Determinants of living well with aphasia in the first year post stroke: a prospective cohort study

Abstract

Objective: To determine factors that contribute to living well with aphasia in the first 12 months post stroke.

Design: Prospective longitudinal cohort study

Setting: Hospitalized care, ambulatory care and general community

Participants: A referred sample of 58 people with a first incidence of aphasia after stroke was assessed at 3, 6, 9 and 12 months post onset. Participants were recruited through speech-language pathologists in two capital cities of Australia. Presence of aphasia was determined through the Western Aphasia Battery Revised (WAB-R)[6] by an experienced speech-language pathologist.

Interventions: N/A

Main outcome measures: The main outcomes were the five domains of the Assessment for Living with Aphasia at 3, 6, 9 and 12 months post stroke. The independent variables included demographics, physical functioning, social network, mood, aphasia severity and a self-rating of successfully living with aphasia at the same time points. Mixed effects modelling was used to determine which factors contributed to the trajectory of each of the five domains of Participation, Impairment, Environment, Personal Factors, Life with Aphasia.

26 Results: Higher household income, larger social network size, being female and having a

27 milder aphasia were positively associated with the Participation domain. Graduate or

28 postgraduate educational levels, low mood and poor physical functioning were negatively

29 associated with the Participation domain. Factors positively associated with other domains

30 included higher income, self-ratings of successfully living with aphasia and aphasia severity.

31 Low mood was consistently negatively associated with all domains.

32

33 Conclusion: Psychosocial determinants were the most significant predictors of living well

34 with aphasia in the first 12 months post onset. Aphasia rehabilitation needs to attend more to

35 these factors to optimise outcomes.

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41 Abbreviations: None

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Introduction

Aphasia rehabilitation may target the language impairment or its consequences[1]. Although there is high level evidence for significant improvements in communication with behavioural intervention [2], many people with aphasia and their families live with aphasia for the remainder of their lives. Some people living with aphasia overcome the debilitating impact of aphasia over the long term, while others remain socially isolated and depressed. What factors contribute to a person successfully or unsuccessfully living with aphasia?

The concept of living well with aphasia is analogous to quality of life or subjective wellbeing. The concept of living well with aphasia however has the advantages of a) asking the person with aphasia to judge life specifically in relation to their aphasia, b) focusing on positive outcomes rather than the deficit model that predominates in rehabilitation, c) reflecting the person-centred approach espoused by many health service organizations. The construct also implies a temporal component and is therefore ideal for describing a process that occurs over time.

We have previously described what successfully living with aphasia means to people with aphasia, their family and speech-language pathologists[3]. Participants with chronic aphasia who were over 12 months post stroke described living successfully with aphasia under three main themes: being able to do things, having meaningful relationships, and maintaining hope and positivity. Similar themes were present at 3 months post onset but with a greater focus on the recovery of communication [4]. From these qualitative results, it appears that psychosocial factors such as social support (relationship status, social network size and satisfaction) and mood (depression and anxiety) may be important to living well with aphasia. Measures such as the Assessment for Living with Aphasia[5] that capture domains associated

68 with living well with aphasia (e.g. psychosocial factors) have now been developed, but there

69 is no known study that has included psychosocial variables to determine the most significant

70 predictors of living well with aphasia during the first year post stroke when most

71 rehabilitation occurs.

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73 In studies to date, the outcome of interest was language recovery. The most recent literature

74 review summarising factors that predict post stroke language recovery[6] concludes that lesion-

75 related factors are the most robust factors, but the interplay between all factors make

76 predicting recovery of aphasia difficult. Prognostic indicators that have been found to be

77 predictive in some studies have included demographic variables (age, sex, education) stroke

78 and aphasia related factors (aphasia and stroke severity and type) and treatment related

79 factors (type of treatment).

80

81 We have previously argued that the goal of aphasia rehabilitation in the first year is not only

82 to maximise recovery of the language but also help the person with aphasia and their family

83 live successfully with aphasia[4]. Aphasia rehabilitation therefore needs to target factors that

84 will have the most impact on outcomes, Hence the aim of this quantitative study is to

85 identify the factors that contribute to living well with aphasia over the first year post stroke.

86

87 **Methods**

88 This study was approved by a Human Ethics Committee of The University of Queensland,

89 Australia and all participants provided informed consent and procedures followed were in

90 accordance with institutional guidelines.

