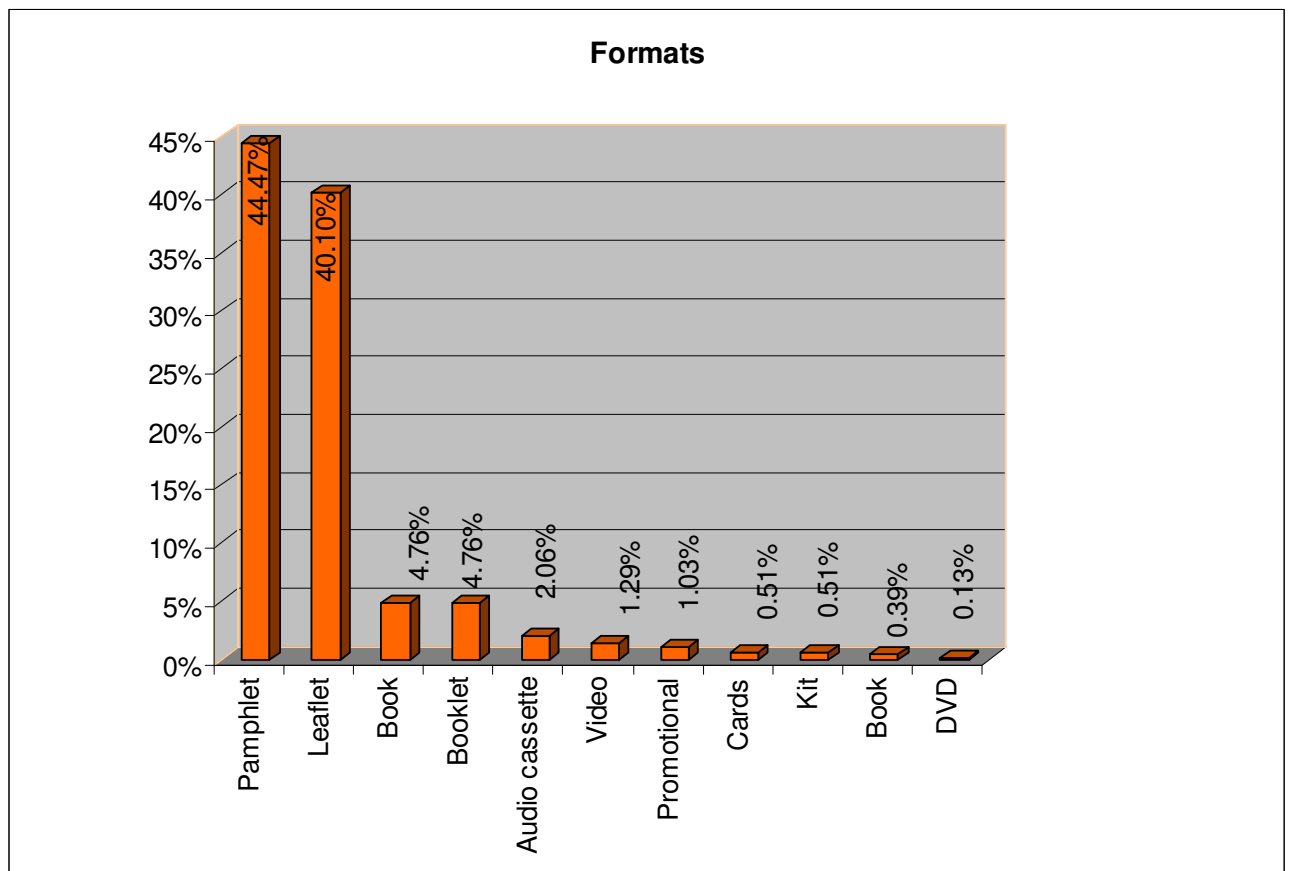


Table 4: Total number of dementia specific resources by subject area

SUBJECT AREAS	Total Dementia Resources	% of Resources
General	60	18.99%
Memory loss	53	16.77%
Service providers	44	13.92%
Care giving	29	9.18%
Behaviours of concern	26	8.23%
Continence	21	6.65%
Communication	20	6.33%
Respite care	14	4.43%
Legal issues	13	4.11%
Grief and loss	12	3.80%
Diagnosis	9	2.85%
Stroke	4	1.27%
Safety	3	0.95%
Stress	3	0.95%
Activities	2	0.63%
Carers	2	0.63%
Assessment	1	0.32%
Total	316	

