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What are the important factors in health-related quality of life for people with aphasia? A systematic review

ABSTRACT

Objective: To determine factors associated with or predictive of poor health-related quality of life (HRQL) in people with aphasia post-stroke. Better understanding of these factors can allow better targeting of rehabilitation programs.

Data Sources: Electronic databases, covering medical (e.g., Medline, EMBASE, EBMR, CINAHL, OVID, AMED) and social sciences (e.g. PsycINFO) were searched and key experts were approached.

Study Selection: Studies including specific information on the HRQL of people with aphasia post-stroke using validated HRQL measures or established ways of analyzing qualitative data were included. Two reviewers independently screened studies against the eligibility criteria.

Data Extraction: This was undertaken independently by two reviewers. Discrepancies were resolved by consensus. Quantitative studies were assessed for quality with Counsell and Dennis' critical appraisal tool for systematic review of prognostic models in acute stroke; qualitative studies with the CASP appraisal tool for Qualitative Research.

Data Synthesis: fourteen research reports met the eligibility criteria. Due to their high heterogeneity, the data synthesis was narrative. The evidence is not strong enough to determine the main predictors of HRQL in people with aphasia. Still, emotional distress/depression, severity of aphasia and communication disability, other medical problems, activity limitations, and aspects of social network and support were important factors.

Conclusions: Emotional distress, aphasia severity, communication and activity limitations, other medical problems and social factors affect HRQL. Stroke HRQL studies need to include people with aphasia and report separately on them, in order to determine the main predictors of their HRQL and to identify what interventions can best address them.

Key Words: aphasia, health status, health status indicators, quality of life, stroke

List of abbreviations

AMED (Allied and Complementary Medicine Database); CASP (Critical Appraisal Skills Programme); CI (Confidence Interval); CINAHL (Cumulative Index to Nursing and Allied Health Literature); DARE (Database of Abstracts of Views of Effects); DH-Data (Department of Health Data); EBMR (Evidence-Based Medicine Reviews); EMBASE (Excerpta Medica Database); EPPI (Evidence for Policy and Practice Information); HMIC (Health Management Information Consortium); HRQL (Health-related quality of life); MESH (Medical Subject Headings); SAH (Sub-arachnoid Hemorrhage); WHOQOL-BREF (World Health Organisation Quality of Life - BREF).

Aphasia is a language disorder affecting use and understanding of language and is most commonly caused by a stroke. About a third of stroke survivors have aphasia at onset,[1] while 15% remain aphasic in the long term.[2] Health-related quality of life (HRQL) reflects the impact of a health state on a person's ability to lead a fulfilling life[3] and covers individuals' perception of/satisfaction with their physical, mental/emotional, family and social functioning.[4] By incorporating HRQL assessments in healthcare evaluations, the impact of disease from the patient's perspective can be captured. In stroke and aphasia, rehabilitation programs specifically aim to improve the client's sense of well-being and quality of life.[5]

A recent population-based study of people living in long-term care facilities in Canada (n=66,193) compared the impact of 60 diseases and 15 conditions on caregiver-assessed preference-based HRQL. After adjusting for age, sex, and other diagnoses, aphasia exhibited the largest negative relationship to preference-based HRQL followed by cancer and Alzheimer's disease.[6] People with aphasia themselves report significantly worse HRQL than non-aphasic stroke controls;[7] and worse quality of life than healthy controls, particularly in terms of independence, social relationships and access to aspects of their environment.[8]

This evidence suggests that aphasia has a profound effect on people's lives. However, before interventions and service provision can be targeted effectively to address improvements in people with aphasia's lives, it is important to understand what the main predictors of their HRQL are. Numerous studies have focused on predictors of HRQL after stroke and a recent synthesis identified depression/emotional distress and functional status/physical disability as the most consistent predictors; other factors included female sex and social factors (socioeconomic status, social support).[9] Findings from stroke studies, though, are not necessarily applicable to people with aphasia. Stroke studies either exclude or selectively include people with aphasia because of their communication problems.[10-20] In the studies that include people with aphasia, proxy respondents are used;[11, 12, 21-25] or results are compromised by incomplete data.[26-29] Some studies provide no information on how people with aphasia manage with complex questionnaires.[16, 30, 31] Lastly, these studies provide no separate results for the HRQL of people with aphasia.

