

Systematic review of facilitated communication 2014–2018 finds no new evidence that messages delivered using facilitated communication are authored by the person with disability

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Abstract

Background and aims: Facilitated Communication (FC) is a technique that involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically with physical support from a “facilitator”. Proponents claim that FC reveals previously undetected literacy and communication skills in people with communication disability. However, systematic reviews conducted up to 2014 reveal no evidence that the messages generated using FC are authored by the person with a disability. This study aimed to conduct a systematic review of the literature on FC published between 2014 and 2018 to inform the 2018 update of the 1995 American Speech-Language-Hearing Association Position Statement on FC.

Method: A systematic search was undertaken to locate articles about FC in English published in the peer reviewed literature since 2014; and to classify these according to the study design for analysis. Studies meeting the inclusion criteria were classified according to four categories of evidence: (a) quantitative experimental data pertaining to authorship, (b) quantitative descriptive data on messages produced using FC, (c) qualitative data, or (d) commentary material on FC.

Main contribution: In total, 18 studies met the inclusion criteria. There were no new empirical studies and no new descriptive quantitative studies addressing the authorship of messages delivered using FC. Three new qualitative studies

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qualified for inclusion; these did not first establish authorship. Of the 15 new commentary papers on FC located, 14 were critical and one was non-critical. The results could be used to inform the development or update of current position statements on FC held locally, nationally, and globally.

Conclusion: There are no new studies on authorship and there remains no evidence that FC is a valid form of communication for individuals with severe communication disabilities. There continue to be no studies available demonstrating that individuals with communication disabilities are the authors of the messages generated using FC. Furthermore, there is substantial peer-reviewed literature that is critical of FC and warns against its use.

Implications: FC continues to be contested in high profile court cases and its use promoted in school settings and workshops at university campuses in the US. Our empty systematic review will influence both clinical practice and future clinical guidance; most immediately the American Speech-Language-Hearing Association Position Statement on FC and any future guidance issued by the 19 associations worldwide with positions against FC.

Keywords

Systematic review, developmental disorders, augmentative and alternative communication

Introduction

Facilitated communication (FC) is also referred to as “Assisted Typing,” “Facilitated Communication Training,” and “Supported Typing” (Lilienfeld, Marshall, Todd, & Shane, 2014). FC is a technique that involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically with physical support from a “facilitator.” The physical support of FC usually occurs on the hand, wrist, elbow, or shoulder (Biklen, Winston Morton, Gold, Berrigan, & Swaminathan, 1992) but can also occur on other parts of the body. Proponents’ claims that FC reveals previously undetected literacy and communication skills in people with communication disability are based on anecdotal reports, testimonials, and descriptive studies. Furthermore, FC is recognized as being associated with several negative and harmful consequences, particularly the harms of false allegations of sexual abuse (Probst, 2005) and other forms of maltreatment (Boynton, 2012; Chan & Nankervis, 2014; Wombles, 2014).

In 2017–2018, the American Speech-Language and Hearing Association (ASHA) resolved to strengthen its 1995 Position Statement on FC (ASHA, 1995). ASHA is responsible for over 198,000 members, and their policies are influential on member practices in accordance with their Code of Ethics. There is worldwide interest in the question of authorship in FC, owing to the known dangers of the technique, and the popularity of FC in the US stemming from the Institute on Communication and Inclusion (formerly the Facilitated Communication Institute; Syracuse University) (Syracuse University School of Education, 2018) and workshops held under the auspices of other Universities (e.g. Marian University, Indiana [Saved By Typing, 2018]). In 2017,

the Ad Hoc committee on Facilitated Communication and Rapid Prompting Method was charged with systematically reviewing the literature on FC in order to inform the update of the position statement on FC. Although the most recent systematic review was published only three years prior (Schlosser et al., 2014), the committee determined that in the interests of basing the position statement on the latest research findings, an updated systematic review including material published in peer-reviewed literature was needed for the years since 2014, to identify any new studies pertaining to authorship of messages using FC.

