

# Management of Cognitive Communication Difficulties in Dementia: A Cross- Sectional Survey of Speech & Language Therapists in Ireland

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**Background:** Cognitive communication difficulties are a characteristic feature of dementia. Speech and language therapists (SLTs) have an important role in managing cognitive communication difficulties associated with dementia. Yet there is a lack of information about the clinical practice of SLTs in dementia care in Ireland and this affects the development and delivery of comprehensive services for people with dementia. The purpose of this study was to survey SLTs working in dementia services in Ireland to review current practice, and to gain insight into their perspectives on service provision in the context of the Irish Dementia Strategy.

**Methods:** A cross sectional survey design was used to review the current practice of SLTs working in dementia services in Ireland. Purposive snowball sampling was used to recruit participants across the Republic of Ireland. The survey comprised 21 questions using various question formats, seeking information on SLT respondent demographics, current practice in the management of cognitive communication disorders in dementia, involvement in research, the levels of satisfaction with existing services for people with dementia and familiarity with the Irish National Dementia Strategy (INDS). Descriptive statistic and thematic analysis were used to organise and analyse the data.

**Results:** Eighty-nine SLTs completed the survey. The most frequently expressed concern across the survey was that dysphagia management takes priority over cognitive communication disorders with 61% (n=89) of respondents spending less than 25% of their clinical time working with communication disorders. There is a low rate of referral for communication interventions and typically people are referred in the advanced stages of dementia. SLTs reported regularly providing specific communication training for families and health care staff to support communication access for the person with dementia. Although the majority of respondents (89%, 59/65) are familiar with the INDS, 40% said they were "not at all confident" and 45% were only "slightly confident" that they could meet the recommendations outlined in the strategy.

Specific key recommendations were identified; increased focus on the management of communication disorders, increased MDT working, improved understanding by other health care professionals of the SLT role in dementia care, as well as improved staffing levels including specialty posts.

**Conclusions:** This is the first Irish survey to date of SLT management of cognitive communication difficulties in people with dementia. These results reflect the range of barriers facing SLTs in clinical practice. While the majority of SLTs provide dysphagia services, this survey identifies areas for service development to specifically manage communication difficulties experienced by people with dementia.

**Key words:** dementia, cognitive communication, speech and language therapy, Ireland

## 1.1 Introduction

It is estimated by that by 2046 ,there will be 152,157 people in Ireland living with dementia (Department of Health, 2014), this is nearly a threefold increase from current 2017 figure of 54,793. Communication difficulties are inherent in a diagnosis of dementia and the person's individual communication profile will vary depending on the stage and subtype of dementia. (Bourgeois and Hickey, 2011, Orange and Colton-Hudson, 1998). It is important to address cognitive communication impairment as problems with communication may be an initial presenting feature of dementia (Bourgeois and Hickey, 2011), and over time dementia causes increased disruption to the cognitive-linguistic system. This changes the way in which the person interacts, reducing communicative flexibility and effectiveness. .This can lead to low self-esteem, reduced levels of independence and quality of life, with significant impact on the personal relationships of the person with dementia (Jones, 2015). It is important that the person's communication needs are addressed at the outset. Worldwide, speech and language therapists (SLTs) have a clearly defined role in dementia (ASHA, 2016, IASLT, 2016, RCSLT, 2014) delivering services to people with dementia to assess and manage communication difficulties, along with any eating, drinking and swallowing (EDS) problems that may develop in the course of the condition.

This study is a cross sectional survey of SLTs working in dementia identifying patterns in the assessment and management of cognitive communication disorders and explores both the strengths and challenges of current service provision. Surveyed SLTs share their perspectives on a range of topics including the Irish National Dementia Strategy (Department of Health, 2014).

The role of the SLT in the management of dementia is well referenced in practice documents by the profession internationally (American Speech Hearing Association, 2016, Irish Association of Speech and Language Therapists, 2016, Royal College of Speech and Language Therapists, 2014). Clinical experience and SLT research suggest that much clinical time is focused on the management of swallowing rather than cognitive communication disorders. In Portugal, there are limited SLT services available to people with dementia (Nóbrega et al., 2016), with just 14% (n=33) of SLTs surveyed were working in the area of dementia care. The American Speech-Language-Hearing Association conducted a survey of caseload characteristics of SLTs (ASHA, 2011), which found that 60% of SLTs surveyed (n=1012) work with adults and spend 42% of their clinical time addressing swallowing difficulties and 15% of their time with cognitive communication disorders in dementia. This is not an indication of the prevalence of communication and swallowing disorders in this population, but rather further confirmation that SLTs do not routinely provide a comprehensive speech and language therapy service to people with dementia. There is an awareness of the low rates of referral to SLT services (Cleary et al., 2003) and the poorly understood role of the SLT although there is limited information on the reasons behind this.

This lack of information about the clinical practice of SLTs in dementia care in Ireland impacts on the development and delivery of comprehensive services for people with dementia. The aim of this research was to survey SLTs working in dementia services in Ireland to review current practice, and to gain insight into SLT experiences and opinions.

## 1.2 Method

A cross sectional survey design was selected to systematically review the current practice of SLTs working in dementia services. This survey collected qualitative information on the SLTs opinions and experiences. Ethical approval was obtained from the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin.

### 1.2.1 Survey Design

Survey content was informed by a literature review on previous surveys in the area and consultation with two experienced SLT colleagues working in dementia care. Topics relevant to the current practice of SLTs working with people with dementia were selected to fit with the aims of the study and were in keeping with the literature. An initial version of the survey was piloted with these SLTs and their feedback informed further the content, face and ecological validity of the survey. Survey revisions included addressing omissions in some dementia assessments listed in the survey, inclusion of questions on palliative care and expanded questions on the INDS. The survey was then refined based on their feedback: these SLTs did not participate further in the study.