A number of studies have looked specifically at people with aphasia to explore the impact of the condition on their lives. Some have not looked at HRQL but related phenomena, like psychosocial adjustment/optimism;[32-34] identity;[35] social participation.[36-39] From the studies that explored HRQL or closely related concepts, such as life satisfaction and well-being, some have used non-validated measures,[40-42] while others have used self-developed questionnaires.[43, 44] Few studies specifically focused on the HRQL of people with aphasia using validated HRQL scales or established qualitative methods. To date, the results of these studies have not been synthesized. This makes the targeting of interventions problematic: if we do not know what predicts HRQL in people with aphasia then we can not provide interventions or services to improve their lives. This was highlighted in a recent systematic review of communication partner training in aphasia, where despite evidence of improvement in communication and activity / participation for people with chronic aphasia, there was no evidence for quality of life improvement.[45]

This systematic review aimed to: a) identify factors associated with or predictive of HRQL in people with aphasia post-stroke; b) review the quality of relevant studies in order to establish the strength of existing evidence.

METHODS

This review follows well-established methods for conducting and reporting systematic literature reviews.[46, 47]

Eligibility criteria

Types of studies: Studies reporting research data on factors associated with or predictive of HRQL in people with aphasia after stroke. Only English-language publications were included. There was no restriction on publication date; geographical location; and study design, as long as studies met criteria below in terms of participants and outcomes. Relevant *theoretical papers, policy documents, opinion* pieces and similar material were identified in order to provide background and context.

Types of participants: Adults who had acquired aphasia following stroke, excluding those focusing exclusively on subarachnoid hemorrhage. No other exclusion criteria, such as age, sex, setting, aphasia type, stroke/aphasia severity or co-morbidities, were applied.

Types of outcomes: Validated HRQL measures (for studies presenting quantitative data), established ways of analyzing data (for qualitative studies) and systematic methodology (for reviews).

Sources of information

Electronic bibliographic and full-text databases were searched: Medline, EMBASE Psychiatry, Evidence-Based Medicine Reviews (EBMR) (Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Database of Abstracts of Views of Effects (DARE), Health Technology Assessment Database), Health Management Information Consortium (HMIC) (DH-Data, Kings Fund Library Catalogue Database, Health Management Information Service), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Allied and Complementary Medicine Database (AMED), British Nursing Index, OVID Nursing Full Text Plus, PsycINFO, PsycARTICLES, Global Health. Requests for material were made to recognized researchers in the fields of stroke and aphasia.

Search strategy

The following strategy was used for Ovid MEDLINE, and modified for use with other resources as appropriate (terms in capital letters are MESH subject headings):

1. aphasi$.tw.
2. dysphasi$.tw.
3. exp APHASIA/
4. or/1-3
5. exp QUALITY OF LIFE/ or exp HEALTH STATUS/ or exp HEALTH STATUS INDICATORS/ or exp QUALITY-ADJUSTED LIFE YEARS/
6. (good health or (health adj5 level) or health status or hrqol or hrql or qol$ or (qualit$ adj5 life) or qualit$ adjusted life year$ or qaly$ or well being or wellbeing or wellness or psychosocial or psycho social or (life adj5 satisfaction)).tw.
7. 5 or 6
8. 4 and 7
9. limit 8 to english language

Additional subject headings used in other databases were: dysphasia, health and quality of life, well being, wellbeing, wellness, life satisfaction.

Data management

Study data were stored and coded within EPPI-Reviewer (Version 4), a collaborative, web-based application produced by the Evidence for Policy and Practice Information and Co-ordinating Centre.[48]

Screening

After the removal of duplicate studies, material resulting from the searches was screened independently by two reviewers against the eligibility criteria. Reasons for (potential) inclusion or exclusion were documented. Where eligibility could not be assessed on the basis of the title and abstract alone, the full text was obtained. The full text of studies passing the screening process was obtained. Discrepancies between the judgments of the two reviewers were discussed by the review team and agreement reached. Studies that were relevant to the review topic but did not meet the criteria for inclusion were set aside to be used for background and context.