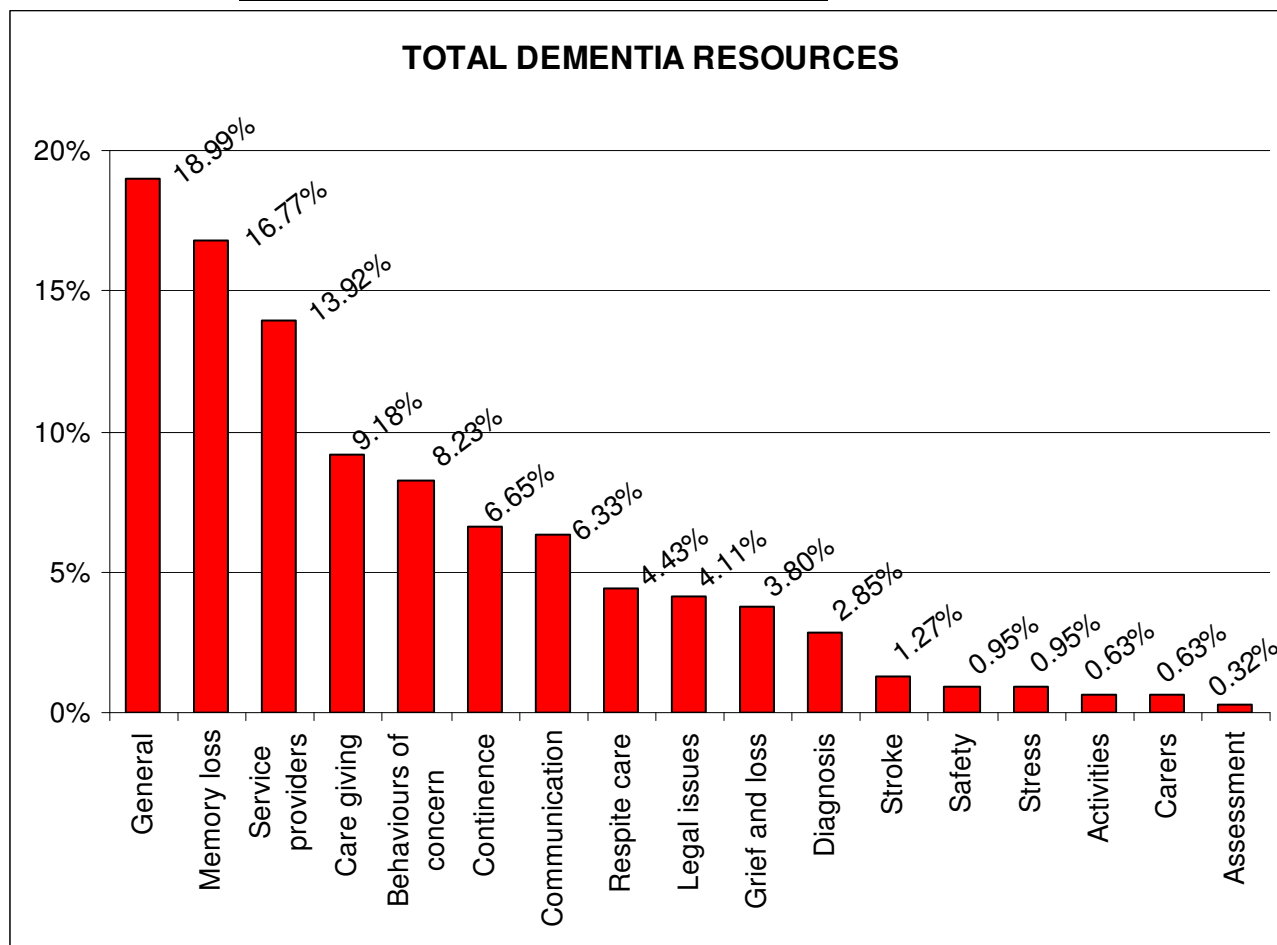


Table 5: Total number of dementia specific resources by author

Authors	Total Dementia Resources	% of Resources
Alzheimer's Australia (NSW)	88	32.71%
Alzheimer's Australia*	57	21.19%
Alzheimer's Australia (SA)*	43	15.99%
SWSAHS	17	6.32%
Aus Dep Health & Ageing	14	5.20%
Alzheimer's Australia (WA)	10	3.72%
DADHC	10	3.72%
Alzheimer's Australia (Vic)*	9	3.35%
Australian Multicultural	8	2.97%
Health Translation Unit	6	2.23%
WHO	3	1.12%
CO.AS.IT	2	0.74%
Alzheimer's Disease Society	1	0.37%
PBS	1	0.37%
Total*	269	

