**Medication Adherence for People with Acquired Communication Disorders: A Systematic Review**

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**Abstract:**

The aims of the current review were to identify, in the context of people with acquired communication disorders: factors which influence medication adherence, current interventions targeting medication adherence, and how medication adherence is currently measured. This study was conducted and reported in accordance with both PRISMA and SWiM guidelines. Two authors independently screened the results of a literature search, assessed risk of bias, and extracted relevant data. Eight studies were identified for inclusion. Four of the studies presented information relating to current interventions which target medication adherence for people with acquired communication disorders. Four of the studies investigated factors which influence medication adherence for people with acquired communication disorders. Seven of these eight studies outlined methods used for measuring medication adherence.

The results of this review indicate that patient related factors are most associated with medication non-adherence in a population with acquired communication disorders, followed by socio-economic factors and medication-related factors. Despite the recognised importance of medication adherence, no gold standard of assessment or intervention currently exist for this population. Half of the included studies replaced patients with communication difficulties with caregiver proxies, thus reducing opportunities for patients to participate meaningfully in research. The term “acquired communication disorders” encompasses a range of conditions with diverse aetiologies, presentations, and needs, and future research should be tailored to specific patient groups most at risk of medication non-adherence, namely those with aphasia and cognitive-communication impairments. Patients should be empowered to participate in future research to ensure the literature accurately represents their lived experience.

1. **Background**

Acquired disorders of speech, language, cognitive-communication, and voice are collectively referred to as acquired communication disorders, where the patient displays the loss of a previous capacity to communicate [1]. The most common neurogenic communication disorders acquired in adulthood include aphasia, apraxia of speech, dysarthria, and right hemisphere disorder [2] and are typical sequalae of injury, abnormality, or disease [3].

Acute events are major contributors to the incidence of acquired communication disorders in Europe [4, 5, 6, 7]. In particular, stroke has been identified as the primary contributor to incidence of both neurological impairment in Ireland [8], and overall burden of neurological disorders in the European Union (EU) and United Kingdom (UK) [9]. Similarly, dementia has been identified as the second leading cause of neurogenic disability in the EU, while neurodegenerative disorders such as Parkinson’s Disease, Motor Neurone Disease and Multiple Sclerosis make up a collective 8% of overall neurologic disability in western Europe [9].

Pharmacological interventions play a central role in the management and treatment of these conditions. Antiplatelets, anticoagulants, antihypertensives and lipid-lowering medications such as statins are recommended to reduce the risk of recurrent stroke or transient ischemic attack [10]. The National Institute for Health and Care Excellence recommends cholinesterase inhibitors and memantine be used in the management of most dementias, often in conjunction with pharmacological treatment of non-cognitive symptoms such as depression, anxiety, and sleep problems [11]. Pharmaceutical care in neurodegenerative disorders focuses largely on symptomatic management [12], with an estimated 78% of newly diagnosed patients with Parkinson’s disease receiving pharmaceutical management in the UK [13]. This symptomatic approach to the management of neurodegeneration often results in polypharmacy, with one in four people diagnosed with Multiple Sclerosis routinely taking five or more medications concurrently [14].

However, non-adherence has been pinpointed as the most prevalent medication-related issue among patients with chronic conditions [15]. Within the EU, medication non-adherence is associated with almost 200,000 deaths per annum, and €80–€125 billion of potentially preventable costs [16]. Non-adherence is a complex issue, for which there may be a range of causes and influencing factors [17]. For adults with chronic, non-communicable conditions, patient-related factors such as poor health literacy were cited as the most common indicators of medication taking behaviour [18]. Health literacy has been positively associated with increased medication adherence [19]. A diagnosis of an acquired communication disorder has been associated with lower health literacy [20]. Therefore, patients with an acquired communication disorder as a result of stroke or neurodegenerative disease are at a higher risk of medication non-adherence. Particular skills such as reading comprehension, word recognition, composition, grammar, and punctuation are central to effective literacy [41], placing those with language disorders such as aphasia, acquired dyslexia, and acquired dysgraphia at higher risk of non-adherence than those diagnosed with motor speech or voice disorders.