Data extraction and critical appraisal

Data extraction and assessment of methodological quality for each study were undertaken independently by two reviewers and recorded on electronic data collection forms within EPPI-Reviewer. Reviewers were not also authors of papers they reviewed. Any discrepancies were resolved by discussion within the review team.

Data extracted for each study included: full publication details; study design; background and aims; country and setting; time of assessment(s); study population (sample size; gender; age; ethnic group; socioeconomic classification; educational background; proportion with aphasia; type, class and severity of stroke; type and severity of aphasia; presence and nature of any co-morbidities); respondent (self-report/proxy); factors predicting/influencing HRQL; primary and secondary outcome measures; main findings.

Studies reporting quantitative data were assessed for quality using the critical appraisal tool developed by Counsell and Dennis[49] for their systematic review of prognostic models in acute stroke. This tool assesses external and internal validity, statistical validity, model evaluation, practicality of model and, where applicable predictive ability.

Qualitative studies were assessed using the Critical Appraisal Skills Programme (CASP) tool for Qualitative Research developed by the Public Health Resource Unit, which assesses rigor, credibility and relevance.[50]

Data analysis

Given the high levels of heterogeneity among the included studies, data analysis took the form of a narrative synthesis of the evidence, an approach which is appropriate for synthesizing the results of studies with disparate study designs and aims.[51]

RESULTS

Study selection

Electronic database searches were conducted in September 2010 and resulted in a total of 2,254 references. 19 references were received from requests for information from subject experts. Study flow in the review and reasons for exclusion are given in Figure 1 (only one reason is given per excluded study, though in many cases studies could have been excluded for more than one reason). After de-duplication, 1,791 (79%) remained. The screening process resulted in the exclusion of 1,746 references. The full-text of the 45 remaining references was reviewed and a further 31 were excluded: 15 presented no specific data for the subgroup of aphasic participants;[9, 16, 26, 30, 31, 52-61] seven did not examine factors predictive of/associated with HRQL;[6-8, 62-65] four were non-systematic reviews/overviews;[66-69] three were quantitative studies which did not utilize a valid HRQL measure;[27, 43, 44] one was a qualitative study which used no established method of analysis;[70] and one was exclusively on subarachnoid hemorrhage (SAH).[71] This left 14 studies[72-85] which proceeded, along with three linked papers,[86-88] to the data extraction and critical appraisal stage.

Figure 1: The review process: flow diagram

[Figure 1 about here]

Study characteristics

The 14 reports included describe data from 11 studies as participants with aphasia were the same in the three reports by Cruice and co-workers[73-75] and in two by Hilari.[77, 78] Of the 14 reports, three were qualitative (one using structured interviews,[74] one in-depth interviews[83] and one an ethnographic account of published data;[80] six were cross-sectional;[73, 75, 77-79, 82] three were case-control;[72, 81, 84] one was a cohort study[85] and one was a retrospective study using data drawn from two randomized controlled trials.[76] Four reports involved hospital-based samples in Belgium,[81] Japan,[82] Sweden[76] and the USA.[85] In one report based in the USA[84] it is unclear where the sample is drawn from. Eight reports involved community-based samples in Australia,[73-75] Canada,[72] and the UK.[77-79, 83] Two studies were longitudinal and followed participants from hospital to six months,[76] and from three to six, nine and 12 months,[85] post stroke. The speech and language intervention that people with aphasia received in the latter study is clearly described, but no information on intervention is provided in the former study. In one study[81] time of assessment ranged from 15 days to 43 months post stroke and a sub-group of people with aphasia were re-assessed eight months later (though the latter data were not used in identifying predictors of HRQL). In 11 studies data collection was cross-sectional and participants with aphasia were in the chronic stages post stroke, with a mean of about 42 months (range 6-250 months) in most studies.[72-75, 77-79, 84]