The final survey comprised 21 questions using various question formats; multiple choice, closed questions, rating scales and matrix questions (see Table 1.1). Open-ended questions and comment boxes were incorporated to allow for individual comments and expansion of opinions. Information was sought on SLT respondent demographics, current practice in the management of cognitive communication disorders in dementia, involvement in research, the levels of satisfaction with existing services for people with dementia and familiarity with the INDS.

*Table 1.1 Survey: SLT Practice in Management of Cognitive Communication Difficulties in People with Dementia in Ireland*

<b>Questions and Response Options</b>
<b>Section 1: Demographics</b>
1. In what type of setting are you currently working with people with dementia?
2. Approximately what percentage of your clinical time do you spend working in dementia?
3. Approximately what percentage of this clinical time is spent working with people with dementia on the assessment and management of their communication difficulties (i.e. not dysphagia management)?
4. At which stage of their dementia are people most commonly referred?
5. Who most frequently refers the person with dementia to your speech & language therapy service?
<b>Section 2: Service delivery</b>
6. How satisfied are you with the current level of speech & language therapy service delivery to people with dementia in your setting?
7. Please rank the following factors by how you believe they would improve service delivery for people with dementia in your clinical setting. (Rank in order of importance from 1-6, 1 being the most important factor and 6 being the least important).
<ul style="list-style-type: none"> <li>• Early referral to your speech &amp; language therapy services from medical and community health teams</li> <li>• Timely access to your speech &amp; language therapy services</li> </ul>

<ul style="list-style-type: none"> <li>• Improved knowledge of the role of the SLT by other professions such as physiotherapy, occupational therapy, medical and nursing professions</li> <li>• Increased multi-disciplinary management of people with dementia</li> <li>• The use of a speech &amp; language therapy care pathways for people with dementia</li> <li>• Access to community supports such as “Dementia Cafes” and “Living Well with Dementia” programmes</li> </ul>
<p>8. Please rank the following factors by how you believe they would improve your management of communication difficulties in people with dementia in your clinical setting? (Rank in order of importance from 1-5, 1 being the most important factor and 5 being the least important).</p> <ul style="list-style-type: none"> <li>• Allocated clinical time for services to people with dementia</li> <li>• Availability of appropriate cognitive communication assessments for dementia</li> <li>• Availability of a range of resources for intervention approaches in dementia</li> <li>• Ease of access to the primary communication partner of the person with dementia</li> <li>• Direct clinical experience and specialist clinical skills working with people with dementia</li> </ul>
<p>9. If you could change one aspect of the current speech &amp; language therapy service for people with dementia, what would that be?</p>
<p>10. If you could retain one aspect of the current speech &amp; language therapy service to people with dementia, what would that be?</p>
<p>11. What challenges you in the management of communication difficulties in people with dementia?</p>
<p>Section 3: Assessment and management of cognitive communication disorders in people with dementia</p>
<p>12. Please describe how frequently you complete each of these clinical practices when working with a person with dementia (Rank order from never to always):</p> <ul style="list-style-type: none"> <li>• Informally assess the person with dementia's communication ability</li> <li>• Formally assess the person with dementia's communication ability using published tools</li> <li>• Liaise with the person with dementia's primary communication partner regarding their communication ability and support strategies</li> <li>• Liaise with other members of the care team about the person with dementia's cognitive communication difficulties</li> <li>• Provide "one to one" communication therapy to people with dementia</li> <li>• Provide communication therapy groups for people with dementia</li> <li>• Deliver communication support groups for care givers of people with dementia</li> <li>• Deliver therapy groups for people with dementia and their communication partners</li> <li>• Provide staff training on how to support the communications of people with dementia</li> <li>• Provide training to family and/or staff on enhancing the physical communication environment</li> <li>• Deliver therapy groups for people with dementia jointly with other allied health professionals</li> <li>• Provide communication support with decision making for the person with dementia, the family and multidisciplinary team</li> </ul>
<p>13. What tools do you currently use to assess the communication of people with dementia? (Please select all applicable)</p> <ul style="list-style-type: none"> <li>• Arizona Battery of Communication Disorders in Dementia (ABCD)</li> <li>• Functional Linguistic Communication Inventory (FLCI)</li> <li>• Cognitive Analysis Profile for People with Cognitive Impairment (CAPPCI)</li> <li>• Communication Effectiveness Index (CETI)</li> <li>• Severe Impairment Battery (SIB)</li> <li>• Cognitive Linguistic Quick Test (CLQT)</li> <li>• Threadgold Communication Tool for Persons with Dementia (TCT)</li> <li>• Evaluation of the Environment and Communication Assessment Toolkit (ECAT)</li> <li>• ASHA Functional Assessment of Communication Skills (ASHA FACS)</li> <li>• Measure of Cognitive Linguistic Ability (MCLA)</li> <li>• Communication Activities of Daily Living (CADI-2)</li> </ul>

<ul style="list-style-type: none"> <li>• Ross Information Processing Assessment-2 (RIPA-2)</li> <li>• Boston Naming Test (BNT)</li> <li>• Conversational Analysis Tools</li> </ul>
<p>14. From the list provided below, please identify the equipment used in your work with people with dementia</p> <ul style="list-style-type: none"> <li>• Audio recorder, MP3</li> <li>• Video cameras</li> <li>• Wearable cameras (Sense Cam/ProCam)</li> <li>• Android tablets and/or i-Pads</li> <li>• Phones e.g. mobile, big button phones, photo memory phones</li> <li>• White boards</li> <li>• Memory aids</li> <li>• Wii</li> <li>• Nintendo DS</li> <li>• GPS watches</li> <li>• Other</li> </ul>
<p>15. Please identify which of the following communication and memory supports you routinely use with people with dementia</p> <ul style="list-style-type: none"> <li>• Memory aids e.g. diaries, timetables and white boards, alarms</li> <li>• Life story books</li> <li>• Memory boxes</li> <li>• Communication support books</li> <li>• Talking Mats™</li> </ul>
<p>16. Which of the following intervention approaches do you use when working with people with dementia?</p> <ul style="list-style-type: none"> <li>• Conversation therapy</li> <li>• Environment modification</li> <li>• Simulated presence therapy</li> <li>• Cognitive stimulation therapy</li> <li>• Reminiscence therapy</li> <li>• Montessori based therapy</li> <li>• Validation therapy</li> <li>• Intensive interaction therapy</li> </ul>
<p>17. Do you recommend people with dementia and their families to engage with non-clinical activities and/or services in their communities (e.g. dementia cafes, support groups, choirs, active retirement clubs, online resources)?</p>
<p>18. Have you carried out dementia related research? Yes/No</p>
<p>19. Are you involved in the management of cognitive communication difficulties in people with dementia, in the palliative stages of care? Yes/No</p>
<p><b>Section 4: Irish National Dementia Strategy</b></p>
<p>20. How familiar are you with the recommendations of the Irish National Dementia Strategy 2014? (Ranked response: Not at all familiar to extremely familiar)</p>
<p>21. How confident are you in your ability to meet the recommendations outlined in the Irish National Dementia Strategy 2014 (such as; timely diagnosis &amp; intervention, integrated care and support for people with dementia and their families across all care settings)?</p> <p>(Ranked response: Not at all confident to extremely confident)</p>