Despite this, populations with acquired communication disorders have often been excluded from research due to their intrinsic heterogeneity [21]. As medication adherence is a multifactorial phenomenon, the dearth of literature specific to those with acquired communication disorders may make it difficult for clinicians and researchers to gain a comprehensive picture of the current evidence [17]. The inconsistency, interchangeability and diversity of terms used in the literature describing acquired communication disorders pose an additional challenge in identifying the research that has included this underrepresented cohort [22]. Therefore, this review aims to characterise the literature relating to factors influencing medication adherence for people with acquired communication disorders via the following objectives:

* To identify the factors which influence medication adherence for people with acquired communication disorders;
* To identify the current interventions which target medication adherence for people with acquired communication disorders;
* To identify how medication adherence is currently measured for people with acquired communication disorders.

1. **Methods**

This study was conducted and reported in accordance with both Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Appendix I) and Synthesis Without Meta-Analysis (SWiM) guidelines (Appendix II) [23, 24]. The protocol for this systematic review was published to PROSPERO on 09 March 2022 [25].

* 1. **Search Strategy**

Eight databases were selected for systematic literature search: CINHAL, Cochrane Central Register of Controlled Trials, Cochrane Reviews, NeuroBITE, PsycINFO, PubMed, and SpeechBITE. These databases were searched from January 1st 2002 to January 9th 2023 to identify studies in the English language which meet the inclusion criteria. Databases were not searched from inception as more recent literature has the most relevance to inform contemporary practice relating to medication adherence for people with acquired communication disorders; therefore the 20-year limit was set. Searches were constructed using Boolean operators (AND, OR) and Medical Subject Headings, and contained terms relating to Acquired Communication Disorders, Medication Adherence, and Influencing Factors. Reference lists of included studies were searched for additional articles. The full search strategy for PubMed is provided in Appendix III.

* 1. **Inclusion Criteria**

Papers were included according to the following inclusion hierarchy:

1. Publication Year: 2002- 2022
2. Research Type: Primary research only.
3. Publication Type: Journal articles only.
4. Population: People with acquired communication disorders and/or their caregivers only.
5. Outcomes: People with acquired communication disorders and/or their caregivers are included, and data relates to factors influencing (barriers, facilitators, personal experience) medication adherence or interventions targeting medication non-adherence.
6. Access: Full text available.
   1. **Exclusion Criteria**

Papers were excluded according to the following exclusion hierarchy:

1. Publication Year: Before January 1st, 2002
2. Research Type: Secondary research, editorials, opinion papers, commentaries, expert opinions etc.
3. Publication Type: No conference abstracts, study protocols, book chapters etc.
4. Population: People with acquired communication disorders and/or their caregivers are not included or are included as part of a larger population but their data is not reported separately. To exclude if focused on efficacy of practice and/or healthcare professionals who target medication non-adherence.
5. Outcomes: People with acquired communication disorders and/or their caregivers were included but data does not relate to factors influencing (barriers, facilitators, personal experience) medication adherence or interventions targeting medication non-adherence. To be excluded if rate of medication adherence is mentioned but factors influencing adherence are not easily discerned.
6. Access: Full text could not be obtained, and authors do not respond to an emailed data request and one follow up email.
   1. **Study Selection**

Following the preliminary search all data were uploaded to Rayyan, a web-based systematic review screening tool [26]. Papers were first reviewed by title and abstract independently by S.B. and a second reviewer (either H.K. or L.S.). Following screening, selected full texts were then reviewed independently by S.B. and a second reviewer (either H.K. or L.S.). Any disagreements between individual judges were resolved through discussion with the reviewer who was not initially assigned the paper (either H.K. or L.S.).