Sample size in the qualitative studies ranged from 18 to 50, including a total of 98 people with aphasia. Quantitative studies included 742 people with aphasia (range 12-422) and 1,486 controls/comparison groups (range 18-1,195). Though most reports provided details on either the type or severity of aphasia,[72-75, 77-79, 81-85] less than half provided information on type of stroke[77-79, 81, 82, 84] and no study stated stroke classification or severity. In terms of demographic characteristics, all but one[80] reports stated participant gender and age (range 21-96), ten reports gave socioeconomic classification, employment status or education level[72-75, 77-79, 81, 84, 85] and three stated ethnic background.[77-79]

Risk of bias within studies

Qualitative studies

Table 1 presents the results of the quality assessment of the three qualitative studies.[74, 80, 83] All studies stated their aims clearly and chose an appropriate qualitative methodology to address their aims. Recruitment and data collection was problematic in two of the studies: in the study by Hinckley,[80] of 28 eligible published accounts, eight were unavailable and thus not included in the study, and the sample was highly unrepresentative of the population of people with aphasia as it comprised mostly young, well educated and professionally employed people; and in the study by Cruice and colleagues,[74] participants were recruited from a larger study rather than through purposive sampling. The authors acknowledge that lack of probing or prompting of participant responses means that their responses may not reflect their full appreciation of their quality of life and do not allow us to infer relationships or causation in the data. Data analysis was rigorous in two of the studies,[74, 83] with clear descriptions of how the categories/themes were drawn from the data and sufficient data presented to support the findings. Triangulation of the data and validation with respondents has not been discussed in the included studies. There was one main analyst in two of the studies[74, 80] and in the third[83] it is unclear how many researchers analyzed the data.

[Table 1 about here]

Quantitative studies

Table 2 presents the results of the quality assessment of the quantitative studies. Quality was assessed in terms of external validity, internal validity, and where applicable, statistical validity, evaluation and practicality of model.

[Table 2 about here]

External validity. All studies provided an adequate description of their sample (age and sex) and six involved community-based samples.[72, 73, 75, 77-79] Only four reports[72, 77-79] had no major exclusion criteria, with other studies excluding people based on age,[73, 75, 82, 84] type of aphasia[85] or missing data on outcome measure.[76]

Internal validity. No study had an inception cohort that was explicitly assessed within seven days of stroke, but all studies reported the time since stroke. In the studies where participants were followed-up, over 40% of the sample was lost to follow-up,[76, 81, 85] but follow-up was over 30 days in all of them and participants were assessed at fixed time points in two of them.[76, 85] In the remaining reports,[72, 73, 75, 77-79, 82, 84] participants with aphasia were assessed while in the chronic stage post stroke (> 6 months) but not at a fixed time. Data collection was prospective in all but one study.[76] In terms of outcome measures, valid and reliable scales were used, but two studies did not report on the psychometric properties of the tools used (Satisfaction in Daily Life Scale[82] and WHOQOL-BREF[84]). Predictive variables were clearly defined, clinically valid and reliable, with the exception of the Communication Activities Checklist and Social Activities Checklist,[73] frequency of social contacts[78] and severity of aphasia, rated by hospital doctors.[82] Stroke severity was not included as a predictor variable in any of the studies and age was included only in five.[72, 77, 81, 82, 85] Neither of these two variables was entered in regression models in any of the studies.

Statistical validity and evaluation and practicality of model. Only two studies generated a regression model of predictive variables of HRQL in people with aphasia post stroke: one used stepwise regression analysis;[73] and in the other there was an adequate sample size (events per variable > 10) and multicollinearity was assessed.[77] Neither study met the criteria set for evaluation of the model. In terms of practicality, only one study[77] presented the actual model. Some of the data used in both studies are not routinely available in clinical practice.

Synthesis of results

Full findings of the included studies, with information on what predictor variables were explored and what outcome measures were used, are given in detail in the online only Appendix. Because the study designs, participants and reported outcome measures varied markedly, the results are synthesized descriptively.

