Critical Review: Encouraging positive employment outcomes for individuals who use AAC, through barrier and support identification.

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This critical literature review examines the factors that impact employment outcomes for individuals who rely on augmentative and alternative communication devices and strategies (AAC) to communicate. Five qualitative studies were reviewed, including three questionnaire studies and two focus group studies. Barriers to employment and facilitating factors were identified in the studies by individuals who use AAC, as well as by employers and coworkers. The most common barriers identified include: communication, accessibility, qualifications, specific work related training, and financial issues. The most common supports identified include communication support and general workplace, family, government and professional support. Speech-language pathologists can facilitate positive employment outcomes for individuals who use AAC by enhancing workplace communication, as well as by advocating for and encouraging early vocational skill development and necessary technological advancements.

Introduction

Individuals with disabilities face many disadvantages in today's competitive labour market. To highlight some of the pervasive disadvantages, the National Organization on Disability has conducted surveys which document trends for individuals with disabilities (Harris Survey of Americans with Disabilities, 2004). The most recent study highlighted that "only 35% of people with disabilities reported being employed full or part time, compared to 78% of those who do not have disabilities" (Harris Survey of Americans with Disabilities, 2004). This statistic suggests that individuals with disabilities are underrepresented in the labour market; however, only 17% of the individuals surveyed used devices designed to assist with spoken communication (Harris Survey of Americans with Disabilities, 2004).

There is limited research detailing the employment rates of individuals who rely on alternative and augmentative communication devices and strategies (AAC) in order to communicate. However, existing research has shown that employment rates for these individuals may be much lower than for individuals who have disabilities but do not require AAC. For example, Blackstone (1993) estimated that the rate of employment for individuals who use AAC is at best 15%.

When considering that 63% of individuals with disabilities would prefer to be working, the low rate of employment for individuals who use AAC is of significant concern (Harris Survey of Americans with Disabilities, 2004). This concern is further highlighted by the World Health Organization's International Classification of Functioning, Disability and Health (ICF) model as it includes employment as an important factor in life participation (WHO, 2001). Successful employment is widely noted to be

crucial for achieving financial independence, facilitating social interaction, creating a sense of purpose, fostering positive self esteem and generally improving overall quality of life (Blackorby & Wagner, 1996; Light, Stoltz & McNaughton, 1996; McNaughton, Light & Gulla, 2003).

The value of successful employment and the desire of individuals who use AAC to be employed is clear. Therefore, it is necessary for speech language pathologists who work closely with these individuals to acquire evidence-based knowledge of the factors contributing to low employment rates, as well as the supports necessary to facilitate positive employment outcomes.

Objectives

The primary objective of this paper is to evaluate existing literature examining the employment barriers that face individuals who use AAC, and the supports necessary to overcome these barriers. From this evaluation of the literature, a summary of barriers and facilitators will be developed from the perspective of individuals who use AAC, as well as employers and coworkers. The secondary objective is to provide recommendations for speech-language pathologists in order to facilitate positive employment outcomes for individuals who use AAC.

Methods

Search Strategy:

Computerized databases including Proquest, ScholarsPortal, PubMed, PsychINFO, CINAHL, Scopus, Web of Science and Google Scholar were searched using the following search strategy:

[(AAC) OR (alternative communication) OR (augmentative communication) OR (augmentative and alternative communication)] AND [(employment) OR (jobs)] AND [(barriers) OR

(challenges)] AND [(facilitators) OR (supports)]. Reference lists of previously searched articles were also used to obtain other relevant studies.

Selection Criteria:

Studies included in this critical review paper were required to have examined the barriers and supports to employment for individuals who use AAC, from the perspective of the individual, employer or coworker. No limits were set on the dates of the articles, demographics of research participants or study designs.

Data Collection:

Results of the literature search yielded five qualitative research studies that met the above selection criteria. These included three questionnaire studies and two qualitative studies using focus group methodology.

