

Communication partner training for healthcare workers engaging with people with aphasia: Enacting Sustainable Development Goal 17 in Austria, Egypt, Greece, India and Serbia

Jytte Isaksen ^a, Suzanne Beeke ^b, Analisa Pais ^c, Evangelia-Antonia Efstratiadou ^d, Apoorva Pauranik ^e, Susannah K. Revkin ^f, V.P. Vandana ^g, Fabián Valencia ^h, Jasmina Vuksanović ⁱ, & Caroline Jagoe ^j

^aUniversity of Southern Denmark, Denmark

^b University College London, United Kingdom

^cUniversity of Essex, United Kingdom

^dUniversity of the Peloponnese, Greece

^ePauranik Academy of Medical Education, India

^fRehabilitation Clinic Vienna Baumgarten, Austria

^gNational Institute of Mental Health and Neurosciences, India

^hCES University, Medellín, Columbia

ⁱInstitute for Medical Research, University of Belgrade, Serbia

^jTrinity College Dublin, The University of Dublin, Ireland

Correspondence: Caroline Jagoe, Department of Clinical Speech & Language Studies, 7-9 South Leinster Street, Trinity College Dublin, Dublin 2, Ireland.

Email: cjagoe@tcd.ie

Abstract

Purpose: This commentary describes how a grassroot-led partnership initiated by members of the organisations World Federation of NeuroRehabilitation and Collaboration of Aphasia Trialists is addressing the marginalisation of people with aphasia, through education and knowledge exchange related to communication partner training of health professionals.

Result: A partnership between academics and healthcare professionals across Austria, Denmark, Egypt, Ireland, Greece, India, Serbia and the United Kingdom was established in 2020. Through bimonthly online sessions in 2021-2022 a Danish communication partner training program was introduced while six teams adapted and translated the training and its materials to their local contexts.

Conclusion: A collaborative partnership enabled multiple translations of an existing communication partner training program for healthcare professionals working with people with aphasia to support a sustainable delivery model that is linguistic and culturally sensitive. This commentary paper focusses on Sustainable Development Goal (SDG) 17 and also addresses SDG 10.

Keywords: Sustainable Development Goals (SDGs); communication disability; aphasia; communication partner training; intervention adaptation; Reduced Inequalities (SDG 10), Partnerships for the Goals (SDG 17)

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Introduction

The Sustainable Development Goals (SDGs) comprise 17 individual but interrelated goals adopted by the United Nations in 2015. This ambitious vision sets out targets for achieving peace and prosperity by 2030, recognising that reducing disparities within and across countries requires tackling multiple domains. SDG 17 addresses “partnership for the goals” and thereby recognises the centrality of collaboration to achieve a more equal world. This commentary focuses on the importance of global partnerships to achieve sustainable development (“partnerships for the goals” SDG 17; United Nations 2015). Specifically, we address the role of “North-South [and] South-South” research partnerships (SDG 17.6) in reducing “inequalities within and between countries” (“reduced inequalities” SDG 10 respectively; United Nations, 2015), with regards to marginalisation of people with communication disabilities such as aphasia.

This commentary takes as its starting point the documented inequalities experienced by people with aphasia, specifically in relation to healthcare contexts, and the global impact of stroke. Communication partner training in aphasia is outlined. We then explore how, in order to reduce inequalities between and within countries, a partnership approach was applied to develop context-sensitive, culturally adapted versions of an evidence-based communication partner training program.

Global inequalities and the ethics of adaptation

The terms ‘Global North’ and ‘Global South’, while often used as shorthand for high income and low- and middle-income countries respectively, are intended to invoke consideration of large and persisting inequalities that exist between (and within) regions

of the world, based on “an entire history of colonialism, neo-imperialism, and differential economic and social change” (Dados & Connell, 2012, p.13). The terms are not without their limitations, but they benefit from a loose association with geographical regions, and an acknowledgement of the historical context that underpins, and often perpetuates, inequalities. SDG 17.6 specifically uses the phrases of ‘North-South’ and ‘South-South’ cooperation or partnership. Referring to the context of cooperating partners in this way recognises the historical (dis)advantages and, perhaps, the potential assumptions at play.