### 1.2.2 Participants and Recruitment

Purposive snowball sampling was used to recruit participants across the Republic of Ireland. Participants were SLTs working with adult populations in the Republic of Ireland. There are 1,717 SLTs currently

registered with CORU (Health and Social Care Professionals Council) in Ireland. The number of these working with people with dementia and adult caseloads is unknown.

Inclusion criteria for the study were professionally qualified SLTs working in Ireland with Internet access to complete the survey. SLTs involved in content development and piloting were excluded from the study. Participants were recruited through the Irish SLT Dementia Network, the professional body of the IASLT, the Adult Acquired Communication Disorder Special Interest Group and the Irish SLT Managers Group. Gatekeepers were chairpersons of these groups. They received an invitation to consider circulating an attached email that contained information on the project and the survey link to the members of (name of body /group inserted). Potential participants were provided with information about the study and the electronic survey link via email and social media. Survey Monkey (<http://surveymonkey.com>) was used to create and disseminate the survey. Participants self-selected from the information provided to them in the participants' information e-mail. A reminder e-mail (was circulated 2 weeks before the survey closed).

### **1.2.3 Data collection and analysis**

This survey was conducted between 15<sup>th</sup> January to 31<sup>st</sup> March 2018. An initial informal survey was completed in 2015 at the start of the project, but was not published, as ethical approval was not sought for this initial survey. In 2018 this research was completed more thoroughly and officially with ethical approval.

Responses were downloaded and collated using an Excel spreadsheet. Data was anonymised in accordance with data protection legislation (Data Protection Commission, 2018). Descriptive statistic and thematic analysis were used to analyse the data. Analysis of closed questions was completed using descriptive statistics, providing a summary of the data. Thematic analysis (TA) (Braun et al., 2019) enabled a more in-depth analysis of respondents' expanded qualitative comments. This phase involved; familiarisation with the data, code generation, searching for themes and reviewing and defining themes. Important themes from within the data were coded and analysed. All survey responses were analysed.

## **1.3 Results**

Eighty-nine SLTs responded to the survey. The response rate was considered representative of the range of clinical settings where SLTs work with people with dementia and was in line with other international practice surveys (Nóbrega et al., 2016, ASHA, 2011). There was a completion rate of 73% (n=65) (see Table 1.2). Survey participation reduced once SLTs were asked about their level of satisfaction with their dementia service (Question 6), response rates reduced further when they were specifically questioned about communication assessment and intervention for people with dementia (Questions 12-16).

### **1.3.1 SLTs' work settings and caseloads**

Surveyed SLTs worked in a variety of clinical settings and some (11/89, 12%) in a combination of settings such as acute care, long term care and community hospital-community care. Most respondents were employed either in an acute hospital (34/89, 38%) or community care setting (25/89, 29%). The overall proportion of their clinical time working with people with dementia was high (66/89, 68%), working 50% of the time or more with people with dementia. However, this time accounts for management of swallowing

disorders as well as cognitive communication impairments. All SLT respondents worked with people with dementia and all provided a dysphagia service, but frequently exclusively a dysphagia service. Thirteen percent (12/89) responded that they never manage communication difficulties as part of their dementia service. The number of SLTs working in a fulltime capacity in dementia services (dysphagia and communication service) was considered low at 5.6% (5/89). There was just one respondent who worked full time in the management of communication disorders in dementia.

Participants were asked to identify the amount of time spent managing communication impairments. Over half of the SLT respondents (54/89, 61%) worked less than 25% of their clinical time with communication impairments. They were concerned about the lack of clinical time available for the management of the communication needs (32/69,46%) as the management of eating, drinking and swallowing problems demands a higher clinical priority.

### 1.3.2 Referral pattern

Responses to Question 4, “Who refers the person with dementia to your speech and language therapy service?”, identified medical consultants (51/84, 60%), public health nurses/clinical nurse managers (40/84), 48%) and occupational therapists (34/84, 40%). People with dementia do not often self-refer for speech and language therapy (4/84, 5%). Memory clinics were identified as a regular source of referral to speech and language therapy (18/84, 21%). Other health and social care professionals (HSCPs) that refer people to speech and language therapy were physiotherapists and psychologists. Some SLTs reported that due to local policy they can only receive referrals from medical consultants, which restricts the rate and type of referrals to their service. Another participant commented that “*all new residents are seen automatically for baseline assessment on admission*”. A range of referral practices were identified which are unique to their clinical settings and multidisciplinary teams.

Participants were asked (Question 5) at which stages of dementia people were most consistently (regularly or always) referred to speech and language therapy (see Table 1.2). The Global Deterioration Scale (GDS) (Reisberg et al., 1982) was used to guide responses to this question. Responses indicate that referrals to speech and language therapy services increase with progressing dementia.