* 1. **Data Extraction**

A data extraction form was developed and piloted before use. Data were extracted under the following domains: Study Title, Author, Country, Year, Number of Participants, Population, Study Design, Inclusion/Exclusion Criteria, Communicative Abilities of Participants, Method of Analysis, Relevant Outcomes, and Key Findings. Data were extracted by S.B., and extracted data were checked against the source data by F.M. to ensure its accuracy [42]. Nine authors were contacted by email and asked to provide additional data where necessary.

* 1. **Quality Assessment**

The Critical Appraisal Skills Programme (CASP) checklists were used to determine and evaluate the risk of bias for each study included [27]. Due to heterogeneity of included studies, three versions of the CASP checklist were used in assessment of study quality: CASP Randomised Control Trial Checklist [Appendix IV], CASP Qualitative Studies Checklist [Appendix V], and CASP Cohort Studies Checklist [Appendix VI]. As no CASP checklist is currently available for mixed-methods studies, elements of the CASP Qualitative Studies Checklist and CASP Cohort Studies Checklist were combined to evaluate mixed methodologies [Appendix VII]. S.B. reviewed all included studies and a second reviewer (either H.K. or L.S.) completed an independent quality appraisal. Any disagreements between individual judges were resolved through discussion with the reviewer who was not initially assigned the paper (either H.K. or L.S.). In line with CASP recommendations, no numerical grading of quality was undertaken. Studies were instead categorised as being of high, medium, or low quality according to assessor judgements.

* 1. **Synthesis of Results**

Studies were grouped together by: (i) outcomes (factors influencing medication adherence, interventions targeting medication adherence, methods of measuring medication adherence) and (ii) study design (quantitative, qualitative, and mixed methods). Due to heterogeneity in study design, patient subgroups, and outcome measures, pooling of data and formal quantitative analysis could not be carried out. All comparisons made were instead narratively described.

1. **Results** 
   1. **Study Selection**

Database searches identified 8,663 unique results. Duplicate records and retracted papers were removed, with 6173 papers remaining for screening by title and abstract. 232 of these papers were retrieved for full text screening. A total of 17 studies were selected for review, 9 of which were later excluded as data pertaining to those with acquired communication disorders could not be extracted or obtained from study authors. The remaining 8 papers [28, 29, 30, 31, 32, 33, 34, 35] met the inclusion criteria and were included for data extraction (Figure 1).

**Figure 1** - Study selection process for systematic review of medication adherence for people with acquired communication disorders. A flowchart of information

Description automatically generated

* 1. **Characteristics of included studies**

The characteristics of the included studies are presented in Table 1a and Table 1b. Four of the studies presented information relating to current interventions which target medication adherence for people with acquired communication disorders [31, 32, 34, 35]. Four of the studies investigated factors which influence medication adherence for people with acquired communication disorders [28, 29, 30, 33]. Seven of these studies outlined methods used for measuring medication adherence [28, 29, 31, 32, 33, 34, 35]. Study designs employed included five cohort studies [28, 29, 32, 33, 34] one randomised control trial [35], one qualitative study [30] and one mixed-methods study [31]. Seven of the studies address medication adherence [29,30,31,32,33,34,35], with one study focusing on medication persistence [28], generally defined as the time over which a patient continues their medication (and in this study, continuation at 3 months).

The included papers recruited a range of patient populations, including stroke [28, 29, 30, 31], Acquired Brain Injury [32], Parkinson’s Disease [33], Alzheimer’s Disease [34, 35] and mild cognitive impairment of unknown aetiology [35]. Seven of the eight studies focused on a single patient population [28,29,30,31,32,33,34], with one study including patients with both Alzheimer’s Disease and mild cognitive impairment [35]. Indicators of participant communication impairment in these studies were varied, with half of the studies only addressing this by stating the need for communication proxies [28, 30, 31, 32]. The remaining studies used a range of standardised assessment batteries to diagnose language and cognitive-communication impairments including the Mini-Mental State Examination [35], The Pyramids and Palm Trees Test [34], Boston Naming Test [34, 33], tests of verbal fluency [34], the Responsive Naming Test [33], The Everyday Functioning Scale [29], and the Sheffield Screening Test for Acquired Language Disorders [29].