* Excludes services material

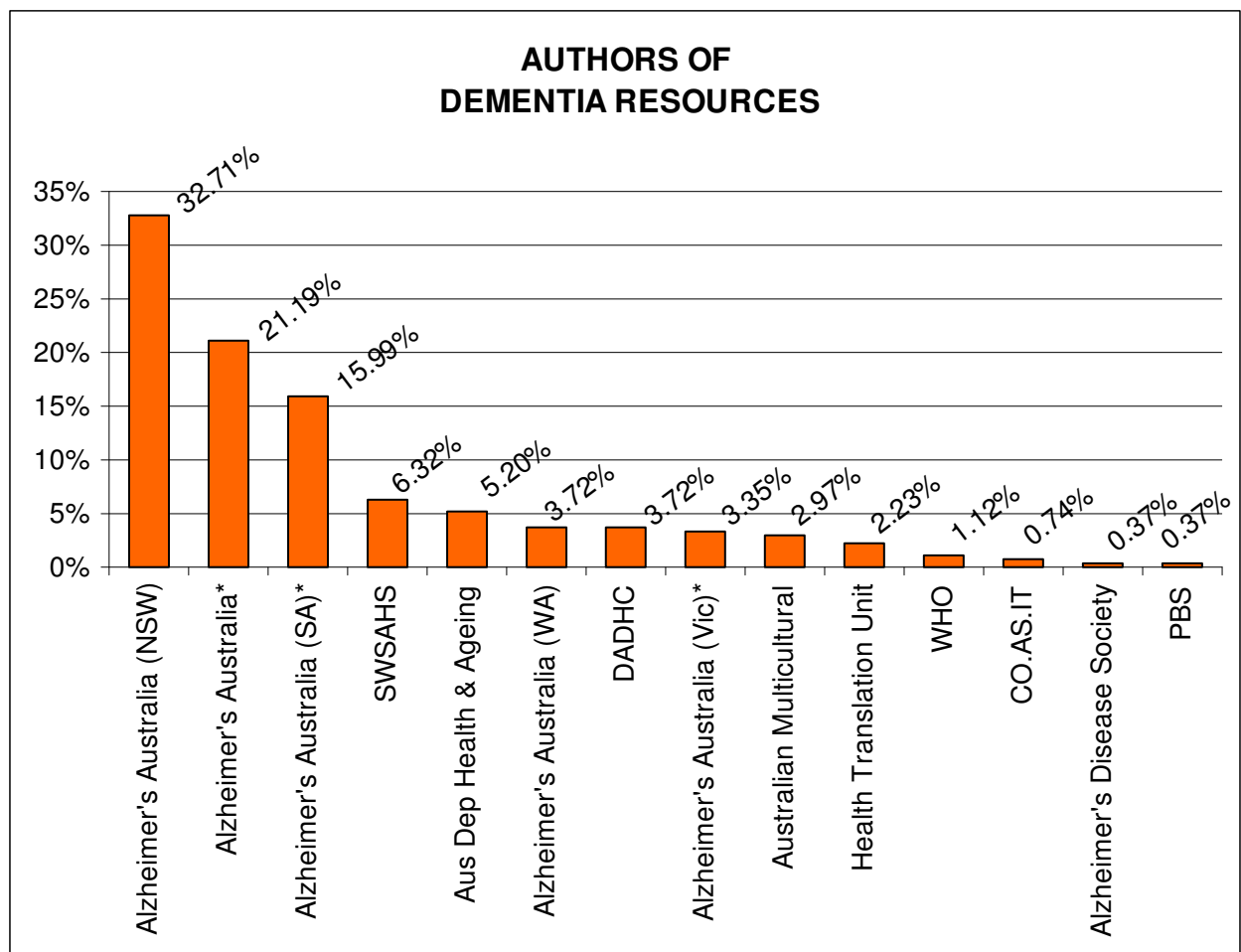


Table 6: Chinese dementia specific resources

CHINESE SUBJECT AREAS	Chinese Resources	% of Resources
General	7	15.56%
Behaviours of concern	5	11.11%
Care giving	5	11.11%
Memory loss	5	11.11%
Communication	4	8.89%
Respite care	4	8.89%
Service providers	4	8.89%
Activities	2	4.44%
Continence	2	4.44%
Diagnosis	2	4.44%
Legal issues	2	4.44%
Assessment	1	2.22%
Safety	1	2.22%
Stress	1	2.22%
Carers	0	0.00%
Grief and loss	0	0.00%
Stroke	0	0.00%
Total	45	

