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How assistive technology use by individuals with disabilities impacts their caregivers: A systematic review of the research evidence

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Portions of the findings from the study have been presented at two conferences:

- a. the 2010 American Congress of Rehabilitation Medicine

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- b. and the 2011 Festival of International Conferences on Caregiving, Disability, Aging and Technology.

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Abstract

Informal caregivers are a critical, yet frequently unacknowledged part of the healthcare system. It is commonly presumed that providing assistive technology (AT) will decrease the burden of their care provision; however, no review has evaluated the evidence behind this assumption. Therefore, a systematic reviews was undertaken to evaluate evidence of the impact of AT use by care-recipients on their informal caregivers. Data Sources included Embase, Medline, Cumulative Index to Nursing and Allied Health Literature, Web of Science, PsychINFO, and active researchers in this area. Twenty-two studies met the specified inclusion criteria. Collectively, the findings suggest that AT use helps caregivers by diminishing some of the physical and emotional effort entailed in supporting individuals with a disability. However, confidence in this causal connection is limited because of the relatively weak study designs that were used. This undermines our understanding of the impacts of AT use on users' informal caregivers.

Keywords

Self-help devices; Caregivers; Outcomes assessment; Review

Each year in the United States, over 50 million individuals act as informal caregivers.¹ Informal caregivers are definable as being individuals who provide unpaid assistance to recipients who are ill or disabled, exclusive of volunteers from care provision organizations.² Informal caregivers provide assistance with basic and instrumental activities of daily living and emotional support.² In attempting to maintain the quality of life of those they help, informal caregivers may experience a great deal of distress, which can include feelings of depression, isolation, anxiety and burnout (i.e. physical, mental, or emotional exhaustion).^{3,4} These potential problems pose a challenge to health care systems, as informal caregivers provide four times as much assistance as formal caregivers.⁵ The replacement value of informal caregiver's unpaid contributions has been estimated at \$350 billion annually in the United States.¹

Many older adults rely on assistive technology (AT), defined as, "any item, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities."⁶ In the United States, estimated rates of AT use for individuals age 65 years and over range from 14%–18%,⁷ and AT usage grows as age increases. Canes, walkers, wheelchairs, grab bars and bath seats are some of the most commonly used devices in later life.^{7–11}

A primary justification for providing AT to older adults is that it reduces their dependence on human assistance. However, notwithstanding the use of AT, daily activities and social participation are likely to remain restricted to some extent, especially for persons with moderate and severe levels of impairment.¹² Consequently, it is not surprising that a combination of AT and human assistance is used by some older people to enhance their daily activities and social participation.^{13–15}

Demers et al.¹⁶ developed a framework for understanding outcomes experienced by caregivers who assist AT users. According to this framework, AT and other contextual factors moderate the relationship between caregiving-related stressors (primary and secondary) and caregiver outcomes. Primary stressors are distinguished in terms of areas and forms of assistance, i.e., the nature, number, safety, and security of tasks, and the time and physical effort/work they require. Secondary caregiving-related stressors include role overload, effective use of time, and home modifications. Caregiver outcomes are comprised of quality of life, physical and psychological health, and social participation.

Systematic reviews of research published prior to 2000 found only limited information about the impact of AT on caregivers. A review of care delivery approaches to promote seniors' independence reported that little research evidence exists to support or refute the claim that AT use decreases dependence on caregivers or that it reduces caregivers' sense of burden.¹⁷ Similarly, a review of the impact of wheeled mobility on adult users and their caregivers found few studies that had looked at outcomes relevant to caregivers.¹⁸

Given 1) the prevalence and importance of informal caregivers, 2) the number of older adults with disabilities, and 3) potential problems associated with caregiver burnout, we sought to identify research evidence that examined the impact of AT used by care-recipients on their informal caregivers. Specifically we wanted to 1) evaluate evidence for the effectiveness of care recipient's AT use on caregiver outcomes, 2) identify methodological limitations that constrain the quality of the evidence they provide, 3) describe the outcome domains that were focused on in the relevant studies, and 4) suggest remedies needed in future research.