Table 1.2 When are people with dementia referred to Speech and Language Therapy

Stages of Dementia	GDS Levels (Reisberg et. al., 1982)	Regularly or always referred to Speech and Language Therapy	Response rate
MCI	2-3	10%	8/81
Early Dementia	4	20%	17/84
Mid-Stage Dementia	5-6	62%	52/84
Late Dementia	7	75%	64/85

### 1.3.3 Assessment Practice

Only 15% (10/65) of respondents reported that they regularly or always use formal assessments with people with dementia (see Table 1.3). Informal cognitive communication assessments were reported as commonly used by three quarters of SLT respondents (49/65, 75%). Respondents cited the following challenges in the use of formal assessment: the clinical setting (acute care) and the lack of available and appropriate cognitive communication assessments.

The four most frequently used cognitive communication assessments reported were; (1) Boston Naming Test (BNT) (Kaplan et al., 2001), (2) Arizona Battery of Communication Disorders in Dementia (ABCD) (Bayles and Tomoeda, 1993), (3) Cognitive Linguistic Quick Test (CLQT) (4) Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994). Two SLT (2/56, 4%) reported using aphasia batteries; the Comprehensive Aphasia Test (CAT) (Swinburn et al., 2004) and the Western Aphasia Battery (WAB) (Kertesz, 2006) to assess communication. Discourse analysis tools for people with dementia were used infrequently such as the Cognitive Analysis Profile for People with Cognitive Impairment (CAPPCI) used by just one SLT respondent. Three SLTs (3/56, 5%) reported using cognitive screening assessments such as the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005).

Expanded feedback from respondents about assessment practice in working with people with intellectually disability (2/56, 4%) said they use informal assessment more frequently as there is a lack of access to appropriate communication assessments. Informal assessment is a suitable approach to assessment of people with severe intellectual disability and dementia. Three SLTs (3/56, 5%) commented that they never use formal communication assessments.

Table 1.3 Communication Assessment Usage (N= 56)

<b>Formal Assessments</b>	<b>Respondents</b>	
	<i>Number of respondents</i>	<i>Percentage of respondents</i>
Arizona Battery Of Communication Disorders in Dementia (ABCD) (Bayles and Tomoeda, 1993)	30	54%
Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994)	23	41%
Cognitive Analysis Profile For People With Cognitive Impairment (CAPPCI)(Perkins et al., 1997)	1	2%
Communication Effectiveness Index (CETI) (Lomas et al., 1989)	1	2%
Severe Impairment Battery (SIB) (Ferris et al., 2009)	0	0%
Cognitive Linguistics Quick (Helm-Estabrooks, 2001)	30	54%
Threadgold Communication Tool for Persons With Dementia (TCT) (Strøm et al., 2016)	0	0%
Environmental & Communication Assessment Toolkit (ECAT) (Bruce et al., 2013)	1	2%



ASHA Functional Assessment of Communication Skills (ASHA-FACS) (Paul et al., 2004)	8	14%
Measure of Cognitive Linguistic Ability (MCLA)	17	30%
Communication Activities Of Daily Living (CADL-2) (Holland et al., 1999)	9	16%
Ross Information Processing Battery-2 (RIPA-2) (Ellmo et al., 1995)	16	29%
Boston Naming Test (BNT)	34	61%
Conversational Analysis Tools	2	4%

### 1.3.4 Intervention Practice

Sixty-five SLTs responded to questions on the management of communication impairments in people with dementia. SLTs reported that “one to one” communication therapy is rarely or never (46/65, 72%) provided to people with dementia. Group therapy was rarely or never provided (55/65, 84%) also.

SLTs said they sometimes or regularly work with families and health care professionals to manage communication disabilities indirectly. They reported providing communication training for staff (33/64, 52%), communication partner training and training on modifying the physical environment to enhance communication (31/65, 47%). Working directly with the CP to improve communication support was the most commonly reported communication intervention by SLTs (61/64, 88%). SLTs said they often (57/65, 87%) liaised with the MDT about the person with dementia’s cognitive communication difficulties and were frequently (32/65, 67%) involved in supporting communication in decision making meetings.

Conversation therapy and reminiscence therapy are popular therapeutic approaches, used by over 70% of SLT respondents. This finding does not reflect the initial reports by SLTs outlined in the previous paragraph, that they do not often provide “one to one” therapy, as a conversational therapy approach is a direct approach to intervention. This finding will be discussed in Section 1.1. Environmental modification (see Figure 1.1) was reported as the most frequently used intervention with people with dementia (48/58, 82.76%).

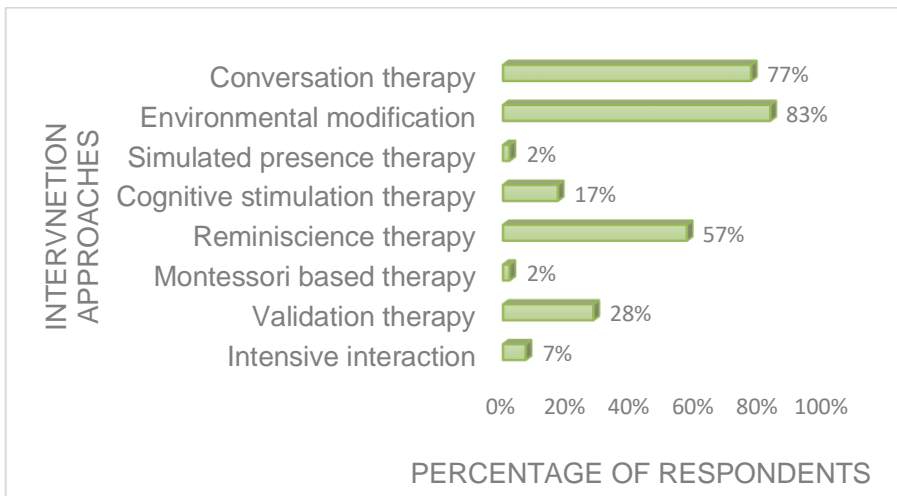


Figure 1.1 Intervention approaches used with people with dementia

Types of communication and memory support routinely used by SLTs in therapy with people with dementia (Question 15), were identified (see Figure 1.2). Communication support books are used by the majority of SLTs (43/60, 72%) and Talking Mats™ (13/60, 22%) were used by a smaller number of SLT respondents. Eight percent of SLT respondents (48/60) used both memory aids (diaries and calendars) and life story books. Fewer SLTs use reminiscence materials such as memory boxes (16/60, 27%).