The stark inequalities between countries with regards to access to rehabilitation services (Jesus et al., 2017), including speech-language pathology (Wylie et al., 2013), and the rising incidence of stroke in the Global South (Kim et al., 2015), points to the risk for multiple layers of inequalities for people with aphasia depending on where they live. A global approach is required to ensure equality of access and inclusion for people with aphasia across the world. The goal of providing a respectful and appropriate service for clients across diverse contexts requires culturally and linguistically attuned interventions. However, the mechanics of providing interventions that are culturally appropriate and relevant in the context in which they are delivered raises both practical and ethical questions (Trimble et al., 2012, p. 45). Balancing ecological validity and empirical evidence raises questions as to whether to adapt an existing intervention (with an evidence base) or create a new intervention for a specific group. The decision to adapt (rather than create) an intervention was taken jointly. Adaptation of an existing intervention from the Global North carries a risk of new colonialism in which the cultural assumptions implicit in the intervention are taken as the ‘default’, to be imported with superficial engagement of contextual considerations. In this project we actively mitigated this risk through partnership with country teams; explicit recognition

of assumptions within the intervention; proactive encouragement to adjust or exclude components or insert new elements; and reflective practice on the part of the facilitators (JI, CJ, AP, SB).

Communication partner training for people with aphasia

People with aphasia experience marginalisation and exclusion (e.g., Parr, 2007). The exclusion arguably begins in days and weeks following the stroke. Research suggests that those with communication disabilities are marginalised in healthcare encounters: they experience more adverse events in hospital (Bartlett et al., 2008), including risk of falls (Sullivan & Harding, 2019); and experience exclusion from healthcare discussions and decision-making (Hemsley et al., 2013).

Communication partner training is an umbrella term for interventions that aim to optimise communication between people with aphasia and a range of communication partners including healthcare professionals, volunteers, and family members, through components including education, strategy identification, feedback and practise delivered to individuals, dyads and groups with/without the person with aphasia present, across a range of health and social care settings (Cruice et al., 2018). It is known to be protective of mental health; for people with aphasia a period of communication partner training can prevent the evolution of low mood into clinical depression (Baker et al., 2018). A systematic review and subsequent update covering 56 studies demonstrated that communication partner training is effective at changing the communication behaviours of a partner (Simmons-Mackie et al., 2010; 2016), and interacting with a trained partner is likely to result in increased participation for a person with chronic aphasia in healthcare and social interactions. Most studies targeted English-speaking people with aphasia (some Finnish, Danish and Swedish speakers were also represented) within the context of high-income countries, and both reviews were restricted to studies published

in English. In a first synthesis of communication partner training published in languages other than English, Kong et al. (2021) reviews 37 articles involving Chinese-speaking people with aphasia, with 11 meeting the intervention definition (the remaining focused on how communication partners could be trained to conduct therapy tasks). There was no evidence found of adaptations to communication partner training, but the measurement of outcomes suggested consideration of culturally specific factors. For example, some studies used outcome measures addressing mutual communication satisfaction, “compatible with the collectivist value of harmony and solidarity within a group” (Kong et al., 2021 p. 6) and distinct from the majority of the outcome reported in the Simmons-Mackie et al. reviews (2010; 2016) of studies from countries with a more individualistic culture. The authors conclude however that “Further examinations of how generational or socioeconomic differences and cultural mismatch between the [person with aphasia] and caregiver may affect their interactions and [communication partner training] are warranted” (Kong et al., 2021, p. 6). There is growing evidence from conversation analytic studies that interactional principles, such as turn taking, are robustly universal, with cultural difference reflected in features such as speed of response (Stivers et al., 2009).

The existing literature on adaptations of interventions demonstrates that such adaptation may involve modifying terminology, language used, mode of delivery, recipient cohort, and elements that are not relevant to the context for which it is being developed (Stirman et al., 2013). In the process of intervention adaptation, researchers typically consult an expert or team of theoretical, contextual and socio-cultural experts (Kiran & Krishnan, 2013) on the relevance of the original resource (e.g. training content and materials); develop an in-depth understanding of the cultural context; carefully modify the items, elements and processes regarded as contextually (Stirman et al., 2013)

and culturally (Kiran & Krishnan, 2013) irrelevant; and finally, evaluate the adapted intervention and resources. One way in which acceptability can be optimised is to ensure that local perspectives are fully incorporated from the beginning of the adaptation process. In the partnership local country teams (with theoretical, contextual and socio-cultural expertise by virtue of their professional training, context of work, identity and lived experience) led individual adaptations of the intervention to imbue ownership and maximise cultural and linguistic acceptability.

The communication partner training approach central to this partnership is the Danish program KomTil (an abbreviation of **K**ommunikativ **T**ilgængelighed, which means “communicative accessibility” and is a play on words, with the saying “at komme til” meaning “to get a chance”). KomTil is a program for healthcare professionals working with people with aphasia in all rehabilitation phases, developed as a part of a project in 2017-2020 to improve the care pathway for people with aphasia in the Southwest of Denmark (Bertram et al., 2021). KomTil was co-designed with people with aphasia, relatives, healthcare professionals, and researchers and is inspired by other communication partner training programs (e.g., Kagan et al., 2001). KomTil basic training is delivered as two 3-hour long sessions to provide communication partners with knowledge of aphasia and skills in communication with people with aphasia. KomTil trainers have extensive training in the program, aphasia, the research behind communication partner training, behaviour change, implementation, and adult learning. Any healthcare professionals with experience in working with aphasia can be trained as trainers.