Methods

We addressed the study objectives by conducting a systematic review of research in this area.

Inclusion Criteria

The review focused on the population of informal caregivers of adults with physical and/or cognitive disabilities. We focused on adults because another review recently examined the impact of AT on children's caregivers.¹⁹ Informal caregivers were considered to be individuals who provide unpaid assistance to recipients who are ill or disabled. The informal caregivers studied encompassed individuals who did or did not cohabit with the person receiving assistance, and thus included friends, family members, acquaintances, and neighbors. The interventions that were examined comprised AT intended to enhance user self-care, mobility, or memory; device training; and environmental modifications.²⁰ Because we were interested in the broad impact of these interventions, both objectively and subjectively assessed outcomes were covered.²⁰ Given that we wanted to be able to evaluate the quality of the original research and we were concerned with real rather than hypothetical outcomes, included studies had to present original data describing outcomes of using the AT being investigated.

Exclusion Criteria

Studies were excluded for three reasons. 1) They did not include AT as the main component of the intervention, as this would represent substantial co-intervention. 2) They pooled data from both users and non-users of AT (e.g., individuals with multiple sclerosis, only some of whom used AT), making it impossible to isolate the impact of AT on caregivers. 3) They were published before 1990.

Search Strategy

We searched Embase, Medline (combined and in progress citations), PsychINFO, and the Cumulative Index to Nursing and Allied Health Literature. We targeted articles that had been published from 1990 until August 2011, as the first formal and legal definition of AT was first published in 1988.⁶ We used a variety of database specific medical subject headings and keywords. Among those terms were self-help device, AT, mobility aid, disability aid, wheelchair, communication AT for the disabled, caregiver, informal care, informal hours of care, family, spouses, significant other, caregiver burden, and caregiver support. Systematic reviews were examined to identify relevant original research.

After deleting duplicates, the first author reviewed the titles of all citations and the abstracts of potentially eligible studies. We obtained the full articles for abstracts that appeared to meet the inclusion and exclusion criteria. The first and second authors independently reviewed the articles and discussed any disagreement until reaching consensus. We reviewed the reference lists of included studies to identify additional candidate studies, and used Web of Science to identify papers that cited the included studies. Finally, we contacted authors who had recently published in this area to identify any unpublished studies of relevance, examined systematic reviews to identify relevant original research, and reviewed abstracts revealed by the electronic searches of databases.

Evaluation of Evidence for the Effectiveness of Care Recipients' AT Use on Caregiver Outcomes

We used a study-specific protocol to abstract information from each included study. It was adapted from one used by the World Health Organization,²¹ and is available from the first author upon request. Based on pilot testing, we added specific items to facilitate the inclusion of qualitative studies. This form included information about the study design, sampling methods, theoretical perspective, hypotheses, participants (i.e., age, sex, diagnosis), intervention provided (i.e., AT used, environmental modification made, or training given), outcome measures (reliability, validity, quality control, missing data), results, and summary of potential biases (i.e., selection biases, measurement biases, and intervention biases such as co-intervention and contamination).

Quantitative studies were assigned a level of evidence based on criteria recommended by the Centre for Evidence Based Medicine (1a=systematic reviews of randomized control trials (RCTs), 1b=individual RCTs, 2a=systematic reviews of cohort studies, 2b=individual cohort studies, 3a=systematic reviews of case control studies, 3b=individual case control studies, 4=case-series studies, and 5=expert opinion).²² Cross-sectional surveys were assigned a value of "4" for the purposes of the review.

Qualitative studies were assigned a level of evidence based on Kearney's criteria.²³ To be consistent with the Centre for Evidence Based Medicine levels, we reverse scored Kearney's levels as follows: I=dense explanatory description, II=depiction of experiential variation, III=shared pathway or meaning, IV=descriptive categories, V=findings restricted by *a priori* frameworks. We evaluated the quantitative and qualitative aspects of mixed-methods studies separately using the previously described approaches. Final quality scores and levels of evidence were arrived at consensually. A narrative synthesis of each included study was formulated and the studies were categorized in terms of design, level of evidence, population, type of ATs, and AT outcomes identified.