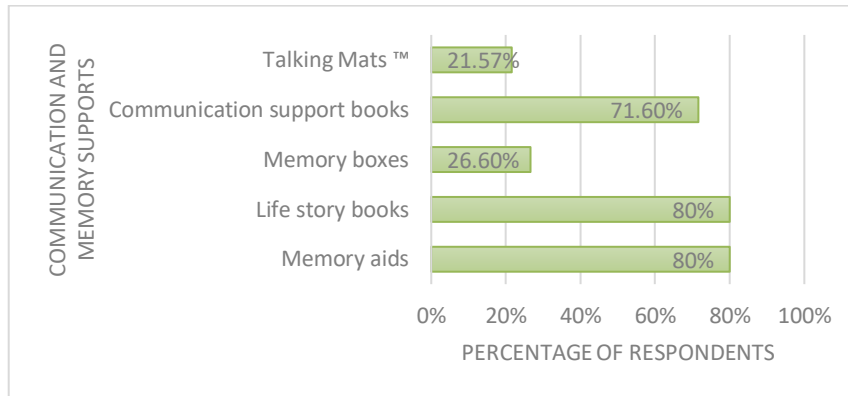


Figure 1.2 Communication and memory supports used

Clinical equipment used by SLT respondents (see Figure 1.3) to provide communication and memory support, include phones (20/56, 36%) and tablets (22/60, 39%). Low-tech communication aids such as white boards are also used (36/60, 64%). However, some SLTs (6/56, 10%) reported not using any such equipment, “none used routinely”.

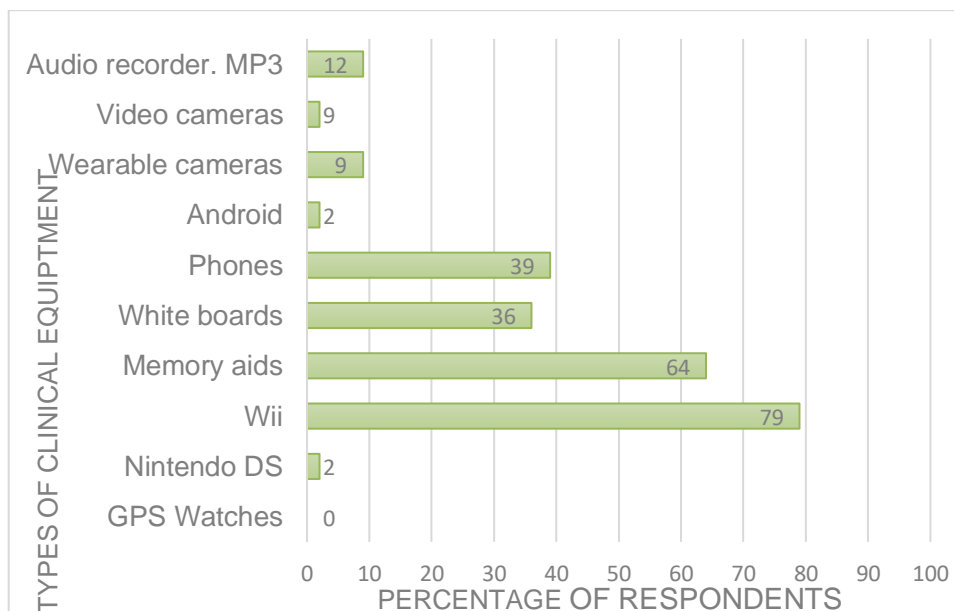


Figure 1.3 Equipment used with people with dementia

Survey Question 17 enquired about the practice of social prescribing (i.e. advising people with dementia and their families to engage in non-clinical activities such as sporting, artistic and social interests). This was common practice (47/64,73%) amongst respondents. SLTs said that they recommend and refer people with dementia to dementia specific and/or local community-based clubs including; tea dances, choirs, walking groups, “Men’s Sheds” and Dementia Cafés. In terms of long-term management of communication difficulties in people with dementia, over a third of SLTs surveyed (24/64, 37%) provide communication intervention in the palliative stages of care (Question 19). Nine percent (6/64) of SLTs commented that their clinical management in the palliative phase of care was exclusively a dysphagia service; “very much dysphagia focused at this stage” and “dysphagia input but not communication”.

A small number of SLTs (9/65, 14%) said that they have undertaken dementia related research. Their research interests included; “family carer’s views on feeding and swallowing challenges in the person with dementia”, “the communication environment in the acute care setting”, “the use of communication passports in acute care” and “the efficacy of speech and language therapy with the younger person with dementia”.

### **1.3.5 SLT satisfaction levels with current service**

Participants were asked to rate their satisfaction levels with the current level of SLT service (Question 6) on a 5-point scale (“not at all satisfied” to “extremely satisfied”). Descriptive statistics were used to analyse this SLT feedback. Forty one percent of SLT respondents (28/68) were “moderately satisfied”, while 21% (14/68) were “not at all satisfied”, with no participants feeling “extremely satisfied” with service delivery. Participants were then asked to identify and rank the most important factors in improving service delivery to people with dementia (Question 7)). These included early referral, timely access to services, improved knowledge of the role of the SLT by other professionals, increased MDT liaison, the use of speech and language therapy care pathways and improved access to community-based dementia support groups. The highest ranked factors on improving service delivery were; early referral to speech and language therapy (22/69,35%) and improved knowledge of the role of SLTs by other healthcare professionals (20/69, 31%). MDT management (12/69,18%) and the use of SLT care pathways were also identified as important factors in improving service delivery.

