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The impact of assistive living technology on perceived independence of people with a physical disability in executing daily activities: a systematic literature review

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ABSTRACT

Purpose: People with physical disabilities often require lifetime support and experience challenges to maintain or (re)define their level of independence. Assistive living technologies (ALT) are promising to increase independent living and execution of activities of daily living (ADL). This paper provides a systematic literature review that aims to analyse the present state of the literature about the impact of ALT on perceived independence of people with a physical disability receiving long-term care.

Materials and methods: Databases Embase, Medline, and Web of Science were searched for eligible studies from 2010 or later.

Results: Nine studies were included, of which seven qualitative, one quantitative, and one mixed methods. Quality was generally high. ALT enabled participants to execute ADL. We found six themes for the impact of ALT on perceived independence: feeling enabled, choice and control, feeling secure, time alone, feeling less needy, and participation.

Conclusions: ALT appears to impact perceived independence in many ways, exceeding merely the executional aspect of independence. Existing research is limited and quite one-sided. More large-scale studies are needed in order to inform care organisations how to implement ALT, especially considering societal developments and challenges impacting long-term care.

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Activities of daily living; assistive living technology; physical disability; independence; autonomy; long-term care

► IMPLICATIONS FOR REHABILITATION

- People with a physical disability receiving long-term care experience that assistive living technology impacted their independence.
- Their independence is increased by making them feel enabled, secure, and less needy and increasing their choice and control, time alone, and participation.
- Most studies focused on the use of environmental control systems by people with spinal cord injury.
- More research is needed to evaluate long-term effects of diverse assistive living technologies used by people with a physical disability receiving long-term care.

Introduction

Background


The UN Convention on the Rights of Persons with Disabilities states that people with disabilities should have equal opportunity to experience personal autonomy and live independently in the community as every other person [1]. Regardless of the type, complexity or severity of the disability, they deserve the opportunity to decide how to live, work, and participate in society. People with physical disabilities such as multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), or spinal cord injury (SCI) often require lifetime support and experience challenges to maintain or (re)define their level of independence and autonomy. They may experience that their independence is compromised or restricted

because of the actual or apparent conditions deriving from their disability [2,3]. For example, they may need help with activities of daily living (ADL) such as eating, drinking, toileting, clothing or washing themselves, making transfers or walking, social interaction, and managing their living environment (e.g., opening and closing curtains, doors, and windows).

Independence

Multiple studies have shown that independence and having control over their lives and their disability increases the quality of life for persons with a disability [1,4–6]. In the literature, there is no standard definition of independence. Independence is often used as a broad concept involving a wide variety of aspects. Especially

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for people with a disability, the term “independence” is complex and can mean different things [7,8]. Reindal [7] describes how professionals generally focus on independence in terms of execution of ADL, while people with disabilities themselves tend to define independence as “an ability to be in control of and make decisions about one’s life”. Forber-Pratt [8] studied the meaning of independence for people with physical disabilities that used wheelchairs (including herself), and found that people with a physical disability defined independence as “the ability to manage personal hygiene needs, to navigate the world, and to know one’s equipment”. More importantly it was not necessary to do all this oneself, but rather “having the personal agency and ability to manage one’s own care and having one’s voice heard during these types of tasks.”

Assistive living technology

As a concrete step towards realizing the goals of the UN Convention on the Rights of Persons with Disabilities, the WHO is coordinating the Global Cooperation on Assistive Technology (GATE) to improve access to high-quality affordable assistive technology for people with a disability all over the world [9]. Assistive living technology (ALT) is used by the WHO as an umbrella term covering “any assistive items, services, and any related systems developed to optimize or preserve an individual’s daily functioning” [10]. ALT is expected to have great potential to assist persons with a disability in living independently, to participate in social activities and to promote well-being [11,12]. For example, Brose et al. [13] describe how robotic systems are promising to enable people with physical disabilities such as SCI or neuromuscular disease (e.g., to eat, prepare a meal, brush their teeth, shave, dress themselves, open cabinet doors, load a dishwasher, and fetch items in their daily living environment). ALT is widely studied in elderly people living independently in the community or in care facilities for people with dementia [14,15]. Also, assistive technologies used in rehabilitation in order to enhance strength and to compensate for limitations such as exoskeletons, are a topic of interest in the motor recovery of people with physical disabilities [16]. These studies are mostly conducted in an acute phase after injury [17]. Little is known about the impact of ALT for people with physical disabilities receiving long-term care.