Methodological Limitations of Included Studies

To identify methodological limitations, the first author and a trained master's-level research assistant critically appraised all studies. The methods of quantitative studies were evaluated using Downs and Black's review criteria²⁴ because they are not restricted to evaluating randomized or quasi-experimental studies. The criteria are represented by 26 dichotomous and one six-point rating scales (for sample size) that assess how findings are reported, as well as issues of internal and external validity and power. Consistent with the practice of Strong et al.,²⁵ we scored all items dichotomously, and particular scoring ranges were assigned the quality designations of excellent (26–27), good (20–25), fair (15–19), and poor (0–14).

Qualitative studies were reviewed using the Critical Appraisal Skills Program (CASP) qualitative evaluation form²⁶ The CASP was selected because it is a generic appraisal tool that is not specific to any particular type of qualitative methodology. The CASP includes 10 dichotomous questions, each having 1–7 sub-questions that assess research design, recruitment, methods, reflexivity, analysis, and findings. Main questions were scored positively if the majority of sub-questions were answered affirmatively. Specific ranges of CASP score were assigned to corresponding levels of quality: excellent (9–10), good (6–8), fair (3–5), and poor (1–2).

We recorded the potential biases of each study on the data abstraction form, and also documented methodological gaps in how well the AT was described (in terms of training provided and fit with the user's environment), how informal caregivers were defined, and whether the research was based on a conceptual model or research hypothesis.

Outcome Domains

To categorize the outcomes of AT provision on caregivers, we mapped the studies' findings in terms of the stressors and outcomes identified in the Demers and colleagues' conceptual framework for understanding outcomes experienced by caregivers who assist AT users.¹⁶

Results

Our search strategy identified 1124 candidate articles with duplicates removed; 1056 were excluded following review of the abstracts or titles. Of the remaining 68 articles, 46 were excluded following review of the article, leaving 22 studies that met the inclusion and exclusion criteria. The authors who we contacted reported no unpublished studies, and no

relevant conference abstracts were identified. Among the 46 excluded studies, 31 did not describe impacts on informal caregivers, five did not distinguish between formal and informal caregivers, five did not provide an intervention that was AT-focused, and five were review articles. The included studies^{11, 13, 16, 27–45} are described in Table 1 in terms of their study design, theoretical basis, AT user and caregiver demographics, caregiver definition, type of AT, and the informant who provided judgments from which the outcomes were derived (user only, caregiver only, user and caregiver, or researcher).

Methods Used in Included Studies

Methodologically, 7 studies were qualitative, 13 were quantitative, and 2 used mixed-methods. Among the qualitative studies, one used focus groups and six used qualitative interviews, including one with participant observations. Four of the eight quantitative studies using survey data^{11, 13, 27, 28} were based on representative, population-based data from phase 2 of the United States Adult Disability Follow-back Survey (1994–5).⁴⁶ Two were case studies and three were intervention studies without a control group that recorded both the pre- and post-intervention status of the participants. Both mixed-methods studies consisted of an intervention supplemented by interviews. Fifteen of the 22 studies that met the inclusion/exclusion criteria were published after 2000. All were conducted in North America or Europe.

Research Participants

The studies incorporated a variety of AT users and informal caregivers (defined and described in different ways) and had a wide range of sample sizes. Five were limited to individuals with cognitive impairments. The remainder included users with a variety of diagnoses and physical functioning problems. Five did not provide demographic information about caregivers. Most caregivers in the remaining studies were older than age 60 years. Eight studies included only relatives of the AT users. Two of these only dealt with spouses, and one included individuals who self-defined themselves as being caregivers, but the term's operational definition was not specified. Excluding four studies based on national survey data, most had sample sizes less than 50 participants. None explored differences in outcomes between male and female caregivers.