### **1.3.6 Key areas for service improvement**

SLT participants were asked to describe key areas for service improvement. SLT respondents’ views and experiences were analysed and their recommendations charted (see Table 1.4). They made specific recommendations for service improvement including; increased focus on the management of communication, improved staffing levels, MDT working, and clinical specialist positions.

Table 1.4 Recommended Service Improvements

Key areas for change	No. of references to key area in transcripts (n=66)	SLT Respondent Comments
Focus on communication needs of the person with dementia and their family	25	<i>"Allocating time for communication focus"</i> <i>"Rarely get a chance to work on communication"</i>
Increase SLT staffing levels	12	<i>"services are ad hoc, mostly dysphagia no funded post for dementia but there are two memory clinics".</i> <i>"increased time and SLT resources to provide adequate level of SLT input to this population particularly around communication"</i>
Improve interdisciplinary working	11	<i>"better links between consultants diagnosing dementia and SLT"</i> <i>"reminding other professionals that SLT can and do make a difference to the quality of life of the person with dementia and their family"</i>
Increase knowledge of the role of the SLT in dementia care	7	<i>"educate other professionals on the role of SLT in dementia"</i> <i>"Raise the awareness of the role of SLT in dementia"</i>
Increased specialized training in working with people with dementia	6	<i>"functional approach need training on this"</i> <i>"more CPD opportunities in this area "</i>
Improve referral management Earlier referral Increased referral	16	<i>"early referral is essential"</i> <i>"greater referrals, I rarely receive referrals for dementia"</i>
Specialist SLTs in dementia	3	<i>"Clinical specialists in dementia to advocate for integration of dysphagia/communication services for people with dementia"</i>

Respondents ranked issues impacting on the management of communication difficulties using these headings; SLT clinical experience, availability of appropriate cognitive communication assessments and interventions and availability of the primary communication partner to engage in therapy sessions. More than half of the participants (51%, 35/69) ranked the allocation of clinical time as the most important factor in improving service delivery. This reflects the feedback given on service challenges also. Direct clinical experience and training of the SLT (14/69, 21%) was identified as a priority as was the availability of appropriate assessment and intervention resources (12/69,18.5%).

### 1.3.7 SLT familiarity and confidence levels with current dementia policy

The INDS was published in 2014 with the aim of improving dementia care in Ireland. Strategy objectives include that people with dementia have timely services and supports delivered in the best way possible. SLTs were asked two questions; “How familiar are you with the recommendations of the INDS?” and “How confident are you in your ability to meet the recommendations outlined in the strategy?”. These recommendations include timely diagnosis and intervention, integrated care and support for people with dementia and their families across all care settings. SLT feedback has been charted (see Figures 1.4 and 1.5). Four years after its publication, the majority of SLTs said they were familiar with the strategy to some degree (58/65, 89%).

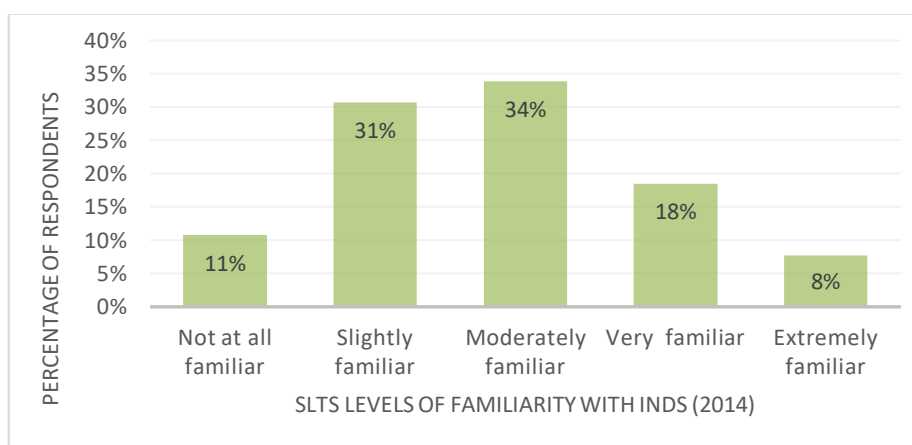


Figure 1.4 SLT Rating of their familiarity with the INDS

A lack of confidence was expressed on the part of SLT respondents about their ability to meet INDS recommendations in Question 21. Most (55/65, 85%) were not at all confident or only slight confident that they could meet strategy recommendations. There were a range of reasons given for this; “insufficient SLT resourcing for dementia services”, “limitations of the strategy” and “the need for attitudinal change around SLTs working with people with dementia”. Issues such as being understaffed and dementia not being a clinical priority, reoccurred in the survey comments. One respondent said, “we are limited by resources and demand for services far outstrips capacity”. However, there was the aspiration that these issues could be resolved in the future: “I would hope that the culture of practice can change gradually, over time with sufficient avocation for our role”.

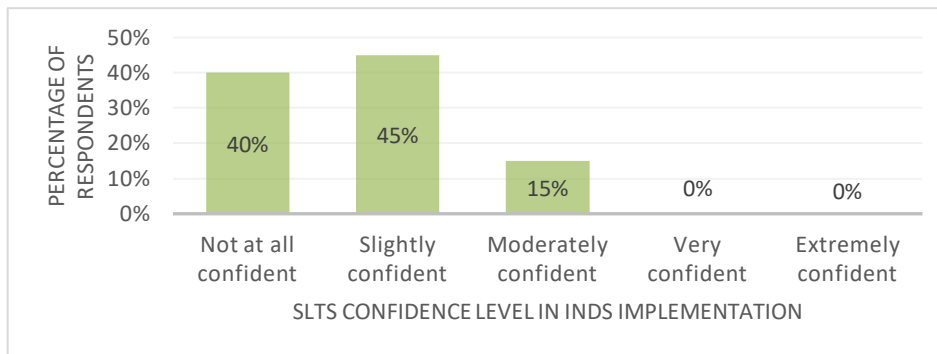


Figure 1.5 SLT confidence levels to implementation the INDS

### 1.3.8 Emerging themes: Speech and language therapy service delivery

SLTs were asked to identify aspects of their current service that they would like to retain and to describe the challenges they faced in service delivery (see Table 1.1). Thematic analysis (TA) (Braun and Clarke, 2006) was used to synthesise SLT comments in more detail. There were a range of responses addressing some of the timely and appropriate care interventions available for people with dementia. Survey questions were categorised under the headings of service strengths, challenges and SLT satisfaction with service provision. Further data analysis allowed key themes to be identified; SLT’s clinical competence, need for a change in service provision and challenges in practice.