This paper provides a systematic literature review that aims to analyse the present state of the literature about the impact of ALT on perceived independence of people with a physical disability receiving long-term care. The focus of the review is not on the development or technological validation of ALT.

Method

The review is written in accordance with the PRISMA statement for systematic reviews [18]. A detailed protocol is published in the International Prospective Register of Systemic Reviews (PROSPERO 2021 CRD42021265176).

Search strategy

Together with an information specialist, the researchers RB, MG, and KvD developed and finalized a search strategy for the databases Embase (Ovid SP) and Medline (see [Supplementary Appendix I](#) online). Snowballing was conducted through references of eligible articles in the database Web of Science. We selected articles that were published between January 1st, 2010 up until May 17th, 2022, when the search was conducted. Because

technology is developing rapidly, articles describing technology before 2010 were deemed to be irrelevant and not representative to answer our research question. We included research that met the following inclusion criteria:

- original peer reviewed articles in Dutch or English;
- qualitative, quantitative or mixed methods research;
- research in which participants have a physical disability, are aged 18 years or older, and receive long-term care;
- research examining the use of ALT in the daily living environment for execution of ADL (including communication);
- self-reported outcomes regarding independence, such as the execution of ADL or perceived independence.

Exclusion criteria were:

- review articles and book chapters;
- research that focused exclusively on the ALT itself e.g., validation study in an experimental set-up;
- ALT that is used only by care providers;
- ALT for (gait) training purposes in a rehabilitation setting;
- research in which participants are in an (acute) phase of rehabilitation.

Study selection

After conducting the search, duplicate articles were deleted. The articles found were assessed in two steps to ascertain whether they were eligible for inclusion. The first step involved the title and the abstract. When no exclusion criteria were detected here, the second step concerned the full text. The assessment was based on content-analysis and performed independently by two reviewers (RB and KvD). In case of disagreement about eligibility, consensus was reached by consulting a third reviewer (MG).

Data extraction and synthesis

One reviewer (KvD) created a spread sheet and charted information extracted from the included studies that contributed to answering the research question. A second reviewer (MG) checked the extracted information. The following data were extracted: author and year of publication, country where the research was conducted, study design, data collection methods, number and disability of study participants, living situation of study participants, type of technology researched, primary outcome, and main findings. We focused exclusively on research questions and results about independence; whenever other factors were researched (such as user satisfaction or barriers and facilitators for technology uptake), we only mention outcomes regarding independence in this review. To establish themes regarding the impact of ALT on the perceived independence of research participants, themes and quotes described in the included studies were extracted and grouped into categories by one reviewer (KvD) and checked by a second reviewer (MG).

Quality assessment

The scientific quality of the selected studies was evaluated independently by two reviewers (KvD and MG). They matched their results to produce a single score. For most items (84%), the reviewers’ evaluations corresponded. The reviewers discussed the items they judged differently (the other 16%) until consensus was reached. Qualitative studies were assessed on risk of bias using the Critical Appraisal Skills Program [19]. The CASP deploys 10 criteria such as study relevance, design and methods, ethical considerations, reflection on the role of the researcher in relation to participants,

rigorousness, and explicitness of findings. Quantitative or mixed studies were assessed using the MMAT (Mixed Methods Appraisal Tool), which contains 2 general screening criteria and 5 criteria to assess either quantitative, qualitative or mixed method research [20]. The criteria for mixed methods research specifically focus on the relevance of using mixed methods and integration of quantitative and qualitative findings. Articles were not excluded based on the quality assessment [21,22]. For both the CASP and MMAT, the compliance of studies with the criteria were judged on the basis of three options: “yes”, “no”, or “can’t tell”.