91 A battery of assessments was completed at 3, 6, 9 and 12 months post-onset. How well they

92 were living with aphasia, the dependent variable, was measured by the aphasia friendly self-

report tool – the *Assessment for Living with Aphasia (ALA)*[5]. Measures of factors that have

been found in previous studies to be predictive of stroke and language recovery were

included as the independent variables. These included demographic variables of age, gender,

status, education and socioeconomic status[5]. The psychosocial factors of marital status and

social network size and satisfaction were also included because support from other people

was found to be important in our qualitative studies of living successfully with aphasia [3,4].

Stroke and aphasia severity and type were considered to be most predictive of language

recovery[6] so aphasia severity and severity of physical functioning were included as

independent variables. Our previous study [7] has shown that the presence of depression

influences quality of life so an additional measure of depression was added to the list of

independent variables. Watila & Balbarare[6] also found that the type of intervention predicted

outcome, so we aimed to collect information from treating therapists to include in the

analysis.

Participants were 58 individuals with a first incidence of aphasia following stroke aged 26 to

93 [mean 66.07 SD (13.59)] who were recruited through speech-language pathologists in two

capital cities of Australia. For full demographic details at baseline see Table 1. Presence of

aphasia was determined through the Western Aphasia Battery Revised (WAB-R)[8] by an

experienced speech-language pathologist. Individuals were eligible to participate if they were

18 years or older, had no significant complicating concomitant diagnoses (for example,

dementia or schizophrenia) and were proficient in English. Participants were assessed at a

place of their choosing and included hospital and home settings over the year after their

stroke.

The outcome (dependent) measure was the ALA[5] at 3, 6, 9 and 12 months post-onset. The

ALA is a biopsychosocial measure based on ICF domains and consists of 38 items that are

self-rated. A typical item is "How would you rate your talking? The anchors on the response

scale are "A big problem" to "No problem". Scores obtained for each item are summed to calculate five individual domain scores, with higher scores representing a more desirable life with aphasia. The five different domains on the ALA include: Aphasia (impairment), Participation, Environment, Personal, and Life with Aphasia. The concept of the final domain of Life with Aphasia is viewed as overlapping the other four domains[5]. A psychometric evaluation of the ALA has been completed on a sample of 101 people with aphasia resulting in moderate to high test-retest reliability (Intraclass correlation = .87) and internal consistency (Cronbach's alpha = 0.81), acceptable to high construct validity, and strong face validity[5]. In our data analysis, we were unable to definitively confirm the unidimensionality of the total score, and since the internal validity of each domain was good (Cronbach's alpha of Aphasia= 0.86; Participation= 0.81; Environment = 0.72; Personal = 0.83; Life with Aphasia is a one item domain), we chose to model the factors that affected each of the five domains.

The explanatory (independent) variables chosen from the literature review and our own qualitative studies included demographics (age, gender, socio-economic status, level of education); level of physical functioning after stroke as an indicator of the severity of stroke using the Burden of Stroke Scale (BOSS)[9]; Western Aphasia Battery Aphasia Quotient[8] as a measure of the severity of aphasia, psychological distress using the Hospital Anxiety and Depression Scale (HADS)[10]; quantity of aphasia therapy Social Network Convoy Model[11] as an indicator of social support and using the Successfully Living with Aphasia Rating Scale (SLARS)[4] as a one item self-report of the temporal aspect of living successfully with aphasia, We included the one item rating of successfully living with aphasia as an independent variable to determine if a simple rating scale captured the same information as the 38 item Assessment for Living with Aphasia.

142 We were unable to collect sufficient data about quantity of therapy from participants' speech-

143 language pathologists. Age was measured in years at time of stroke. Socio-economic status

144 was based on self-reported total annual household income, categorised as low (<$30k AUD

145 per annum, equivalent to pension), below the median Australian household income of

146 approximately $70k ($30k to $69,999 AUD), and above the median Australian household

147 income ($70k AUD and over). Level of education was measured as years of education, and

148 categorised as up to year 8, year 9-12, and graduate/postgraduate. Demographic details were

149 collected at the first assessment only. Social networks were categorised per 10 people (0-10,

150 11-20, 20-30 and 30+).

151

152 To examine the possible contribution of explanatory variables on the trajectory of each of the

153 five domains of the Assessment for Living with Aphasia (ALA), linear mixed effects

154 modelling was implemented. This type of modelling takes into account the relationships

155 between repeated measures of the outcome events of interest and offers adjusted effects of

156 explanatory variables on the outcome of interest. One of the unique advantages of mixed

157 effects modelling is the handling of missing data by incorporating all available information.

158 Before performing any multivariable modelling, collinearity of the factors was assessed using

159 variance inflation factors (VIF). The residuals of the fitted final models were examined to

160 ensure that all required assumptions were met. An alpha level of 0.05 was considered as

161 significant in the final modelling.