Results

Although qualitative research (Evidence Level 3) may be considered a lower level of evidence, it is an appropriate approach to use when investigating the experiences and opinions of research participants. While the studies reviewed are beneficial to consider when investigating perspectives on the employment situation for individuals who use AAC, all of the studies presented with some common limitations. Firstly, none of the authors presented their research in an explicit theoretical frame (e.g., phenomenology). This is problematic as it is difficult to know what perspective is taken for interpreting the data and results. Secondly, none of the researchers acknowledged any potential biases that may have influenced their understanding and interpretation of the data collected. Finally, all of the sampling frames are small and unrepresentative. However, acquiring a representative sample of individuals who use AAC is challenging as the population itself is small and diverse. Given these common limitations and the various limitations of each individual study, the results must be interpreted with caution.

Survey Research:

McNaughton, Light and Gulla (2003) utilized a questionnaire to investigate the experiences of employers and co-workers who had worked with individuals who used AAC in community based jobs. Ten successfully employed individuals who used AAC were followed up from a previous study by McNaughton, Light and Arnold (2002). These individuals nominated 14 employers and coworkers from their employment situation to participate in the current study. Selection criteria included: employment status equal to or above the employee, familiarity with employee's job responsibilities and work performance, and familiarity with supports and

barriers. No participants were unsuitable for the research and a 100% response rate was reported.

The questionnaire was created based on a literature review. It was then appraised by three researchers and pilot tested with one employer. The questionnaire consisted of 10 multiple choice questions and 19 open ended questions. The questionnaire was distributed to respondents via email, postal mail or telephone interviews according to the participant's choice. Each participant was asked the same questions regardless of the means of distribution and follow up questions were conducted if any answer was unclear or incomplete. Responses were transcribed verbatim and an appropriate thematic analysis of the data was completed which included: unitizing the data, organizing themes based on content and topic, and creating operational definitions. A reliability check was completed with a trained coder.

Results of the survey identified challenges to the employment situation from the perspective of the employers and coworkers. These included: finding a good job match (lack of "low input high output" jobs, difficulty obtaining a realistic picture of the employee's skills), communication issues (increased time needed for exchanges, unreliable equipment, reluctance of coworkers to socialize), education and skill levels (insufficient education and literacy level, lack of work experience), lack of knowledge of work culture/etiquette, accessibility (telephone, computer, workplace, transportation issues), need for assistance (personal care and AAC troubleshooting) and financial barriers due to increased insurance costs. Factors that facilitated overcoming these barriers were also identified, including: communication (use of acceleration techniques, more reliable AAC, increased communication skills of the individual who uses AAC, co-workers planning extra time for exchanges), education and skill levels (literacy training, increased personal experiences of the employee, specific training with the AAC devices), accessibility (alternative access techniques, employers willingness to modify tasks, use of telecommunications, funding to make workplace accessibility modifications), personal care assistance, and personal commitment of the employers/coworkers to people with disabilities. Respondents provided recommendations for professionals in the field of AAC which included creating a guide for hiring individuals who use AAC, as well as supporting programs that teach vocational skills.

These findings highlight various barriers and facilitators to employment for individuals who use AAC; however, this study has limitations that must

be considered when interpreting the results. Firstly, while an open-ended questionnaire was an appropriate method to use, a focus group or interview would have encouraged respondents to provide more in depth information. This is especially true for those participants who were limited to the space provided on the mailed questionnaires. Secondly, the questionnaire is described briefly but is not included for review. Weak claims for the validity and reliability of the survey are made, and it was piloted only on one employer, not on a co-worker. Thus, it is unknown if the instrument was clear and representative. Finally, the sample presents a bias as the perspectives of employers and co-workers who have no experience working with individuals who use AAC and who refuse to do so are not included. These perspectives are necessary to fully explore barriers to successful employment.