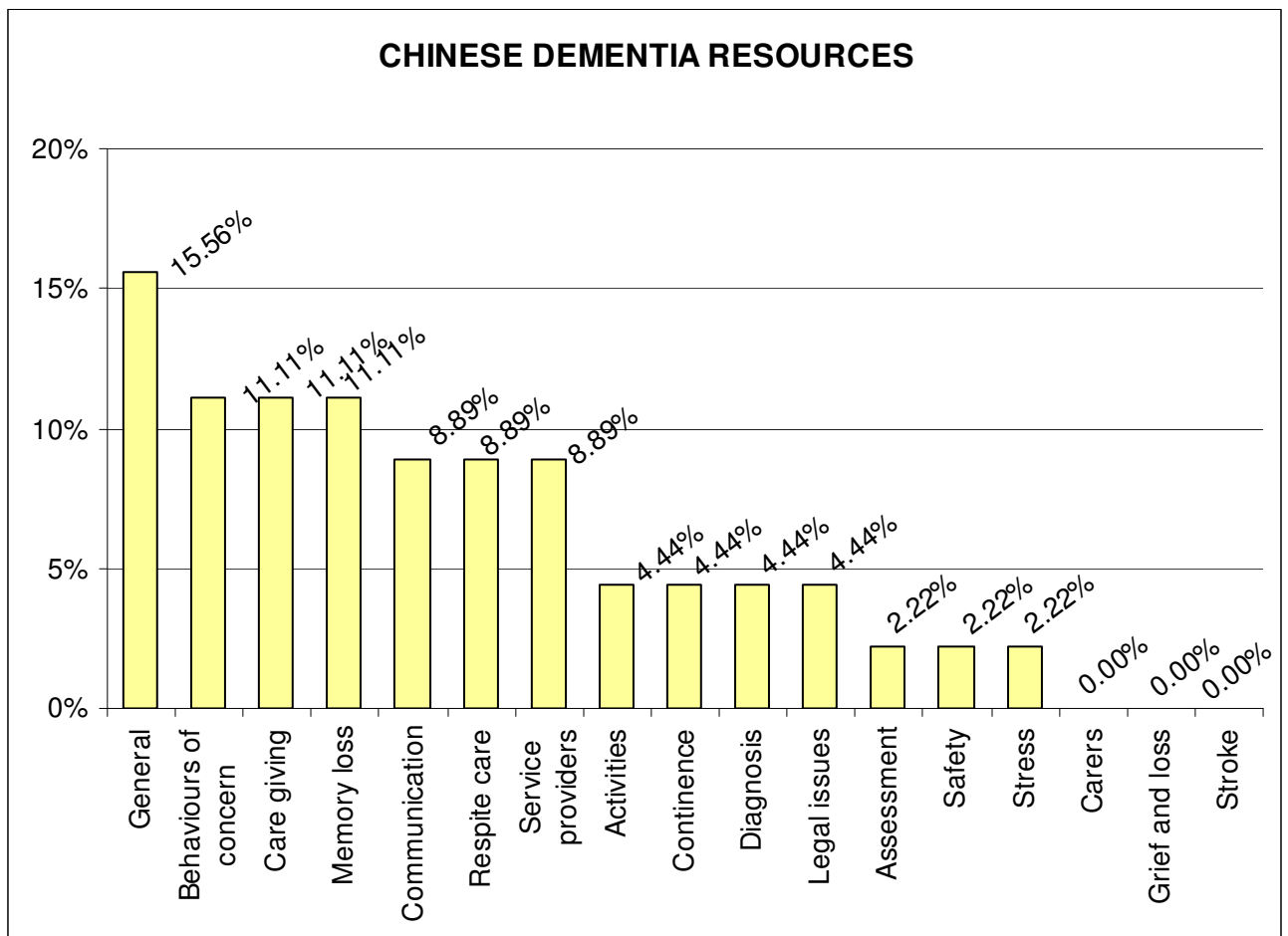


Table 7: Italian dementia specific resources

ITALIAN SUBJECT AREAS	Italian Resources	% of Resources
General	12	24.00%
Memory loss	9	18.00%
Behaviours of concern	5	10.00%
Service providers	4	8.00%
Communication	3	6.00%
Grief and loss	3	6.00%
Respite care	3	6.00%
Care giving	2	4.00%
Continence	2	4.00%
Diagnosis	2	4.00%
Legal issues	2	4.00%
Safety	1	2.00%
Stress	1	2.00%
Stroke	1	2.00%
Activities	0	0.00%
Assessment	0	0.00%
Carers	0	0.00%
Total	50	