* 1. **Quality Assessment**

The quality of evidence from included studies indicates that only one study reached high methodological quality based on the CASP tool [30]. The CASP indicates that if the answer to the first two questions (cohort studies, qualitative studies) or three questions (randomised control trials) is not “yes”, then this may indicate that the evidence is of poor quality [36]. Based on this criterion, two studies were classified as being of low quality [29, 34]. The remaining studies indicate moderate quality [28,31,32,33,35].

**Figure 2** – Quality Appraisal of included studies using CASP tool

**CASP Cohort Studies**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Q11 | Q12 |
| Bushnell et al., 2010 | Y | Y | U | U | Y | U | Y | Y | Y | U | U | Y |
| Coetzee et al., 2008 | Y | U | Y | U | N | U | Y | U | U | U | U | N |
| Oyesana et al., 2020 | Y | Y | Y | Y | U | Y | Y | U | Y | U | U | Y |
| Sumbul-Sekerci et al., 2021 | Y | Y | Y | Y | U | Y | Y | U | Y | U | Y | Y |
| Tellier et al., 2020 | Y | U | U | N | N | Y | Y | U | Y | U | U | Y |

**CASP RCT**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Q11 |
| Kim et al., 2022 | Y | Y | Y | U | Y | Y | U | N | U | N | U |

**CASP Qualitative**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 |
| Jamison et al., 2017 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |

**Mixed Methods**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | Q11 | Q12 | Q13 | Q14 | Q15 | Q16 | Q17 |
| Nichols et al., 2017 | Y | Y | Y | Y | Y | Y | Y | N | N | Y | U | Y | Y | Y | Y | U | U |

Key:

Y = Yes

N= No

U = Unclear

* 1. **Results of Individual Sources of Evidence**
     1. **Factors Influencing Medication Adherence**

Of the four studies which investigated factors influencing medication adherence, three were quantitative cohort studies [28,29,33] which addressed patient-specific factors that may affect medication adherence. Severity of disability was found to be a significant barrier to adherence, where lower disability was associated with higher adherence [28]. Two of the cohort studies identified cognitive impairment to be the most significant predictor of non-adherence in populations with stroke and Parkinson’s Disease [29,33]. In particular, Coetzee et al., found that poor organisation and memory issues account for 80% of non-adherence in a population post-stroke based on patient self-report [29]. However, Sumbul-Sekerci and colleagues found that the general ability to manage medications may not be a barrier to medication adherence, as no significant relationship was found between these parameters [33]. This is due in part to the fact that medication management relies solely on intrinsic patient factors such as language and memory which, when supported by treatment and environmental factors, may result in adequate patient adherence [33].

Two of the cohort studies investigated external factors which may impact medication adherence. Both Coetzee and Bushnell found that level of medical and social support increased medication adherence [28,29], and having medication insurance was independently associated with medication persistence [28]. However, there was no relationship between medication persistence and self-reported satisfaction with provider communication, including physician listening skills, clear medication explanations, physician use of understandable language, and patient involvement in treatment decision [28]. Instead, clear patient-provider communication has been shown to increase medication adherence post-stroke, particularly when the patient is well-educated about the reasons behind taking their medication, and how to obtain medication refills [28].

The final study provides a qualitative perspective of barriers and facilitators to medication adherence post-stroke from the perspectives of patients and caregivers [30]. Dealing with medication side effects, challenging doctors' prescribing procedures, and negative preconceptions of medications were perceived as barriers to adherence [30]. Difficulty swallowing pills, financial burden, and treatment cost were the main practical obstacles, while managing intentional and unintentional non-adherence often fell to caregivers in this study [30]. Facilitators to adherence were lack of side effects, understanding the importance of medication, having positive personal treatment experiences, and personalised treatment plans. Utilizing medicine storage devices, adhering to routines, and receiving assistance from caregivers with prescriptions were considered important drivers of adherence [30].