Knowing the author of messages produced using FC is paramount to determining the validity of the technique and ensuring that the communication produced is that of the person with a disability and not of the facilitator. While different message passing or picture identification/naming tasks can reveal authorship, the gold standard for separating legitimate communicators from unwittingly influenced participants is to shield messages or content from each party in an FC dyad. Tests of authorship “are typically conducted by controlling access of the facilitator to the information given to the client (i.e. the person being facilitated)” (Saloviita, Leppänen, & Ojalampi, 2014, p. 213). Such a double-blind test is a relatively straightforward process whereby the facilitator and the individual using FC are unaware or blind as to what the other person in the dyad has been exposed to (Saloviita et al., 2014). By adhering to these procedures, quantitative experimental research can inform clinical questions about the source or “authorship” of the communication. As Shane (1994) advises “if the source of communication is questionable, there is no assurance that communications are authentic” (p. 259).

Independent communication is fundamental to the human right of communication for individuals with communication disability (United Nations General Assembly, 1948, 2006). There is a substantial body of evidence gathered over the last 26 years showing facilitator influence in relation to the production of messages using FC. Furthermore, known harms of FC are well-documented in the peer-reviewed literature and the foundation of repeated warnings of at least 19 professional and disability advocacy organizations worldwide against the use of FC (Behavior Analysis Association of Michigan, 2018). Therefore, the Ad Hoc committee determined that the main focus of the review would be to locate studies pertaining to authorship of messages obtained through the use of FC.

To inform the International Society for Augmentative and Alternative Communication (ISAAC) Position Statement on FC (International Society for Augmentative and Alternative Communication (ISAAC), 2014), Schlosser et al. (2014) sought any literature that related to FC. In the scientific databases, Schlosser et al. (2014) located one synopsis (Schlosser & Wendt, 2008), seven systematic reviews in English (Cummins & Prior, 1992; Felce, 1994; Jacobson, Mulick, & Schwartz, 1995; Mostert, 2001, 2010; Simpson & Myles, 1995a; Wehrenfennig & Surian, 2008) and German (Probst, 2005), four experimental quantitative studies (Olney, 2001; Perini, Rollo, & Gazzotti, 2010; Saloviita et al., 2014; Schiavo, Tressoldi, & Martinez, 2005), 11 descriptive quantitative studies, 7 qualitative studies, and 24 anecdotal reports on FC.

The descriptive quantitative studies and qualitative studies Schlosser et al. (2014) located analyzed the content and structure of messages produced using FC, without empirically testing authorship of participants who used FC; and hence made assumptions that the facilitators did not influence the messages forming the basis of the data analyzed in the studies. Having concluded from an analysis of the prior synopses, systematic reviews, and individual quantitative experimental studies addressing authorship in FC that the facilitators influence authorship, Schlosser et al. (2014) did not go on to further analyze the descriptive quantitative studies, qualitative studies, or anecdotal reports located in the search. Schlosser et al. (2014) concluded that in using FC, the facilitator influences the authorship of messages and therefore FC does not reflect the communication of the person with disability. Thus, considering the importance of (a) authorship studies to determining the validity of FC as a method of communication, and (b) position statements produced to guide speech-language pathologists in their practice being based on the most recent research, the purpose

of this review was to update the findings of the most recent systematic review of authorship in FC (Schlosser et al., 2014).

Method

Search for synopses, systematic reviews, narrative reviews, and studies

A pre-determined scientific search strategy, adapted from the method of Schlosser et al. (2014) was used to identify potentially relevant studies, including synopses, systematic reviews, narrative reviews, and individual studies of any type including qualitative, quantitative, and mixed-methods designs relating directly to FC and published in peer-reviewed literature and in English. First, LB searched the electronic databases including Cumulative Index of Nursing and Allied Health Literatures (CINAHL); Educational Resources Information Clearinghouse (ERIC); Medline (via PubMed); Language and Linguistics Behavior Abstracts (LLBA); and PsychINFO (via EBSCO). Because “Facilitated Communication” is typically not a keyword indexed in the thesaurus of most databases, we used the following terms as free-text phrases: “facilitated communication” “supported typing” and “assisted typing”. This strategy resulted in the identification of material that included these phrases in the title, abstract, or text regardless of how a particular database chose to index the entry (Schlosser, Wendt, Angermeier, & Shetty, 2005). There was no explicit attempt to search for non-English papers, as no more than one member of the committee (name) could read any languages other than English. Next, ancestry searches of the bibliographies obtained from the studies, reviews, previous position statements, and websites were conducted to identify additional studies that may have qualified for inclusion. Finally, the journal *Evidence-Based Communication Assessment and Intervention*, the Database of Abstracts of Reviews of Effects (DARE), and the Evidence Maps of the American Speech-Language-Hearing Association were searched for synopses of systematic reviews.