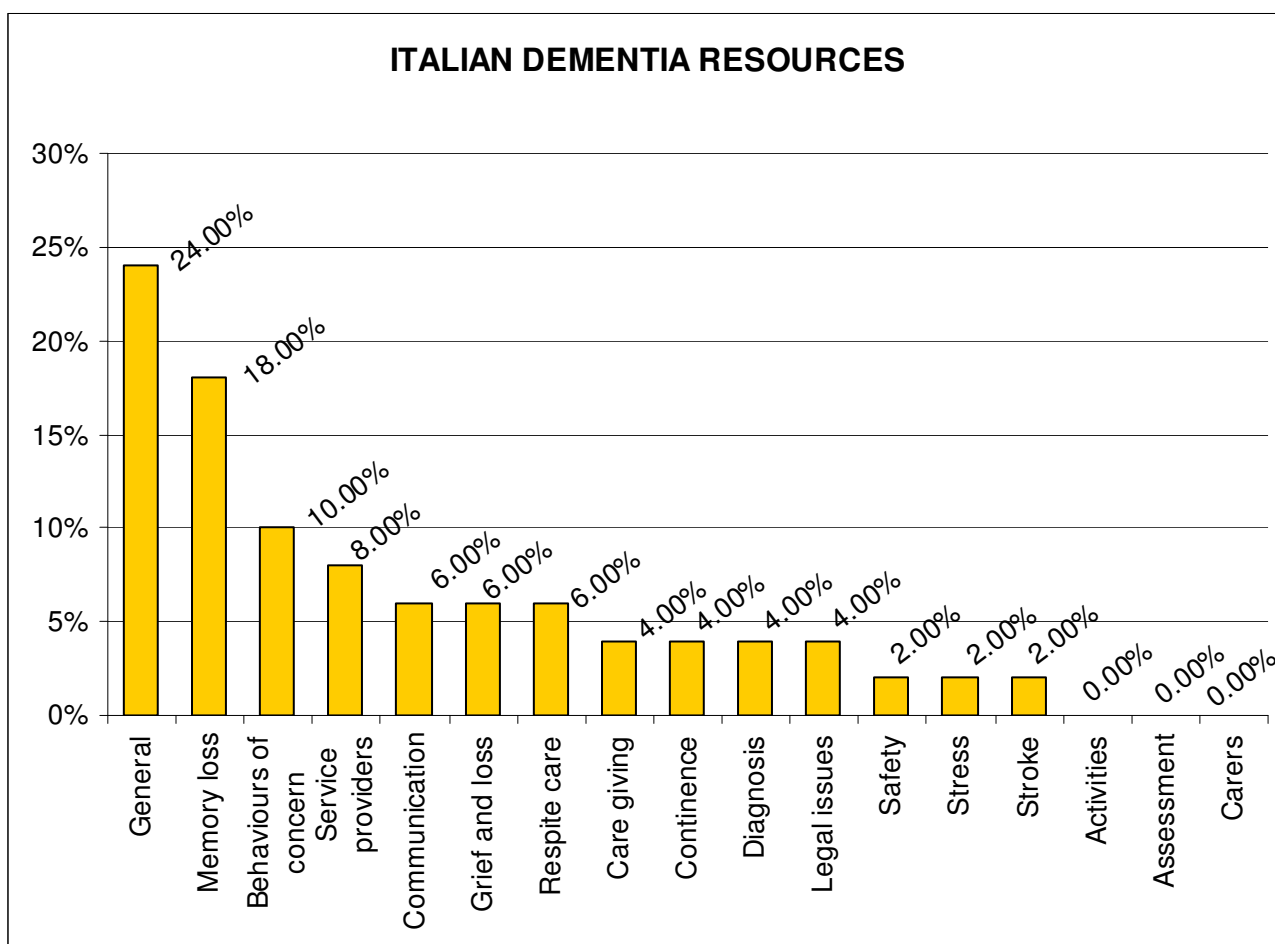


Table 8: Greek dementia specific resources

GREEK SUBJECT AREAS	Italian Resources	% of Resources
General	9	18.75%
Memory loss	7	14.58%
Service providers	5	10.42%
Behaviours of concern	4	8.33%
Care giving	4	8.33%
Communication	4	8.33%
Grief and loss	3	6.25%
Respite care	3	6.25%
Continance	2	4.17%
Diagnosis	2	4.17%
Legal issues	2	4.17%
Safety	1	2.08%
Stress	1	2.08%
Stroke	1	2.08%
Activities	0	0.00%
Assessment	0	0.00%
Carers	0	0.00%
Total	48	