Bryen, Carey and Potts (2007) utilized a questionnaire study in order to investigate the job requirements, recruitment strategies and hiring processes of employers in the United States with respect to individuals who use AAC. The sample of respondents consisted of nominated and nonnominated employers. Nominated employers were recruited via follow up from a previous study by Bryen, Carey and Potts (2006). In that study, 38 individuals who used AAC identified desirable jobs and employers who hired for the positions. Of the 41 employers nominated, 16 participated in the current study, a response rate of 39%. Non-nominated employers were randomly selected from the Philadelphia metropolitan area phone book, in order to provide a comparison to the open labour market. Of the 64 individuals contacted, 11 participated in the survey, resulting in a response rate of 17%. Respondents were asked to supplement the list of desirable jobs with positions for which they commonly hired, along with substituting jobs that they felt were suited to people who use AAC. A total of 48 jobs were identified. The 27 employers participated in a survey developed specifically for this study. The survey was pilot tested by two employers and distributed via telephone interviews, in-person interviews or in writing submitted by mail.

Results of the survey identified numerous barriers including: limited work-related skills/abilities (time management, workplace culture, problem solving and co-worker relationships), small employment related networks, limited references, challenges during interviews and general communication issues (relating to clients/public, telephone difficulties, unreliable/insufficient AAC). Accessibility was occasionally mentioned by employers, although did not represent a major barrier. Potential supports were

also identified in the study. These include: specific work related training by educators and professionals in time management, problem solving, technology, workplace culture and communication skills; support to strengthen social networks and references; increased access to technology; accommodations during the interview process and more reliable AAC equipment with more standard sounding voices.

While the findings of this study are useful to consider, it is important to note its limitations. Firstly, the sample of employers and jobs is fairly small and unrepresentative of the open labour market. It is also not representative of the jobs listed as desirable by individuals who use AAC in the study by Bryen et al. (2006). These authors did not mention how many of the jobs in the final sample were substituted with ones that employers deemed more suitable. Although exploring the perspectives of nonnominated employers is a strength of this article, the comparison was poorly made when presenting the results.

There are also inherent limitations with the methodology used in this research. The questions posed may not be reflective of all the issues that employers might encounter when hiring individuals who use AAC and there is no evidence for the reliability and validity of the survey instrument. The questionnaire is not provided and it is unknown whether the questions are clear and comprehensive. Given the low response rates, it is possible that the questionnaire was poorly developed. A qualitative research design using semi-structured interviews or focus groups may have been a more appropriate method for in depth, accurate and comprehensive information. Finally, the authors did not present any data analysis procedures. Thus it is unknown whether participant responses were accurately interpreted and analyzed in order to obtain the results.

Light, Stoltz and McNaughton (1996) utilized a questionnaire study in order to gain insight into the factors associated with successful employment of individuals who use AAC and the barriers they encounter. Selection criteria for participants included: individuals aged 18 and older, severe speech impediments, use of AAC, living in North America, and employed at least 10 hours per week in community based jobs. Of the 25 participants, 18 (72%) were male and 7(28%) were female and their ages ranged from 22 to 56 years. Most of the participants reported having cerebral palsy (76%) and the remaining participants reported other disabilities including: intellectual disabilities, traumatic brain injury, autism and concomitant visual and hearing impairments. The respondents reported using various computer-based AAC systems to communicate with varied access techniques.

The questionnaire was developed based on a literature review as well as from input from individuals who use AAC (both employed and unemployed), professionals in the AAC field, and vocational counsellors. A statistical consultant reviewed the questionnaire to verify that it was psychometrically sound. The questionnaire is available for review in the article, and the questions appear appropriate for the study. Participants received the questionnaire by mail, along with instructions for administration. Responses were appropriately analyzed through operational definitions and thematic coding, followed by an establishment of inter-rater agreement.

Results of this study highlight many barriers that individuals who use AAC face in the employment situation. While 54% of the successfully employed participants did not have a high school diploma and 52% reported being only functionally literate, it appears that low education and literacy levels are not necessarily a major barrier to attaining employment. However, participants suggested that low education and literacy levels did present a barrier to advancement opportunities. Half of the respondents stated that school did not prepare them for their job and felt that they had limited training in the following areas: marketable skills, interpersonal skills, work ethic (punctuality, effort, commitment), and general employment skills (negotiating transport, paying taxes). Specific barriers reported include: communication difficulties (frequent communication breakdown, difficulty participating due to slow rate of communication, and lack of access to work-related vocabulary), assistive technology (recurrent breakdowns and funding limitations), colleague interactions/social attitudes and transportation (unreliable, inaccessible and unavailable public transit). Supports to these barriers included: multimodal communication, appropriate work-related vocabulary, acceleration techniques, more reliable technology, increased funding support, more efficient access methods, increased interpersonal skills, and reliance on private transportation and family. Partner instruction is suggested for supervisors and coworkers to assist in successful communication.