#### *SLT’s Clinical Competence*

Although SLT feedback related to the whole scope of SLT management in the provision of dementia care there was a clear narrative of the existence of a strong clinical competence to serve people with dementia. SLTs providing interventions “enhancing quality of life”, “understanding the dynamics of communication” and “the ability to work on both dysphagia and communication”. Responses reflected the range of clinical approaches being used in dementia management such as a “functional person-centered approach”, “family friendly approach” and “relationship centered care”. SLTs provided a lot of examples of interventions available, these referenced both dysphagia “timely access to dysphagia assessment and follow-up”, and communication-based services “home visits for naturalistic communication assessments”.

#### *Need for change*

A theme of needing to expand the landscape of current service provision was identified, “it needs to revamp at the moment” in SLT feedback. SLTs were highly aware of current gaps in clinical services to people with dementia “no current communication service”, “we currently only look at the dysphagia aspect” and “focusing on communication and dysphagia, not just dysphagia”. Other SLTs are resourced to provide high quality and holistic dementia care. This was evident in the wide range of communication interventions being offered and approaches used (described in the previous paragraph). Collaborative team working was frequently expressed by respondents “good MDT collaboration”, “MDT seem to acknowledge the

importance of SLT” and “continue to work closely with OT”. These reports point to changes in SLT practice where timely intervention can sometimes be provided as part of an integrated team approach.

### ***Challenges in Practice***

There were many responses identifying “*lack of time*” as a frequent and ongoing frustration for SLTs in practice. It seems that communication therapy services to people with dementia are often not available, restricted or not timely. SLTs must give priority to dysphagia management. This is a current challenge for SLTs in practice. SLTs said they were frustrated that more could be done but there is no time resource to provide communication assessment and therapy, “*Due to caseload demands, I feel as though providing an optimum service i.e. in-depth and multifaceted assessment, diagnosis and treatment of cognitive communication difficulties, is very limited. I am constantly aware that addressing these difficulties is within my scope of practice, however it is not routinely provided*”.

Another identified challenge in clinical practice was others knowledge about the role of SLT in dementia care; “*there is a lack of awareness on the ground of the role of SLT*”. Providing training for the MDT was identified across comments on service challenges and recommended improvements “*education of staff on the possibility that we can help out with communication*” and “*lack of understanding from other services, what SLT can offer*”. This lack of awareness of the SLT role impacts in turn on the rate and timing of referrals to speech and language therapy services.

## **1.4 Discussion**

Survey findings provide perspectives on the clinical practice of a group of SLTs in the management of cognitive communication disorders in dementia in Ireland. There is a consensus that communication problems in dementia are inevitable but are treatable also. SLTs have low expertise in the assessment and management of communication disorders, which can contribute to earlier diagnosis, timely intervention and effective interventions (Bourgeois and Hickey, 2011). Speech and language therapy services in this area, as suggested in the survey are underdeveloped and under resourced.

### **1.4.1 Understanding the SLT role**

The role of the SLT in dementia care in Ireland is not widely understood by other professionals and this was frequently expressed by SLT respondents. This lack of awareness of our role impacts on the timing and rate of referral of people with dementia for SLT management and this is in keeping with findings reported in a SLT clinical practice surveys in Ireland (O’Reilly and Walshe, 2015) and internationally (Nóbrega et al., 2016). The need to promote the work of SLTs in dementia management is acknowledged by the profession, to ensure better outcomes for people with dementia (IASLT, 2016). This IASLT position paper for SLTs working in dementia care published 2016, has provided clinical guidance for SLTs in practice. Lack of awareness of the role of SLT may result in under referral. Lack of awareness of the SLT role seems to apply predominantly to the management of cognitive communication impairments and not dysphagia.

### **1.4.2 Dysphagia versus Communication**

Clinical setting frequently determines the level and range of SLT services available to the person with dementia. The dominant focus on dysphagia management rather than communication therapy was not surprising and has been a service delivery trend for the past 20 years (Cleary et al., 2003, Enderby and Petheram, 2002). The prevalence of dysphagia at different stages of dementia has been estimated at up to 50% (Alagiakrishnan et al., 2013, Langmore et al., 2002). The trend towards later referral is associated with the development of eating, drinking and swallowing problems as dementia progresses. Opportunities for early intervention will be missed when the person is referred in the later stages of dementia. Modifying diet consistency may increase life expectancy in people with dementia although it may not increase quality of life (Flynn et al., 2018). Dysphagia services are rightly driven by clinical priority, however in some settings this is the only service offered to people with dementia. Some SLTs reported a “high-quality” dysphagia service that is timely and “person centered”. The proportion of time allocated to the management of cognitive communication disorders was reported as low and multiple causative factors (including those already described) were identified by respondents; prioritization policies, limited staff and clinical resources and training.

Communication difficulties can then be overlooked or inadequately managed due to service prioritisation. This theme of “lack of time” was recurrent in the survey feedback and is a frustration for SLTs who want to be able to provide a quality service to people with dementia. Some established memory services do not have an associated SLTs position “no funded post for dementia but there are two memory clinics”, which impacts on service provision and emphasises the lack of knowledge of our role in dementia management. Restricted time resources for managing communication difficulties has been reported as a barrier to service provision in SLT management post stroke and with Parkinson’s disease (Miller et al., 2011, Miller and Bloch, 2017) also.