162

163 **Results**

164 Table 2 shows the factors associated with the five domains of the ALA. They are presented in

165 order of the ALA domains with the largest effects of independent variables. Highly non-

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166 significant variables are not included for clarity of presentation.   Hence only significant

167 independent variables and those trending towards significance are presented.

168   *Insert table 2 around here*

169 <u>Participation domain</u>

170 Mixed effect modelling of the Participation domain of the ALA was significantly and

171 positively associated with gender, household income, milder aphasia, and social networks.

172 Participants with the highest income (over $70k) had much better Participation with the ALA

173 Participation domain scores 6.7 points higher than participants whose household income was

174 lowest (<$30K per year) (p=0.004). Females were 5.03 points higher than males in the

175 Participation domain (p=0.004) so females had better Participation than males. The mean

176 Participation score was 4.88 points higher for people who had a large social network size (31

177 or more) compared to those who had a small social network size (10 or less) (p=0.006).

178 People with milder aphasia on the WAB AQ were associated with better Participation domain

179 scores. However, graduate and postgraduate levels of education (-7.75 points), were

180 negatively and significantly associated with the Participation domain scores. Better physical

181 functioning as measured by the BOSS (-0.35), and lower anxiety and depression scores (-

182 0.84) were associated with better Participation domain scores.

183 Aphasia Domain

184 The Aphasia domain score (i.e. self-report of severity of impairment) was found to be

185 significantly and positively associated with being in a higher income group. The mean

186 Aphasia domain score in the highest income group (70K or more per year) was 2.19 points

187 higher compared to the mean Aphasia domain score of the lowest income group (<30K per

188 year) (p=0.006). People who rated themselves as successfully living with aphasia had 2.05

189 points higher Aphasia domain score compared with people not living successfully with

190 aphasia (p<0.001). There was a trend towards significance that aphasia severity as measured

191 by the WAB-R AQ was associated with the Aphasia domain scores (p=0.057). Better

192 physical functioning and mood were associated with the higher Aphasia domain scores.

193 Personal domain

194 People who rated themselves as successfully living with aphasia had a 1.58 point higher

195 mean Personal domain score (e.g. identity, confidence) compared to people not living

196 successfully with aphasia (p=0.04) after adjusting for other factors. WAB AQ was positively

197 and significantly associated with the Personal domain score (p=0.03). Less anxiety and

198 depression was associated with better Personal domain scores (p<0.001).

199 Environmental domain

200 Better mood was associated with perceived support in communication within the immediate

201 (at home) and community environment (p<0.001)

202 Life with Aphasia domain

203 In the final Life with Aphasia domain, higher successfully living with aphasia ratings were on

204 average 0.60 points higher on the mean Life with Aphasia scores (p<0.001) while again,

205 physical functioning and mood were negatively associated (p<0.001, p= 0.014).

206 The one item SLARS was a significant factor in only three of the five domains so was not

207 considered to reflect all domains of the 38 item ALA.

208 **Discussion**

209 The largest effects were seen in the Participation domain with point differences as high as -

210 7.75 (negative effect of high levels of education), +6.70 (highest household income), and

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211 +5.03 (female). Across all domains of the ALA, the most consistent factor affecting more

212 positive scores was self-ratings of successfully living with aphasia. The most consistent

213 factor affecting more negative scores across all domains of the ALA was lower mood on the

214 depression screener. Higher household income was associated with both the higher

215 Participation and Aphasia domain scores, while poorer physical functioning as measured on

216 the BOSS was associated with the poorer Participation, Aphasia, and Life with Aphasia

217 domains. Age was not associated with any domain while WAB AQ was only associated with

218 the Personal domain score. Gender, social network size, and level of education were

219 associated with Participation only.

220 The models suggest that for those people with aphasia who have life participation as their

221 primary goal, the emphasis for services in the first 12 months should be to maximize physical

222 recovery, social network size, household income (through support for return to work or

223 claiming welfare), and prevent or treat mood disorders. For people with aphasia whose focus

224 is to improve the language impairment of aphasia, a focus on the same factors without the

225 emphasis on social networks and a self-rating that they are successfully living with aphasia, is

226 likely to result in a positive perception of aphasia impairment in the first 12 months post

227 stroke. Better physical and emotional functioning together with a self-rating of successfully

228 living with aphasia will also lead to better perceptions of how much aphasia is affecting life

229 overall. Regardless of the goal of intervention, the commonalities across the results suggest

230 the major focus of intervention during the first 12 months post aphasia should be to maximize

231 physical recovery, optimize household income, prevent or treat mood disorders and develop a