It is necessary to consider these results in light of the study's limitations. Although efforts were made to obtain a representative sample, the majority of the respondents (76%) had cerebral palsy and individuals with degenerative neurological disorders were not included in this study. Furthermore, this study investigated the perspectives of successfully

employed individuals. Insight from individuals who are not successfully employed is necessary to achieve a full picture of the barriers that exist.

The use of a questionnaire is also problematic as individuals who use AAC may have had difficulty responding due to language, literacy and physical limitations. A focus group or interview may have been a more appropriate method. Finally, since this study was published in 1996, some of the pertinent issues may have changed due to technological advancements, government policy changes and increased public awareness.

Focus group studies:

McNaughton, Light and Groszyk (2001) and McNaughton, Light and Arnold (2002) conducted two similar focus group studies on two different populations of individuals who use AAC. The two focus groups were conducted online, which was appropriate for these studies as it allowed participants to contribute to the discussion at their own pace, without the need for travelling. Responses to the focus group questions were appropriately analyzed by unitizing the data and then thematically coding it using operational definitions. A reliability check was completed, and a summary of the results was confirmed by the participants. While the procedures were similar for both studies, participants and results varied.

McNaughton et al. (2001) investigated the barriers faced and supports required by individuals who require AAC due to amyotropic lateral sclerosis (ALS). Participants included three women and two men, ages 50 to 57 years. All of the individuals reported successful employment experiences while using AAC devices. They represented a range of demographics, employment activities, education levels and AAC devices.

The barriers reported by the participants included: Architectural (lacking workplace accommodations), technological (cost, learning demands and limitations of assistive technology), negative attitudes (towards ALS and terminal illness), policy/funding (lack of enforcement of government policies, lack of funding), financial (decreased pay due to decreased responsibilities, reduction in disability payments due to salary), limited availability of information and services (limited service providers, lack of expertise regarding AAC devices), psychosocial adjustment (difficulty accepting diagnosis and asking for help, physical manifestations of degenerative disease). Limited availability of information and services was noted as particularly problematic as participants reported that many people diagnosed with ALS are not aware that AAC services are available.

Participants also reported a lack of quick, easy access to reliable information about AAC. Supports necessary for successful employment included: effective service delivery and technical support by professionals, government policies, information support provided by ALS chapters, service organizations and the internet, employer supports (policies to support participation, facility accommodations, provision of technology), and personal support networks (for personal care, moral support, financial and transport assistance).

McNaughton et al. (2002) investigated the experiences of successfully employed individuals with cerebral palsy who used AAC. Eight males aged 30 to 57 participated in the study, all of whom had cerebral palsy, relied on AAC to communicate and were employed at least 35 hours per week in paid competitive employment. They represented a range of employment activities, demographics and education levels and all used a variety of low and high technology devices to communicate.

The findings of this study highlighted numerous barriers including: attitudes (negative attitudes of society and employers), education (low expectations of educators, inappropriate education), technology (limitations of AAC technology, technology breakdowns, limited technology support services), policy/funding (lack of funding for assistive technology, inefficiency of vocational rehabilitation services, under-representation of individuals with disabilities in the vocational rehabilitation system), transportation (scheduling difficulties, long travel times) and personal care/support services (lack of reliable personal care attendant services). Supports required for successful employment included: personal characteristics (commitment to employment, strong work ethic, determination, time management), education/experience (education level, volunteer experience, work experience), technology (specific device features that facilitate participation e.g., voice output), policy/funding (improved government legislations and funding), family supports (transportation, personal care) and workplace supports (mentoring and networking). Recommendations were given to educators to provide challenging activities and prepare students with workplace skills.