* + 1. **Current Interventions targeting medication adherence**

Of the four studies evaluating current approaches to intervention, one was a randomised control trial [35], one a mixed-methods study [31], and two were cohort studies [32,34]. Three of the interventions evaluated medication reminder services and tools [31, 34, 35]. Kim et al., (2022) aimed to evaluate the effectiveness of automated telephone reminders in improving medication adherence for patients with mild cognitive impairment [35]. No significant difference was found between treatment and control groups, however subgroup analysis showed better medication adherence among participants with over 70% answering rates to the telephone reminders [35]. Tellier and colleagues investigated the effect of an electronic pillbox on daily medication management for people with Alzheimer’s Disease [34] and found significant effect sizes, with participants showing over 80% medication adherence 12 weeks post-training [34]. However, it is worth noting the small sample of four patients in this study, and limited follow-up period [34].

While Nichols et al., [31]evaluated a similar automated text, phone call or email service to that described by Kim et al [35], they aimed to categorise feasibility and stakeholder attitudes towards the service [31]. Almost all (99.5%) participants expressed a willingness to participate in a research study involving mobile health services, and 96.5% thought such a study would be worthwhile to conduct. Cost, training, and continuity of connectivity were identified as the greatest barriers to accessing these mobile health services [31].

Oyesanya et al. (2020) describes the efficacy of pre-discharge, medication management intervention to improve perceived knowledge and perceived confidence for post-discharge medication management for rehabilitation patients with spinal cord injuries (SCI) and families of patients with SCI or acquired brain injuries (ABI) [32]. Findings showed that at 60-days post-discharge, treatment group patients and family members of patients with ABI were more likely to use a medication list and a pillbox to manage the patient’s medications effectively [32]. There was no significant relationship found between the intervention, perceived knowledge, and perceived confidence at 60 days post-discharge [32].

* + 1. **Current measures of medication adherence**

A range of methods were used to measure and report medication adherence in each included paper. The Morisky Medication Adherence Scale was employed in two studies [31,33], while an adapted, unvalidated form of the scale was used in a third [32]. Pill counts alone were used in one investigation [35],and were supplemented with patient self-report using the Treatment Assessment Schedule in another [29]. One study determined adherence by comparing the complete discharge medication list with self-reported medications currently used by the patient [28]. Tellier and colleagues (2020) measured adherence using an adherence log which was generated using an electronic medication management device, and monitored medication taken correctly, taken late, errors or omissions [34].

1. **Discussion**

This systematic review is among the first to specifically examine the literature relating to factors influencing medication adherence for people with acquired communication disorders. Literature relating to factors influencing medication adherence in different populations have been widely published [17, 18] and are commonly broadly categorised into the five WHO dimensions of adherence [37]. The results of this review indicate that patient related factors are most commonly associated with medication non-adherence in a population with acquired communication disorders [28,29,33], followed by socio-economic factors [28,29, 30] and medication-related factors [30]. This aligns with a previous systematic review conducted by Peh et al., (2021) who designed a conceptual model for factors contributing to medication adherence based on 102 individual conceptual frameworks [18]. This conceptual model highlights patient-related factors as the most prominent contributor to medication adherence, followed closely by socio-economic factors [18]. Interestingly, this model highlights systemic and healthcare professional-related factors as the third-ranked contributor to medication adherence, where this was found to have no effect on medication adherence in Bushnell’s 2010 study of 2598 post-stroke patients [28].

Despite the recognised importance of medication adherence, no gold standard of assessment or intervention currently exist [38]. The most common methods of identifying patients at risk for non-adherence are patient self-report [38], which is reflected in the results of this review [31,32,33,28]. However, patient self-reports are subjective measures, and may over or underestimate patient adherence [38]. Conditions such as aphasia may result in an impaired ability to accurately calculate or report measures, while conditions such as right hemisphere disorder and dementia may cause impaired self-awareness, insight, and memory impairment, which may contribute to inaccurate reporting of results [29, 33]. Therefore, healthcare professionals and researchers must be particularly aware of the subjective nature of patient self-reporting when interacting with people with acquired communication disorders. Sumbul-Sekerci and colleagues (2021) found no difference in adherence based on self-report in a cohort of Parkinson’s Disease patients with and without cognitive impairment, despite findings from previous studies [33]. We can hypothesise that inaccurate self-evaluation in reports of medication adherence may have contributed to this [33].