Selecting studies and criteria for inclusion

The inclusion checklist of Schlosser et al. (2014) was used to classify the papers located in the scientific databases as being about FC or not and being peer-reviewed or not. The additional criteria of being in English were applied so that the first two authors could read and code the studies for exclusion and data extraction. Thus, papers were excluded from the review if (a) the paper did not relate to FC or only tangentially referred

to FC, (b) was not a full paper, (c) was not peer-reviewed, or (d) was not in English. All papers meeting the inclusion criteria were analyzed according to their suitability for evaluating authorship, the central critical question relating to FC which underpins any further consideration of studies based on messages produced using FC. To determine suitability for evaluating authorship, the same categories of papers were used to classify the papers about FC, as those described in Schlosser et al. (2014):

1. *Level one papers* were studies and reviews that provided quantitative experimental data that related to the authorship of the messages were included for level one analysis. Quantitative experimental studies (or systematic reviews of such studies) involved an *a priori* controlled manipulation of knowledge/stimuli presented to the facilitator and FC used by the individual in an attempt to empirically establish who was authoring the messages produced in response to the stimuli. These studies are suitable for evaluating authorship in FC.
2. *Level two papers* were studies and reviews that included quantitative descriptive data on the output generated through the process of FC without *a priori* testing of authorship (i.e. without empirical manipulation related to authorship). These studies are not suitable for evaluating authorship.
3. *Level three papers* were studies with qualitative descriptive data on the output generated through the process of FC without pretesting of authorship, and qualitative research methods such as participant observations and interviews. These studies are not suitable for evaluating authorship.
4. *Level four papers* were those representing anecdotal reports written by individuals using FC, individuals who previously used FC, facilitators, former facilitators and others sharing their perspectives on FC. These papers are not suitable for evaluating authorship.

Inter-rater agreement on study inclusion and data extraction

The first author coded all of the potentially relevant papers located in the search ($n = 134$) for inclusion and, in order to obtain a measure of inter-rater agreement (IOA), the second author independently coded 100% of the potentially relevant papers located in the search (Schlosser, Wendt, & Sigafoos, 2007). The same procedure was followed to determine agreement on the data extraction for the coding classifications of the included papers. The IOA was 100% in terms of the inclusion of papers and in terms of the data extraction for coding classifications.

In total, the systematic search procedures identified 134 papers (excluding duplicates, $n = 87$). Of these, 18 papers met inclusion criteria for further analysis. See Figure 1 for a PRISMA diagram of the review process. In total, 116 papers were excluded because they (a) did not relate to FC ($n = 104$), or only referred to FC tangentially ($n = 3$); (b) were not published in a peer-reviewed journal ($n = 7$) (Baladerian, 2017; Bennett, 2016; Evans, 2015; Heinzen, Lilienfeld, & Nolan, 2015, 2016; International Society for Augmentative and Alternative Communication (ISAAC), 2014; Travers, Tincani, Thompson, & Simpson, 2016); or (c) had appeared the Schlosser et al. (2014) prior systematic review of FC ($n = 1$) (Saloviita et al., 2014). The original review, Schlosser et al. (2014), was returned in the search and was excluded from this review. A log of the excluded papers is available from the first author.

Results

Quantitative studies (level one and level two papers)

There were no level one or level two papers located in the search. That is, no new studies addressing authorship and no new studies engaging in a descriptive quantitative analysis of the output produced by FC users were found. As such, no new research since 2014 was found that is suitable for evaluating authorship in FC.