Results

Study selection

Figure 1 depicts the study selection process. The database searches yielded 824 articles, of which 63 full articles were screened. Additionally, 14 articles were found through

snowballing and fully screened for eligibility. We identified 9 studies that met the inclusion criteria. Study characteristics are described in Table 1.

Description of the selected studies

The selected studies were published between 2011 and 2021. Only two studies were published before 2015 [23,24]. Five studies were executed in Australia [25–29], the other four studies took place in different countries [22,24,30,31]. The number of participants varied from $n=3$ to $n=22$ (mean $n=10$), with a total of $n=91$ participants. Participants with SCI were represented in six studies [23–25,27–29], one study studied participants with acquired brain injury [26] and one study participants with ALS [31], while two studies researched heterogenic groups of participants with varying physical disabilities (sclerosis, transverse myelitis, and spasm, MS, Duchenne, and locked-in syndrome) [24,30].

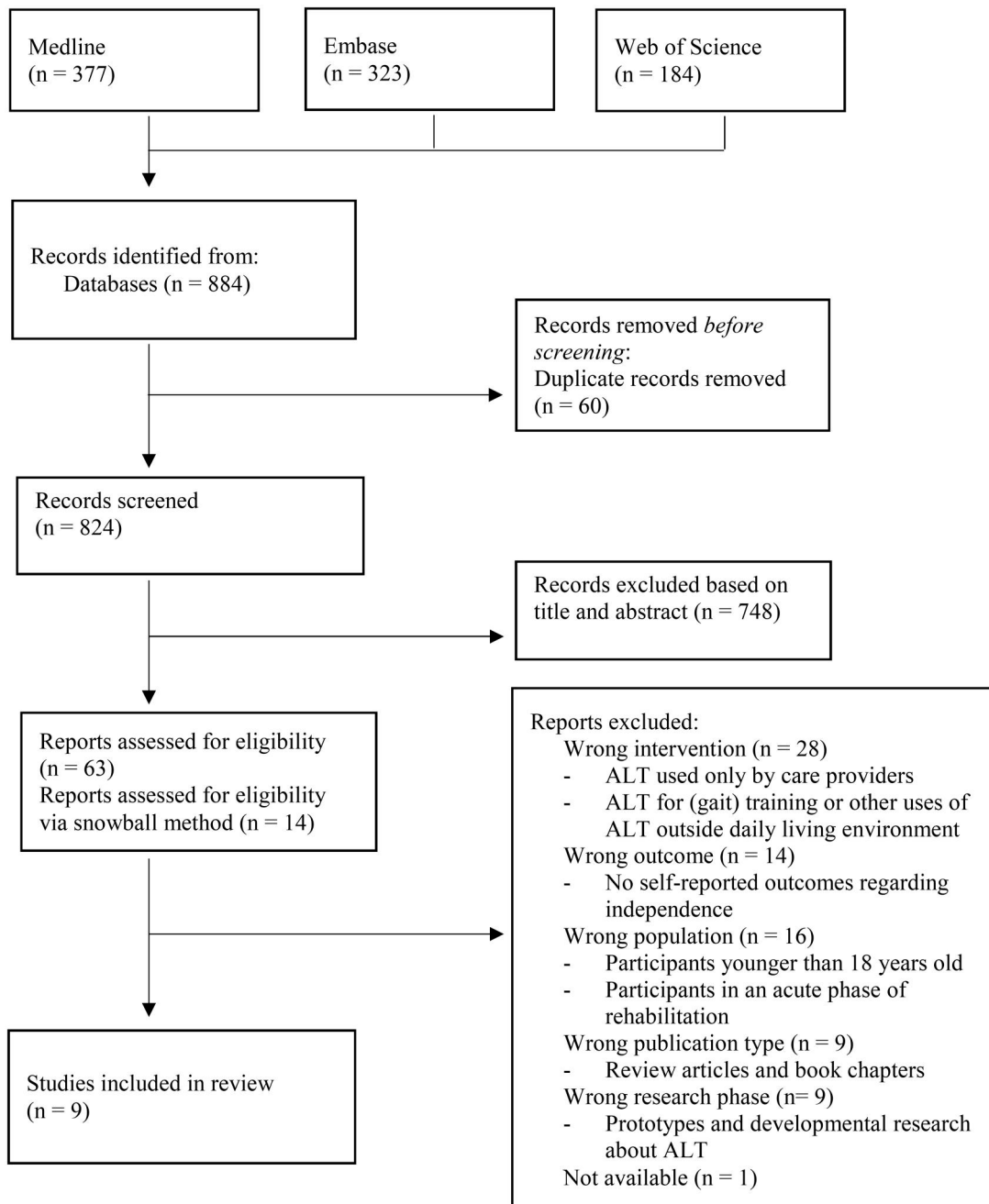


Figure 1. Study flowchart.

Table 1. Study characteristics.

First author (year)	Country	Study aim	Study design	Data collection	Population	Living situation	Type of technology	Primary outcome; perceived independence in executing ADL	Main findings
Verdonck et al. (2011) [23]	Ireland	Explore experiences and deeper meaning of living with ECS from both users' and potential users' perspectives	Qualitative	Focus groups: one of users and one of non-users of technology	Spinal cord injury (SCI), quadriplegia C3–5 level (n = 15): 11 men, 4 women, age mean 36.7 (range 20–75) years, discharged from rehabilitation mean 10.1 (range 1–31) years	Mixed: 12 in the community, 3 in a long-term care facility	ECS (environmental control system)	Autonomy in everyday life	ECS increased experience of autonomy in users (and non-users expected it to increase) through "time alone" and "changed relationships"
Blach Rossen et al. (2012) [24]	Denmark	Explore how electric wheelchair users experience their everyday life and how their daily occupation is influenced by the use of the electric wheelchair	Qualitative	Semi-structured interviews	Functional impairments (SCI and progressive diseases (sclerosis, transverse myelitis, spasm) (n = 9): 5 men, 4 women, age mean 52.1 (range 25–57) years, in electric wheelchair mean 10.3 (range 1–29) years	In the community	Electric wheelchairs: 1 class A (light weight wheelchair, which is fit for ground without irregularities and suitable for indoor use), 8 class B (wheelchair suitable for both outdoor and indoor life)	Meaningful activities and new possibilities in everyday life assisted by the electric wheelchair	An electric wheelchair positively impacted the feeling of autonomy and increased the possibility of accomplishing desired and valuable occupation