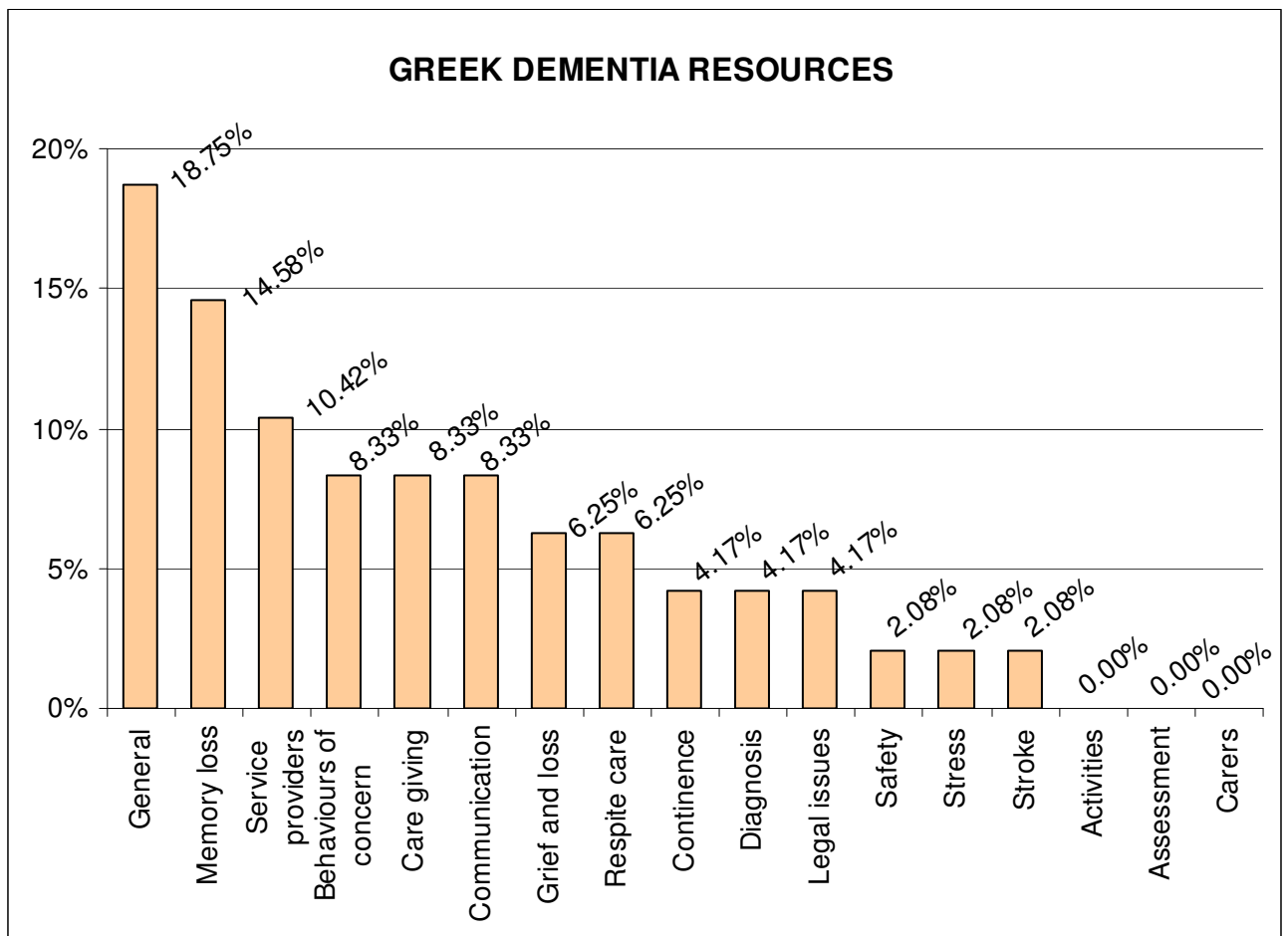