Qualitative studies (level three papers)

Three studies (dated 2014–2015) met the criteria for being level three papers: Ashby, Jung, Woodfield, Vroman, and Orsati (2015), Wilson, de Jonge, de Souza, and Carlson (2014), and Woodfield, Jung, and Ashby (2014). As in the qualitative studies about FC cited in Schlosser et al. (2014), authors of these qualitative studies analyzed characteristics of FC messages without first empirically testing authorship to determine any facilitator influence. As such, they made inferences about the abilities of individuals using FC and indirectly asserted the validity of FC. As noted by Schlosser et al. (2014) such evidence cannot inform the question of authorship. The results of these studies were not further analyzed as the authors of these studies “failed to pre-establish authorship by their participants” (Schlosser et al., 2014, p. 365).

Anecdotal reports and commentaries on FC (level four papers)

In total, 15 papers (dated 2014–2016) met the criteria for being level four papers: Agran (2014), Cardinal and Falvey (2014), Chan and Nankervis (2014), Hemsley

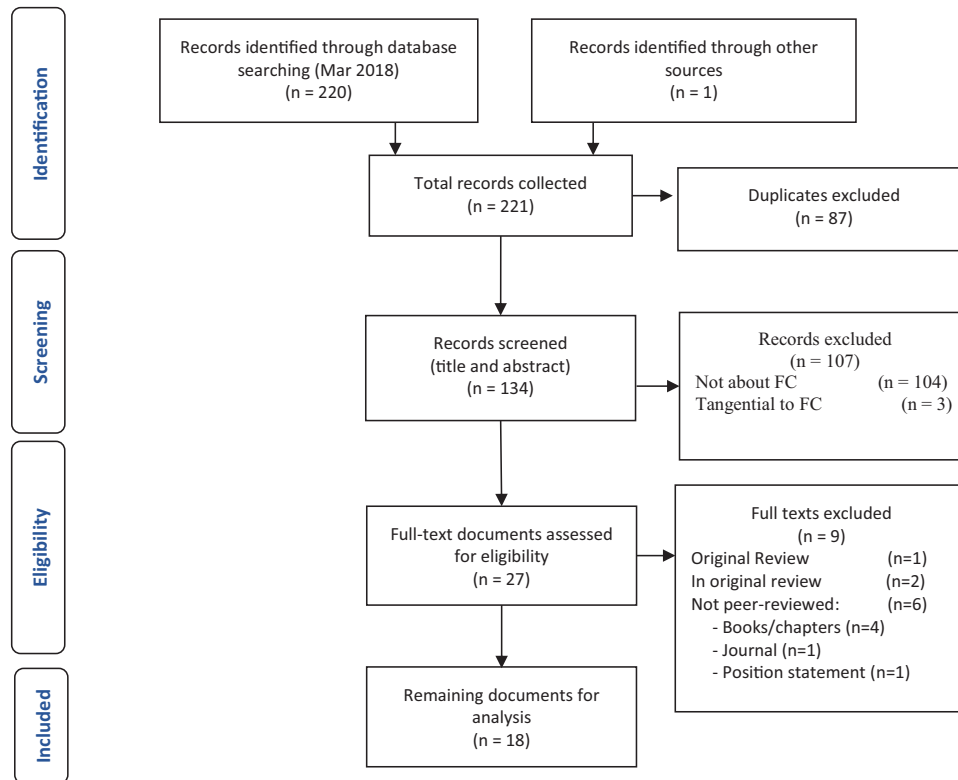


Figure 1. Flowchart for literature identification, review and exclusion.

Adapted from Prisma diagram.

From: Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6(7), e1000097. doi:10.1371/journal.pmed1000097

and Dann (2014), Lilienfeld et al. (2014), Miranda (2014), Mostert (2014, 2015), Sherry (2016), Singer, Horner, Dunlap, and Wang (2014), Tostanoski, Lang, Raulston, Carnett, and Davis (2014), Travers and Ayres (2015), Travers, Tincani, and Lang (2014), Trembath, Paynter, Keen, and Ecker (2015), and Wombles (2014). These papers cannot be used to evaluate authorship but provide commentary on the use of FC.