Folan et al. (2015) [25]	Australia	Gain an understanding of the experiences of clients with tetraplegia trialing assistive technologies for computer access during different stages in a public rehabilitation service	Qualitative	Semi-structured interviews; observation with reflective journal on skill training	SCI tetraplegia C4–5 With significant upper limb impairment (n = 7): all men, age mean 36.9 (range 20–60) years, mean 21.5 (range 6–48) months since injury	Mixed: 4 in the community, 3 in a long-term care facility	ALT for computer access: voice activation, trackball mouse, microphone, finger splints, QuadJoy	Self-efficacy in computer use	ALT impacted self-efficacy through 3 themes: "getting back into life", "assisting in adjusting to injury", and "learning new skills"
Wästlund et al. (2015) [30]	Sweden	Evaluate whether access to a gaze-driven electric wheelchair with navigation support is perceived as meaningful in terms of independence and participation	Qualitative	Observations; questionnaires to compare expectation versus experience	Severe motor impairment (MS, Duchenne, and locked-in syndrome) (n = 3); 2 men, 1 woman, age mean 55.3 (range 35–70) years	In the community	Add-on system for an electric wheelchair with gaze-driven control system and navigation support system	Independence and participation in everyday life	The system improved level of mobility capacity, communication, and participation with increased independence and freedom to make choices.
Jamwal et al. (2017) [26]	Australia	Assess psychosocial impact of assistive technology and participation and support needs	Mixed methods	Semi-structured interviews; surveys CANS (care and needs scale) and PIADS (psychosocial impact of assistive devices scale)	Acquired brain injury (ABI) (n = 22): 16 men, 6 women, age mean 43.7 (range 28–63) years, mean CANS rating of 5.55 (range 3–7), indicating that in general participants could be left alone for part of the day, but not overnight	Long-term care facility	ECS, and mainstream devices such as mobile phones or tablets	Support need and psychosocial impact	EAT positively impacted respondents' participation in valued life roles, instrumental and community activities of daily living, and social communication.