Qualitative studies

Looking at the three qualitative studies, Cruice and colleagues[74] reported that their participants with aphasia identified as main factors that contribute to or detract from their quality of life: activities, verbal communication, people, and body functioning. Other factors that influenced quality of life included stroke, mobility, positive personal outlook, in/dependence, home, and health. In Hinckley's study,[80] four themes emerged in terms of living successfully with aphasia. First, social support was identified as a critical factor, which links with the importance of people identified by Cruice and colleagues, above. Second, successful living appeared to require an adaptation of one's perception of self. Third, most of the writers of the accounts reviewed looked to the future and set new goals. Finally, all of the published accounts noted the importance of taking charge of one's own continued communication improvement. Adaptation of one's perception of self and identity emerged as a theme in the third study[83] too: learning to live with aphasia involved a sound understanding of aphasia, developing a strong personal identity and finding others with aphasia to develop a collective identity. It also involved sharing responsibility with non-aphasic people to dismantle disabling barriers faced by people with aphasia. Educating other people and those providing services about aphasia would help address environmental and structural barriers; promoting awareness of aphasia would tackle attitudinal barriers; and making information more easily accessible would reduce informational barriers.

Quantitative studies

Table 3 summarizes the factors that were found to be associated with or predictive of poorer HRQL in people with aphasia in quantitative studies. A total of 21 factors were explored though only seven (age, sex, education, time post onset, aphasia severity/language impairment, communication disability, and distress/depression) were explored in three or more studies. The factors most consistently associated with reduced HRQL comprised aphasia severity/language impairment (7/8 studies), communication disability (3/4 studies) and depression (3/3 studies). Activity level was explored with validated scales only in two studies but both found it to be important. The evidence for the influence of demographic variables was limited: older people may be more severely affected (3/5 studies); and women may be more severely affected, particularly when interactions with other variables are taken into account: severity of aphasia and reduced social network (3/5 studies). When considered together, having other medical problems (2/2 studies) and social factors (3/4) also contributed to more severely affected HRQL. Factors that were confirmed as predictors of HRQL using regression models were depression/ high emotional distress (2/2), communication disability (2/2), having other medical problems (2/2), language impairment (1/2), and activity level (1/2).

[Table 3 about here]

DISCUSSION

Summary and implications of findings

Fourteen reports were found that reported factors associated with or predictive of HRQL in people with aphasia. Emotional distress/depression, extent of aphasic impairment and communication disability, presence of other medical problems and activity level were the predictors of HRQL emerging from quantitative studies. Social factors also emerged as important. Themes drawn from qualitative studies - looking to the future/having a positive outlook, verbal communication, body functioning, and people and social support - supported these findings. They also added to them, by identifying adaptation of personal identity and development of a collective identity, and working to remove the barriers that people with aphasia face as ways to reduce disability and live successfully with aphasia.

Our findings on the impact of emotional distress/depression on the HRQL of people with aphasia are in line with the findings of long-term outcome stroke studies.[21, 25, 89-91] Depression appears to be more of a problem for people with aphasia, where the frequency of depression is higher[92] (62% at one year post-stroke) than for other stroke survivors (34% at over six months post stroke[93]). Depression after stroke has been associated with poor recovery,[94] poor functional outcomes,[95] poor social outcomes,[24] increased healthcare use[96] and mortality.[97] Recent evidence on the treatment of post-stroke depression (excluding people with aphasia) suggests that outcomes are better when pharmacological treatment is combined with psychosocial-behavior intervention.[98] There is a pressing need to explore such treatments for people with aphasia, where depression is a persisting problem impacting on HRQL.

The extent of aphasia (severity, language impairment, communication disability) was associated with or predictive of lower HRQL in 7/8 reviewed studies. This finding needs to be interpreted with caution as none of the reviewed studies considered severity of stroke. Still, our findings suggest that stroke outcome studies that selectively exclude people with aphasia are likely to suffer from selection bias and to report optimistic results. Longitudinal studies are needed to begin to unravel the impact of severe aphasia as opposed to the impact of severe stroke.