In order for treatment to be effective, it must be tailored to the individual needs of the patient [39]. Three recent systematic reviews found electronic reminders to have positive effects on medication adherence for patients with chronic disease [45, 46, 47]. However, these have often not been specifically designed with communication impairments in mind and may not prove as effective with this population [40]. Patient education has been proven to be effective in improving medication adherence, though has been found to be less effective when used in isolation than when combined with other forms of intervention [39]. A multicomponent intervention encompassing communicatively tailored patient education and electronic reminder systems may be most effective in targeting medication non-adherence for people with acquired communication disorders.

Another contributing factor to the absence of assessments, “gold standard” interventions, and consistent reporting of factors influencing medication adherence for people with acquired communication disorders is the heterogeneity within and between groups. The term “acquired communication disorder” encompasses a range of conditions with diverse aetiologies, presentations, and needs. Future research should aim to investigate specific links between medication adherence and the most common acquired communication disorders. In particular, disorders such as aphasia, right hemisphere and cognitive-communication impairments may have the most profound impact on medication adherence, and assessment, measurement and interventions should be specifically tailored to each of these patient groups. Current research methodologies used in this field are not as rigorous as they could be, with only one of eight studies conducted in line with Randomised Control Trial protocol. The majority of the research included in this review is quantitative in nature, which provides useful objective data. However, an increase in qualitative investigations in this field will provide further insights into patient and caregiver experiences and allow for a deeper understanding of medication-taking behaviours [43]. Finally, future research should have the primary aim of recognising patients with acquired communication disorders as experts in their own needs. Despite patient self-reports not being a reliable source of objective, quantitative data for this cohort, these may be beneficial in gaining insight into the lived experience of the patient. While caregiver opinions and insights are valuable resources, particularly as many of them support or fully manage medication for the patients, half of the studies included in this systematic review replaced patients with communication difficulties with caregiver proxies [28, 30, 31, 32], thus reducing opportunities for patients to participate meaningfully in research. In addition, encouraging and empowering the patient to accept accountability for the management of their condition can lead to better health outcomes and lower health-related costs [44].

* 1. **Strengths**

An intensive and thorough search of selected databases was carried out to identify studies relevant to our research question. Speech and Language Therapy specific databases SpeechBITE and NeuroBITE were included to increase the likelihood of identifying papers specific to people with acquired communication disorders. Boolean phrases and MeSH terms were utilized throughout the database search to ensure all relevant papers were identified. Each stage of the screening, quality appraisal, and data extraction processes were carried out by two independent reviewers, with disagreements mediated by an impartial third reviewer. As this review aimed to evaluate the literature at the intersection of acquired communication disorders and medication adherence, we felt that it was important that Pharmacists (LS, FM) and Speech and Language Therapists (SB, HK) be equally represented within the research team.

* 1. **Limitations**

Heterogeneity in the data of included studies did not allow for meta-analysis or summarising of effects across studies. The inconsistency, interchangeability and diversity of terms used to describe acquired communication disorders may have led to some terms being unknowingly omitted from the search strategy carried out in this review. However, two of the authors are speech and language therapists who specialise in acquired communication impairment and so key terms relating to aphasia, dementia and neurodegenerative disorders were included as these health conditions are most commonly associated with both medication-taking and acquired communication disorders. Grey literature such as conference abstracts and study protocols were not included in this review, which may lead to some publication bias. However, searches were repeated prior to data analysis in order to identify newly published literature.

1. **Conclusions**

This systematic review synthesises the literature relating to factors influencing medication adherence for people with acquired communication disorders. Patient related factors such as condition severity are most commonly associated with medication non-adherence in this population. While no gold standard of assessment of or intervention for medication adherence currently exists for a population with acquired communication disorders, existing tools may be successfully modified to their individual needs.

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