(continued)

Table 1. Continued.

First author (year)	Country	Study aim	Study design	Data collection	Population	Living situation	Type of technology	Primary outcome: independence in executing ADL	Main findings
Myburg et al. (2017) [27]	Australia	Gain insight into why some ECS users embrace technology, while others underutilise the systems	Qualitative	Semi-structured interviews	SCI tetraplegia level C2-5 (n = 15): 12 men, 3 women, age mean 43 (range 22-68) years, mean 65 (range 33-168) hours personal lifestyle support per week	In the community	ECS, chair mounted and bed mounted devices	Perceptions of autonomy when using ECS in everyday life	ECS positively impacted personal security, both practically and symbolically, and decreased frustration and improved participants' sense of wellbeing.
Hooper et al. (2018) [28]	Australia	Examine the lived experience of five participants to create a single case describing the experience of using a smart-device ECS	Qualitative	Semi-structured interviews	SCI cervical level C3-5 (n = 5); all men, age mean 41.4 (range 21-60) years	In the community	smart-device ECS	Experience of using smart-device ECS in everyday life	Smart-device ECS positively impacted independent control, choice, peace of mind, connection, and control over smartphone functions and applications.
Verdonck et al. (2018) [29]	Australia	Provide a deeper understanding of the subjective meaning of ECS	Qualitative	Unstructured / in-depth interviews	SCI high cervical level C1-4 (n = 5): 4 men, 1 woman, age range 22-55 years, discharged from rehabilitation for at least 3 years	In the community	ECS (environmental control system)	Subjective meaning of ECS in everyday life	ECS positively impacted independence and feelings of pleasure, safety and sense of self expressed in the theme "taking back a little of what you have lost" with two main components: "reclaiming a little doing" and "feeling enabled"
Bona et al. (2021) [31]	Italy	Verify the feasibility and usability of the ECO-ALS system in advanced stages of ALS	Quantitative	Surveys IPPA (evaluation of individual prioritized problems) and PIADS (psychosocial impact of assistive device scale)	Advanced ALS (n = 10): 7 men, 3 women, age mean 55.6 (range 49-60) years, mean 85.5 (range 66-113) months since disease onset	In the community	Smart glasses to control an electric wheelchair and an powered adjustable bed (EAB)	Effect on importance and difficulty of daily activities, psychosocial impact, and time required to perform 15 predefined tasks for controlling the EAB	The system improved and recovered patients' perceived autonomy because of independent EAB management: this increased confidence and reduced caregiver assistance to change their bed position.

Table 3. Results of the MMAT.

	Adequate rationale for using mixed methods design	Effective integration of study components	Adequate interpretation of integration outputs	Adequate address of inconsistent results	Adherence to quality criteria of each tradition of methods
Jamwal et al. (2017) [26]	+ Relevant sampling strategy	+ Representative sample	+ Appropriate measures	+ Low risk of nonresponse bias	- Appropriate statistical analysis
Bona et al. (2021) [31]	+	?	+	?	+

Table 4. Overview of ADL supported by the use of ALT.