The process of building the multi-country team

The development of the team has been an organic process through the existing networks World Federation for NeuroRehabilitation and Collaboration of Aphasia

Trialists. Members of a World Federation for NeuroRehabilitation special interest group wished to learn more about communication partner training and initial contact was made through Dr Rebecca Palmer of the Collaboration of Aphasia Trialists. After a series of meetings chaired by Dr Palmer, we jointly decided to form a project group where teams from different countries would be trained as KomTil trainers while at the same time adapting the program for their local contexts. Through the Collaboration of Aphasia Trialists network additional country teams were added (see Table 1).

Table 1 here

Each team lead recruited other team members. The facilitators (JI, CJ, AP, SB, all with experience in communication partner training and cultural adaptation of materials) proposed a structure to support the adaptation process, with five bimonthly online meetings from September 2021 to May 2022. During each meeting a new part of KomTil was presented together with topics underpinning the future use of adaptations (e.g. cultural adaptation, implementation, and professional behaviour change). Between meetings the local teams worked on translation and adaptation. Active engagement within teams or across teams took place asynchronously outside of the meeting times and continues to date. There are different plans in the country teams of how and when to start implementing the adapted KomTil programs with Austria having the most advances plans of starting their staff training in July 2022. The collaboration is currently unfunded.

Capturing the learning: Documenting and reflecting

During each online meeting the team reported what modifications of the last presented part of the KomTil program they had made. A framework proposed by Stirman et al. (2013, 2019) was applied to record modifications, and maintenance of the fidelity of each of the adapted KomTil interventions. FRAME: An expanded framework

for reporting adaptations and modifications to evidence-based interventions (Stirman et al., 2019) offers a comprehensive coding system, which allows both reporting and understanding of the specific modifications that might contribute to reduced fidelity as well as what modifications are acceptable during implementation in each country context, different from that for which it was originally designed (Stirman et al., 2013).

Active discussion on cultural perspectives was facilitated, and the potential limitations of some of the components of communication partner training (e.g. role-play), were debated. In-depth discussions regarding the adaptations were subsequently carried out asynchronously within each country team. Ultimately each team made decisions about what elements required adaptation, exclusion or new material, in line with their insider cultural and professional expertise. Some issues remained unresolved (e.g. the tension between the evidence that practice is important in communication partner training versus the unfamiliarity or irrelevance of role play). In these instances, country teams made contextually informed decisions, sometimes entailing a decision to include role play in the initial implementation of their intervention and seek feedback from participants. Adaptation by country teams was a critical component of this process, given that it is these local teams who will implement the training. Examples of adaptations from teams can be seen in Table I. Two of the European teams (Austria, Greece) report least changes, and they are primarily related to level of politeness, and the delivery model. The Egyptian and two Indian teams have made more substantial changes, for example around concepts/terminology, roleplay and video content, and redrawing pictures.

FRAME was challenging for some of the teams to use owing to the lack of transparency of the terminology for the local teams, who also found it to be more lengthy than usable by a team of busy clinician-researchers. The utility of FRAME was

therefore seen as more related to documenting changes for the purposes of research, rather than having practical consequences for themselves or to induce reflection.

Summary and conclusions

Research on Communication Partner Training in the Global South, and in Global North countries where languages other than English are spoken, remains extremely limited and needs exploration. The challenges to accessing and delivering healthcare that are unique to these contexts are crucial to consider when making advances in the field based on evidence from high income contexts or English-speaking contexts. Persistent inequalities demand that research informs sustainable and contextually appropriate developments in healthcare, in this case for communication disabilities such as aphasia. This research must be underpinned by global partnerships (SDG 17 partnership for the goals) in academia, healthcare, and healthcare education to support the reduction of “inequalities within and between countries” (SDG 10 reduced inequalities). Without addressing the marginalisation of people with aphasia, this group will be left behind in the drive to reduce inequalities.

As reported in this commentary, the partnership has been achieved through existing international networks where members took initiative and carried out this grassroots-led project without financial resources. Crucial to implementation and sustainability of the knowledge exchange in this project was embracing practices of good collaboration with local knowledge holders. However, to further enhance implementation and sustainability, more research and closer collaboration requires financial and leadership support.

Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this article.

Acknowledgements

The authors acknowledge the support of the Collaboration of Aphasia Trialists which is funded by The Tavistock Trust for Aphasia in fostering international and multidisciplinary aphasia research collaboration. We also would like to acknowledge all team members from the five participating countries and Dr. Rebecca Palmer who put all of us in touch with each other.

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