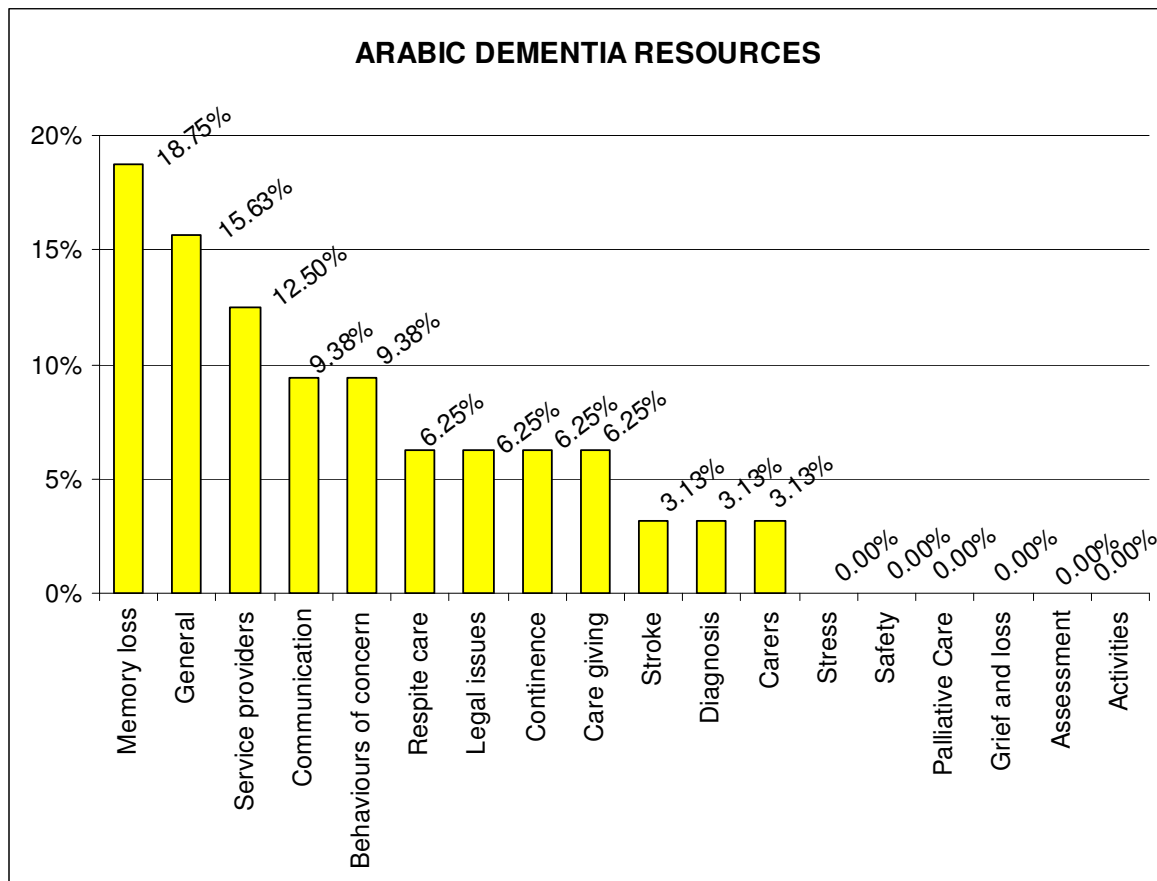