232 positive outlook towards living successfully with aphasia. The modifiable factors that affect

233 all domains include household income, social network size, perspective of life with aphasia,

234 severity of aphasia, mood, and physical functioning. Optimizing household income is

235 generally not considered to be a modifiable factor however it can be accomplished in a

236   variety of ways. Maintaining income may be possible by a return to work. Rehabilitation

237   professionals including speech-language pathologists can play a role in this. Assisting a

238   spouse to return to work by ensuring that the person with aphasia is safe and well cared for is

239   also a strategy. If participants are eligible for social security benefits, then ensuring that they

240   can access aphasia friendly information is within the scope of practice of rehabilitation

241   professionals. Training professionals such as the legal profession to communicate effectively

242   with the person with aphasia may assist when families break down (eg., divorce, family home

243   is sold) as a result of the stroke. These results provide support for a multidimensional and

244   multidisciplinary approach to aphasia rehabilitation.

245   The variable that was not associated with living well with aphasia was marital status, but

246   social network size may be a more sensitive measure and acted as a stronger variable in the

247   analysis. In addition, the severity of the aphasia which is usually the target of intervention by

248   speech-language pathologists was a less significant determinant of living well with aphasia.

249   While still an important and potentially underlying factor to other determinants, this study

250   suggests that working with other health professionals and social services to keep household

251   income above $70k per year, promote a strong social network of over 30 contacts, encourage

252   a positive outlook towards successfully living with aphasia, prevent and treat mood disorders,

253   and maintain physical functioning will contribute more towards living well with aphasia than

254   targeting aphasia severity alone. While this study used a cut off of $70K per year to

255   categorise the household income of participants, there is a need for more study about the

256   amount of household income required to live well with aphasia.

257

258   **Study Limitations**

259 The recruitment of participants with largely mild to moderate aphasia may have contributed

260 to aphasia severity being less significant in the model. Some participants were at ceiling on

261 the WAB-R[8] at 9 and 12 months post stroke although everyone continued to self-report

262 'experiencing' aphasia. Hence recruitment of more severe aphasia participants would be an

263 important area for future research. The other potential limitation is that we were unable to

264 add the effect of intervention by any rehabilitation professional into the model. Although

265 attempts were made to include rehabilitation care data, insufficient reliable data was

266 collected. Missing data was an anticipated problem in this longitudinal study hence mixed

267 effects modelling that uses all available data was used instead of a repeated measure ANOVA

268 that only uses complete cases. Finally, like many studies in aphasia this study is

269 underpowered, therefore the modeling might have failed to identify some real effects and

270 some statistically significant results do not reflect a true result.

271 In addition to continuing this line of research on a larger and more varied population, further

272 research is needed regarding the unexpected result that graduate and post graduate education

273 was a strong negative determinant to successfully living with aphasia in the Participation

274 domain. It is possible that the central role of language and communication in the lives of

275 people with graduate or postgraduate education makes the loss of this core skill particularly

276 devastating. As educational levels increase over generations, the impact of the loss of

277 language associated with aphasia may also increase.

278 Future research should evaluate whether interventions translated from these findings are

279 effective in improving life with aphasia. The team is currently funded to evaluate an early

280 brief intervention called the Aphasia *Action Success Knowledge* (ASK) program. The

281 Aphasia ASK program is a speech-language pathology led intervention that targets low

282 mood, size of social network and a positive approach to living with aphasia. In addition to

283   the aphasia ASK program, other evidence based interventions targeting the key determinants

284   are needed.

285   Participation should be a primary target of rehabilitation; hence psychosocial determinants

286   should be key elements in any intervention program for aphasia. This is contradictory to an

287   approach in which language deficits only are targeted. Efforts to improve living with aphasia

288   should run in parallel with efforts to improve language function. The need to prevent low

289   mood and the need to optimise positive approaches to recovery were consistent findings in

290   this study. The consistency of the findings regarding the impact of mood on recovery across

291   this study indicates that this is an important target for early intervention.

292

293   Conclusion

294   In conclusion, while aphasia research and practice have focused heavily on linguistic

295   function, the severity of aphasia was only one factor that contributed to successfully living

296   with aphasia, and was a less significant predictor. It is clear from the results of this study that

297   additional consequences of aphasia require considerable attention to ensure meaningful and

298   positive outcomes. Social and psychological determinants of health are often downplayed in

299   the aphasia research literature and rehabilitation practice. The results of this study add weight

300   to arguments that greater attention to social and psychological determinants in aphasia

301   research and practice will benefit people with aphasia in the first 12 months post stroke.

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