Type of ADL	Example(s)	References
Eating	<i>taking plates out of the kitchen cupboard; cooking dinner</i>	[24]
Environmental control	<i>turning on the light; closing the curtains</i>	[23,29]
Transfers	<i>controlling the electrical adjustable bed</i>	[31]
Mobility	<i>moving between rooms; getting (around) in the house</i>	[24,30]
Communication	<i>picking up the phone; having a chat; using the computer</i>	[24–26,28–30]
Leisure	<i>turning on the television or stereo; changing tv channels; turning pages of a book</i>	[23,25,29]

Table 5. Impact of ALT on independence.

Theme	Impact on independence	Number of articles	ALT	References
Feeling enabled	Pleasure in doing everyday things Feeling better about oneself	4	ECS; mainstream devices; ALT for computer access	[25,26,28,29]
Choice and control	Freedom to make choices Sense of control	7	ECS; add-on for electric wheelchair; ALT for computer access; mainstream devices	[23,25–28,30]
Feeling secure	Peace of mind Provision of personal security	3	ECS; mainstream devices	[26–28]
Time alone	Space and privacy	4	Electric wheelchair; ECS	[24,27–29]
Less reliance on others	Changed dynamics Increased freedom	4	ECS	[23,27–29]
Participation	Contribution in family or community Connection with others	3	ECS; mainstream devices; ALT for computer access	[25,26,28]

As Verdonck et al. describe, using ECS enabled participants to experience “pleasure in doing everyday things”. They explain that “ECS evoked an emotional response of feeling good and feeling better about oneself ‘because you are doing it yourself’” [29]. Using ECS and mainstream devices to perform ADL made participants feel better about themselves, more self-confident, skillful and useful [25,26,29].

Choice and control

ALT caused participants to feel empowered and in control over their everyday lives [25,26]. ALT increased their options and their ability to make preferred, spontaneous choices [23,29]. For example when to move, as Wästlund et al. [30] found in participants that used an electric wheelchair: “The new opportunity for independent mobility and actions for individuals who are totally dependent on others, some of whom cannot communicate their wishes, has many important benefits. Psychological and emotional well-being improves with the ability to independently choose when and where to move.”. Hooper et al. [28] describe that ECS enabled participants to choose “when and what they could control” and when they wanted carer assistance [28]. Using ECS and mainstream devices gave participants the opportunity to choose how and when to receive communication, for example through the use of social media [26].

Feeling secure

Participants valued ALT for giving them personal security: using ECS and mainstream devices such as mobile phones made participants feel safe [26,27]. Simply knowing they could use ALT when needed gave participants and their families peace of mind [28]. As Myburg et al. [27] summarise for users of ECS: “All participants, even those most frustrated with their system, placed value on its ability to provide some level of personal security.”

Time alone

Using ALT reintroduced participants to spending time alone, which Myburg et al. [27] mention as one of the most powerful advantages of ALT. Because participants could use ECS to call for help, they did not need a physical presence in the same room anymore: “not a shadow with you” [23,24]. “Having an ECS reintroduced the experience of being alone. Being alone provided “space” and privacy in contrast to having constant company.” [29]. Participants using an electric wheelchair reported the electric wheelchair gave them the ability to be away from home by themselves [23,24].

Less reliance on others

Because users of ECS experience that their (physical) reliance on others decreased, the dynamics of the caregiving relationship changed [23,27–29]. Myburg et al. [27] described: “ECS meant ‘less asking’ and could alleviate participants’ sense of ‘being a pain’ to others. Being able to do things without having to ask a carer

decreased frustration and improved participants' sense of well-being." Participants reported less apologizing, feeling less frustrated, and reduced annoyance [23,29]. Participants experienced increased freedom, often not only because they themselves feel more independent, but more importantly because using ECS lifted the caregiver from some of their responsibilities [23,27]. The independence and freedom because of using ECS broke the cycle of worry they both experienced: "Caregivers and family members worried about the person with a [physical disability] who in turn was often worried about the caregiver worrying about them." [23]

Participation

ALT enabled participants to actively participate in their family or community by picking up life roles, such as family member, friend, student, volunteer, and worker [23,26]. ECS and mainstream devices helped them to complete tasks needed for those roles, such as using the computer to arrange the family's money matters as father or partner [25]. Some participants indicated that using ECS enabled them to contribute to their family or community, which they valued as the most important impact of ALT on their personal lives [27]. Also, using ECS and mainstream devices gave participants the opportunity to (re)connect with friends and family and connect with the outside world [26,28].