Overall, since 2014 there is (a) a substantial growth body of peer-reviewed literature that is critical of FC and warns against its use ($n = 14$, Agran, 2014; Chan & Nankervis, 2014; Hemsley & Dann, 2014; Lilienfeld et al., 2014; Miranda, 2014; Mostert, 2014, 2015; Sherry, 2016; Singer et al., 2014; Tostanoski et al., 2014; Travers & Ayres, 2015; Travers et al., 2014; Trembath et al., 2015; Wombles, 2014); and (b) scant peer-reviewed literature that is supportive of FC ($n = 1$, Cardinal & Falvey, 2014). Level four papers comprised 15 reports that included perspectives of individuals from various stakeholder groups regarding FC (e.g. former FC users, parents/family members of FC-users, teachers, speech-language pathologists). As in Schlosser et al. (2014), because these reports were anecdotal, they could not be considered as scientific

evidence regardless of whether the opinions expressed supported or refuted authorship by the individual with a communication disability. Nonetheless, level four articles that are *critical* of FC were located more frequently in this review than in the earlier systematic review of FC (Schlosser et al., 2014).

Summary. A systematic review of peer-reviewed literature in English published since 2014 shows the following findings: (a) no new FC authorship studies were located using the same search terms and databases as outlined by Schlosser et al. (2014); (b) no new quantitative descriptive studies analyzing the output generated through FC (either with or without *a priori* testing of authorship); (c) three new qualitative studies based on messages produced during interviews with people who use FC were found, all of which are supportive of FC; (d) 15 new papers were found that were commentaries or issues papers, literature reviews (non-systematic), and one social media scan (Hemsley & Dann, 2014); and all but one of these papers (Cardinal & Falvey, 2014) were critical of FC. Overall, there were no new studies suitable for evaluating authorship in FC, and the findings of this review and the prior review of Schlosser et al. (2014) should inform the update of the ASHA Position Statement on FC.

Discussion

There have been no FC authorship studies of any type published since 2014, and the most recent original research on FC is a qualitative study (Ashby et al., 2015) that did not first establish authorship. Thus, taking into account previously published systematic reviews and synopses, there is sufficient prior scientific evidence of facilitator influence over authorship to conclude that in FC authorship is influenced by the facilitator, and to warrant the warnings of at least 19 professional and advocacy organizations around the world against its use (Behavior Analysis Association of Michigan, 2018).

The only original research studies located since 2014 ($n=3$) were qualitative in design with the untested assumption that the messages produced using FC in the research were not influenced by the facilitator. Qualitative research on treatments has the potential to lead to a deeper understanding of the human experience of the treatment and explores the views of individuals receiving the treatment (Patton, 2015). However, qualitative research cannot be used to determine the effectiveness or validity of a treatment and cannot be generalized across populations (Patton, 2015). Furthermore, given the substantial scientific evidence on the influence of facilitators over authorship of messages produced using FC, qualitative research on FC that does not include independent authorship testing should not be assumed to reflect the views of the participant with little or no speech. Considering the substantial amount of evidence of facilitator influence over authorship, in studies investigating this matter since 1993 (Wheeler, Jacobson, Paglieri, & Schwartz, 1993) and up until 2014 (Saloviita et al., 2014), it is the duty of responsible researchers, upholding codes for the ethical conduct of research to determine authorship through independent testing prior to assuming that the consent is either fully informed or given freely.

With substantial scientific evidence demonstrating the influence of facilitators over messages produced using FC, it is ethically and scientifically imperative to empirically test authorship of messages produced using FC and analyzing FC message data without authorship testing reduces the credibility of findings. Researchers and facilitators involved in the collection of interview data should be identified (Critical Appraisal Skills Programme, 2018), given their influence over the data collected and the analysis (Thirk & Clark, 2017).

Conclusion

The results of this update of the Schlosser et al. (2014) systematic review on FC and authorship indicate that

there are no new studies on authorship and therefore no evidence that FC is a valid form of communication for individuals with severe communication disabilities. Given that facilitator control has been documented repeatedly and replicated by several different research teams across continents over the last 26 years, it is not surprising to see that there are no additional studies addressing the question of authorship in FC. What is noteworthy, however, is that there are also no studies that demonstrate that the individuals with disabilities are the authors of the messages generated with FC. Furthermore, there is substantial peer-reviewed literature that is critical of FC. Apart from informing the update of the ASHA Position Statement on FC (see ASHA, 2018a, 2018b), these findings could be used to inform the development or update of position statements or policy documents of professional organizations, credentialing, and licensure bodies at the state or national level in any country with regard to the use of FC.

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