### **1.4.3 Communication assessment**

Informal assessment (75%) of cognitive communication disorders in dementia was reported as more commonly used than formal assessment (15%). This may partly be due to a high proportion of respondents working in an acute setting where a rapidly changing clinical baseline is more suited to informal and screening evaluations rather than detailed assessments that would soon be out of date. Informal communication evaluation of people with dementia is very appropriate and can guide management (Volkmer, 2013), however it is not sufficient to inform differential diagnosis, to develop comprehensive communication profiles, to measure interventions and for clinical research. Comprehensive assessment requires both formal and informal assessment providing the foundation for appropriate, individualised interventions (Bayles et al., 2006, Zientz et al., 2007).

Many respondents reported using aphasia batteries, which typically do not focus on cognitive skills and are not standardized for use with people with dementia. The issue of lack of suitable assessments is not unique to communication assessment in dementia but was also a finding in a SLT practice survey on the management of non-progressive dysarthria (Conway and Walshe, 2015) also. It is important that SLTs have access to appropriate assessments to profile cognitive communication skills (Cleary et al., 2003) and guide therapy. SLTs in this survey highlighted that they have limited assessment tools for use with people with intellectual disability and dementia.



A longitudinal follow-up of people with dementia and Down Syndrome in Ireland called for the greater use of appropriate assessment tools that could be used by clinicians (McCarron et al., 2014).

#### **1.4.4 Communication intervention**

A variety of communication interventions including psychosocial therapy, cognitive communication and environmental modification interventions (see Figure 3.1) were identified by respondees, these interventions are well evidenced for use with people with dementia (Kim et al., 2006, Mahendra et al., 2005, Bahar-Fuchs et al., 2013, Zettler, 2008). However, survey responses indicate that these interventions are not routinely offered to people with dementia. Delivery of interventions to people with dementia was low, only 14% of SLTs (9/64) provide one to one communication therapy regularly (Question 12) and 19% (12/64) provide group therapy. This low level of direct therapy cannot be justified when there is clear evidence of the effectiveness of communication intervention in improving quality of life (Moon and Adams, 2013, Zientz et al., 2007, NDO, 2019) and being integral to the delivery of better health care to people (Tomoeda, 2001, Planalp and Trost, 2008).

Linking people with dementia in with local activity and support groups can be beneficial and successful once there are established collaborating networks (Baker and Irving, 2016) and was a popular non-pharmalogical early response to dementia by surveyed SLTs (73%, 47/64). This practice of social prescribing has grown, but it is important for SLTs to evaluate the psychosocial benefits for the person with dementia.

A lack of communication intervention does not apply to SLT management of people with other neurological conditions such as aphasia and PD (Sapir et al., 2007, Brady et al., 2016) but is the norm in dementia care.

#### **1.4.5 Need for further training and education for SLTs**

SLT are well placed as communication experts to provide communication therapy to people with dementia, but some SLTs expressed concern about their clinical skills and competence "*I do not have enough clinical experience and supervision in this area*", "*lack of skills and confidence*" and "*lack of education*". Feedback from four SLTs (4/69, 6%), described high quality and tailored services being delivered to people with dementia and their families, but this was not a general trend in practice.

Inadequate education and training for SLTs in the management of cognitive communication disorders was a reoccurring theme. It was identified as the second biggest challenge faced by SLTs working in the field after lack of clinical time. Despite a current lack of one to one communication therapy, SLTs are approaching intervention through education and training of CPs and HSCPs. The clinical practice survey pointed to frequent involvement of the SLT in the provision of education and training. The provision of psycho education (53%, 33/64) and communication training (47%, 31/65) were provided by SLTs and is key to the provision of dementia services across Ireland. Group training is an effective and efficient approach to the delivery of dementia services. While timely individualised management of communication difficulties is recommended for people with dementia the resources to provide it are not always available.

#### **1.4.6 Irish National Dementia Strategy**

SLTs reported that they were familiar with the 2014 INDS but most of them did not feel confident that they could implement the recommendations. The reasons for this are multifactorial and can be attributed to a range of challenges described by SLTs earlier in this discussion; lack of resources, time and experience. Despite this SLTs expressed an awareness of what needs to change, the need for both service equity and a comprehensive approach to SLT management of people with dementia. SLTs are conscious of these gaps in service delivery and expressed frustration at being unable to address the “communication needs” of people with dementia due to a lack of resources. Does this lack of commitment by service providers reflect the view that “they are just going to get worse” (Hopper, 2003). This view is no longer acceptable in a modern health care system (National Positive Aging Strategy, 2013), where equity of service provision will influence service funding. When communication impairment is not comprehensively managed it will impact on the psychological and emotional well-being of the person with dementia and their family. The dementia care landscape is changing, with the publication of the INDS (2014) and public campaigns driven by the National Dementia Office to raise awareness reduce stigmatisation and improve services to people with dementia.

#### **1.5 Limitations of Survey**

There were a low number of survey responses, but this is possibly representative of SLTs working in dementia care in Ireland. There was the possibility of respondent bias as the researcher is known to SLTs working clinically in dementia care, as dementia management is a developing specialty in Ireland.

#### **1.6 Conclusions**

This is the first Irish survey to date of SLT management of cognitive communication difficulties in people with dementia. These results reflect the complex range of issues facing SLTs in clinical practice. There is growing awareness of the gaps in service delivery to people with dementia. While the majority of SLTs provide dysphagia services there is huge scope for the development of a range of assessment and treatment options to address inherent communication difficulties.

A key finding of this survey was that SLTs do not routinely manage the cognitive communication difficulties that are associated with dementia. This was the most commonly expressed concern or service inadequacy across the survey. One key deficit is the lack of appropriate and available assessments which impacts assessment practice. A review of available assessments in this area may identify gaps in current resources available to SLTs and inform their clinical practice.

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