Presence of other medical problems and activity levels have been consistently identified as predictors of HRQL in stroke studies.[21, 28, 89, 90, 99] In terms of other medical problems, our findings are limited by comprising only very specific problems in one study[73] (near vision, hearing) and number – rather than nature - of comorbid conditions in the other.[77] Comorbid conditions need to be considered in studies of HRQL to identify if any specific ones (diabetes, heart disease) have a greater impact than others; and need to be controlled for as potential confounders when other factors, such as age are considered. In terms of functional status/activity level, our findings are limited as only one study[77] considered this variable with a validated scale in a regression model. Still, activities and working towards goals and dismantling barriers faced by people with aphasia emerged as important themes in the reviewed qualitative studies. Moreover, evidence from other studies suggests that people with aphasia perform fewer social activities than healthy controls[100] and stroke survivors without aphasia[7] and feel their social participation is often characterized by lack of engagement and integration and feelings of exclusion.[101]

Social support was identified as an important theme in the included qualitative studies and was considered in three of the quantitative studies, but each considered different aspects: social network (important for women only[78]), perceived social support (informational support and social companionship were associated with HRQL[78]) and living alone (associated with poorer HRQL for men only[82]). Any conclusions from this evidence are limited. However, related studies have shown that low satisfaction with one's social network has been associated with poor life satisfaction post stroke[11, 12] and in combination with loneliness is predictive of depression post-stroke.[102] In another study, being a housewife and inability to work predicted depression, which in turn was a main predictor of HRQL.[21] A recent study exploring why people lose friends post stroke identified as main reasons: loss of shared activities, reduced energy levels, physical disability, aphasia, unhelpful responses of others, environmental barriers, and changing social desires.[103] Given the links between diminishing social networks and depression and HRQL post stroke, research on what interventions can support people maintain their social networks seems worthwhile.

Limitations and strength of evidence

Overall, the reviewed evidence is not sufficiently robust to determine with confidence the comparative importance of different predictors of HRQL. From the quantitative studies, only two[73, 77] generated regression models, both were cross-sectional with people with chronic aphasia and neither included age and stroke severity in the regression model. Three studies[76, 81, 85] included longitudinal data, but all lost > 40% to follow-up. Selection bias was an issue in six reports with studies excluding people based on age,[73, 75, 82, 84] type of aphasia[85] or missing data on outcome measure.[76] In the qualitative studies, sample representativeness was also an issue[74, 80] and none sufficiently addressed data saturation or credibility of findings.

At the review level, this report is the first synthesis of research on predictors of HRQL in people with aphasia. A strength of the review is the inclusion of both quantitative and qualitative studies with the latter giving more prominence to the voice of people with aphasia. Our literature search aimed to be as inclusive as possible. Given the expected heterogeneity of studies in this area, and the wide range of outcome measures of interest, we had no restrictions for study designs or outcome measures. Secondly, because of the diversity of the vocabulary used to refer to HRQL we included a range of related terms in our search. This may have made the search strategy inefficient and burdensome, but its inclusiveness increased our confidence that we have overlooked few eligible studies. A limitation is that our search was restricted to the English language.

CONCLUSIONS

Design and quality limitations of included studies mean that the existing evidence is not strong enough to determine the main predictors of HRQL in people with aphasia post stroke. Factors that have consistently emerged as important are emotional distress/depression, extent of aphasic impairment and communication disability; and, to a lesser extent, presence of other medical problems, activity levels and aspects of social network and support. There is a need for further research, firstly to explore these factors in detail and determine the main predictors of HRQL, and secondly to identify what interventions can best address these.

We found a number of studies on HRQL after stroke that could not be included in this review because of their limited reporting regarding people with aphasia. There is a need for longitudinal studies of predictors of long-term outcome and HRQL in stroke to a) include people with aphasia and b) report findings for them. The current practice of selectively including people with aphasia with no explicit criteria for inclusion, and either analyzing proxy data alongside self-report data or reporting no data for people with aphasia has resulted in a limited understanding of what determines their HRQL. Adaptive methods can be used to allow people with aphasia to complete self-report measures, such as using interviewer administration to facilitate their communication and modifying the presentation of measures (using large font, printing key words in bold, printing few items per page, using practice items).[102, 104, 105]

Lastly, interventions that aim to improve HRQL for people with aphasia by specifically targeting factors that affect HRQL (e.g. depression, communication disability, engagement in activities, diminishing social networks) need to be systematically evaluated. At present there is preliminary promising evidence for group therapy in terms of psychosocial benefits[106-108] and improved social participation and social connection compared to controls;[109] impairment based therapy for word finding difficulties;[110] and models of community service provision,[40, 111-114] but lack of appropriate controls limit the validity of the results.

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