These qualitative focus group studies present good overall rigour as they attempt to maintain the four components of trustworthiness. Credibility is evident as unclear responses to focus group discussions were clarified and participants verified the summarized results. However, credibility could have been enhanced if data was collected from varied methods

(e.g., interviews and observations) and perspectives (e.g., professionals and employers). Transferability is evident as the participants, procedure and setting are described in adequate detail for both studies. However, caution must be used when generalizing the results. In the McNaughton et al. (2002) study, the sample of participants were all males with cerebral palsy, while in the McNaughton et al. (2001) study, participants were all individuals with ALS. Participants in both studies all reported successful employment and had access to personal computers and a range of AAC technology. In order to fully understand the barriers faced and supports required by the population of individuals who use AAC, perspectives are needed from individuals with: varied disorders, low technology devices, no computer access and unsuccessful employment histories. The studies maintain fair dependability as the explanation of the research process is clear; however, a decision trail was not reported and thus the actual consistency between the data and the findings is unclear. Confirmability is limited as the theoretical perspective is unknown and potential biases are not reported. However, confirmability is evidenced through the reported reliability checks and participant reviews of the results.

Discussion

Although qualitative research is considered to be lower level evidence, the studies reviewed provide necessary perspectives and beneficial insight regarding the employment situation for individuals who use AAC. Given the limitations of these studies, caution must be used when interpreting and generalizing the results.

Small sample sizes were a limitation of all of the studies reviewed. Although it is challenging to achieve a representative sample for this small and diverse population, more in depth information could have been obtained through triangulated methods. This would have enhanced the strength of the qualitative evidence. Furthermore, as the participants in these studies all reported successful experiences, the perspectives of individuals with unsuccessful experiences should be investigated as they would likely propose different barriers and supports. The studies reviewed would also offer stronger qualitative evidence if the authors were to present their research within an explicit theoretical framework, stating potential biases. Response data could then be interpreted into results using a specific perspective, with results incorporated into a clear knowledge base.

Although these studies have limitations, the barriers and supports recurring across all five studies suggest that they are pertinent issues for various individuals who use AAC. A major barrier identified in all of the studies is communication. This includes issues such as increased time required for exchanges, unreliable equipment, technology limitations and reluctant attitudes of communication partners. Accessibility barriers to transportation and technology were also identified in all studies. Other than the individuals with ALS, participants in all of the studies also identified poor education, lacking knowledge of workplace culture and limited work related skills (e.g., time management and problem solving) as significant barriers. Common supports identified in all of the studies include: communication (e.g., acceleration techniques, reliable equipment, good interpersonal skills, multimodal AAC) and personal support (e.g., family, workplace, government, funding and service delivery from professionals).

Clinical Implications

Awareness of the potential barriers and supports to employment for individuals who use AAC is a starting point for clinicians to help facilitate positive employment outcomes.

Speech-language pathologists can use this insight to assist clients in identifying and overcoming their own individual barriers. Speech-language pathologists can also ensure that AAC devices and strategies maximize communication ability and are appropriate for communication needs, skill levels and workplace environments. They can provide support, training, information and servicing of assistive technology to both the individual who uses AAC and to communication partners in the workplace. Clinicians can also liaise with school boards and teachers to ensure that children who use AAC are being taught vocational skills such as problem solving, time management and social skills, as well as being challenged appropriately in their education. Clinicians can relay workplace communication challenges to AAC technology developers to assist in crucial advances such as more reliable equipment and accelerated access techniques. These research results can also be used to inform and direct advocating efforts. It appears that a focus should be placed on acquiring increased government funding for assistive technology and enhanced legislation to ensure equal employment opportunities and accessibility for individuals who use AAC.

Further research is needed to attain a more in-depth understanding of the employment issues encountered by individuals who use AAC. However, a cautious interpretation of the studies reviewed provides beneficial clinical insight and a necessary starting point for facilitating successful employment outcomes.

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