Discussion

This review focused on the impact of ALT on independence experienced by people with a physical disability receiving long-term care. We found eligible articles that demonstrated ALT increases their independence, regarding the execution of ADL as well as their perceived independence.

Most studies only briefly mentioned examples of ADL as their main focus was on the impact of ALT on perceived independence of participants in daily life, which could apply to diverse ADL. We established six themes regarding the impact of ALT on perceived independence, being 1) feeling enabled, 2) choice and control, 3) feeling secure, 4) time alone, 5) improved relationship with caregiver, and 6) participation. These results fit the four types of autonomy/independence defined by Van de Ven et al. [32]. The first type they describe is independence in daily life, or executional autonomy. In our study, this is represented by the ADL activities participants could carry out because of the ALT they used. The second type is self-determination, or decisional autonomy. In our review, we found that choice and control was a reoccurring theme in almost all included studies. Participants indicated that they experienced more freedom to make choices and an increased sense of control as a result of using ALT. Closely linked to this, they experienced more space and privacy because ALT enabled them to spend time alone without the presence of a caregiver. The third type van de Ven et al. describe is participation: "the organising of one's own social roles, affairs, and relationships" [32, p. 250]. We found that because of ALT, participants experienced less reliance on others and more freedom and improved dynamics within their relationship with caregivers. Also, they felt enabled to contribute within their families and communities and connect with others. The fourth type is identification: "the degree to which individuals feel comfortable with their way of living and feel that their way of living befits the person they are" [32, p. 250]. In the studies included in this review, this level of independence was not discussed extensively. However, participants mentioned that because of ALT, they were able to pick up

preferred life roles that they were previously not able to perform (anymore) due to their disability.

As such, the results of this review reflect that independence is not limited to just performing ADL, but also impacts more profound aspects of perceived independence which are more related to autonomy and self-esteem.

With our search strategy we found many studies evaluating technology in the development phase. Existing articles about these technologies focus on the functioning of the technology instead of its effects on the user. These technologies are promising for the independence of people with physical disabilities, but not yet used by them in the real-life daily living environments. Examples of such technologies are a rotating spoon to support self-feeding for people with upper limb dysfunction and several robots, robot arms or wearables, to perform ADL such as shaving, brushing, feeding or drinking for people with SCI or other physical disabilities [33–36]. There is a lack of studies that go beyond this development phase and research the effect of the technology for end users.

We were able to include just nine studies in our review. These studies were of good quality, but researched small samples, with a mean of ten participants, and were quite one-sided as most studies used qualitative methodology and examined similar samples (mostly participants with SCI) and technologies. Four of the nine of the studies we found were performed by the same authors for the same type of technology (ECS) in people with the same physical disability (SCI) [23,27–29]. Three of those studies were performed in the same country (Australia) [27–29]. Most studies researched technologies that were already in use by people with a physical disability. However, two studies monitored the experience of people who tested ALT for the sake of their study and did not use it before [30,31] and one study followed people who started using ALT and received training to do so [25].

In conclusion, this topic seems to be an emerging branch of research. However, in practice, ALT is implemented and needed in many long-term care organisations in response to societal developments and challenges such as the increasing costs of care and shortages of healthcare professionals and the focus on independence of people with a physical disability [37]. Solutions such as technology are essential to maintain care for people with (physical) disabilities in the coming years. There is a need for studies that highlight the value of ALT in order for governments to be more willing to invest in and shape ALT markets [38]. Therefore, further published research on pilots and preferably larger studies should report on cost-effectiveness of specific ALTs and how to properly implement these technologies within the care process. That way, care organisations will be in the position to learn from each other and make more considered choices to use technology rather than having to "invent the wheel" themselves over and over again.

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