Table 9: Arabic dementia specific resources

ARABIC SUBJECT AREAS	Arabic Resources	% of Resources
Memory loss	6	18.75%
General	5	15.63%
Service providers	4	12.50%
Communication	3	9.38%
Behaviours of concern	3	9.38%
Respite care	2	6.25%
Legal issues	2	6.25%
Continance	2	6.25%
Care giving	2	6.25%
Stroke	1	3.13%
Diagnosis	1	3.13%
Carers	1	3.13%
Stress	0	0.00%
Safety	0	0.00%
Palliative Care	0	0.00%
Grief and loss	0	0.00%
Assessment	0	0.00%
Activities	0	0.00%
Total	32	



APPENDIX 4 : Subject Gateways

Selected References

- BIOME. Background: Subject gateway principles. Last modified 11 February 2005. <http://omni.ac.uk/about/background.html> [accessed 25/09/2005]
- Hofman, P., et al. (1997). Specification for resource description methods Part 2: Selection criteria for quality controlled information gateways. In *DESIRE - Development of a European Service for Information on Research and Education* (online) <http://www.ukoln.ac.uk/metadata/desire/quality/> [accessed 25/09/2005]
- Kelly, B., Closier, A. and Hiom, D. (2005). Gateway standardization: A quality assurance framework for metadata. *Library Trends*, **53**(4), pp. 637-650.
- Koch, T. (2000). Quality-controlled subject gateways: definitions, typologies, empirical overview. *Online Information Review*, **24**(1). (online) <http://www.lub.lu.se/~traugott/OIR-SBIG.txt> [accessed 25/09/2005]
- National Library of Australia. (n.d.). Australian Subject Gateway Forum: Articles. Last verified 14 December 2004. <http://www.nla.gov.au/initiatives/sg/articles.html> [accessed 25/09/2005]
- National Library of Australia. (1999). *Best practice checklist for Australian subject gateways*. Modified February 2001 <http://www.nla.gov.au/initiatives/sg/bestpractice.html> [accessed 25/09/2005]
- National Library of Australia.(2000). *Definitions for web-based services*. Update 2003. <http://www.nla.gov.au/initiatives/sg/servicetypes.html> [accessed 25/09/2005]
- Roszkowski, M. and Lukas, C. (1998). A distributed architecture for resource discovery using metadata. *D-Lib Magazine* (online) <http://www.dlib.org/dlib/june98/scout/06roszkowski.html> [accessed 25/09/2005]
- Tennant, R. (1998). The art and science of digital bibliography. *Library Journal*, **123**(17), pp. 28-29.