Evidence for the Effectiveness of AT in Relation to Caregiver Outcomes

As noted in Tables 2 & 3, most studies provided a relatively low level of evidence. At the same time, the qualitative studies were of relatively better quality than the quantitative ones. All quantitative studies provided level 4 evidence. The evidence of one qualitative study was rated as being grade V, two as being grade IV, and four as being grade III. The two mixed-methods studies had level 4 quantitative evidence and grade V qualitative evidence.

Impact of Assistive Technology by Device Type

Eight studies focused on the impact of mobility AT. Four studies concerned with power mobility devices reported that they reduced 1) the perceived need for caregiver supervision of user mobility, 2) assistance with transfers, and 3) the need to push users outside.^{16, 30, 34, 35} Effects on the amount of informal care provided depended on the type of device

being considered. Allen et al. found that the use of canes or crutches decreased hours of informal care, and the use of wheelchairs increased hours of informal care.²⁸ Home modifications to improve wheelchair accessibility were associated with decreased hours of informal care.²⁷ Negative outcomes of wheelchair use included caregiver injury,³⁸ anxiety about AT-user injury,^{15, 30, 35, 41} wheelchair accessibility issues, and social stigma.^{16, 35, 41}

Six studies examined how the use of medic-alert (communication AT designed to summon help when users are unable to get to the telephone, combined with a reminder system) and AT for cognitive problems affected caregivers. Two related studies of a medic-alert device found it increased caregivers' sense of security and decreased their sense of burden.^{36, 44} Four studies looked exclusively at AT for individuals with cognitive impairment. The AT that was investigated included a day/night clock,^{29,33,43} lost item locator,³³ automatic nightlight,³³ gas cooker device,³³ and a picture button telephone.³³ The findings indicated that although some caregivers reported the AT was useful, others were frustrated because of the verbal cueing that care-recipients required in order to operate them.^{29, 33, 43} A study of a stove timer found the device decreased caregiver anxiety, but caused frustration when the device turned off the stove while caregivers were cooking.⁴²

Eight studies looked at the outcomes of providing individual users with a variety of ATs. Caregivers in four studies reported that AT made it easier for them to provide assistance.^{32, 37, 39, 45} Two studies found that use of at least some of the AT resulted in needing to provide fewer hours of care.^{11, 13} Two studies identified negative outcomes including caregiver injury³¹ and concerns about how AT initially altered caregivers' homes and interpersonal relationships.⁴⁰

Methodological Limitations

As noted in Table 2, the quantitative/mixed-methods studies had a range of 5 to 11 and a mean of 8.6 out of 27 on the Downs and Black criteria.²⁴ No studies adequately described the interventions provided or the degree of adherence to those interventions. As none of the studies used blinding or randomization. All of these studies were therefore considered to be of poor quality. As noted in Table 3, the qualitative/mixed-methods studies had a range of 5 to 9 and a mean of 7.2 out of 10 according to the CASP evaluation system. Most of these studies were judged to be of good quality. All of the studies adequately identified their study questions, justified their choice of methods and presented their findings but no study sufficiently described the relationship between the researcher and his or her participants.

The 22 studies had a variety of methodological deficiencies. Only three^{16,36,40} were based on a conceptual model or theory, just three others specified *a priori* hypotheses^{27,28,43} that were based on extrapolations from previous findings, while one study included both.¹¹ Seven of the 15 quantitative/mixed methods studies used outcome measures that had been psychometrically evaluated.^{32,37–39,43–45} Sixteen of the 22 studies supplied only scant information about the AT provided, how appropriately their capabilities met users' needs (in terms of their capabilities and environment), and about any training that was provided. None of the intervention studies described the characteristics of participants lost to follow-up. Fourteen studies^{13,16,29–32,36,38–40,42,44–45} did not explicitly define the caregivers they included and eight^{11,13,27–28,32, 34–35,38} relied on care recipients' perceptions in order to

establish caregivers' outcomes. None documented the usage frequency of the AT being studied in any manner. None of the intervention studies reported data about possible co-interventions. None of the studies described how their findings may have been affected by seasonal influences. None performed an economic analysis examining the cost-benefit of various forms of AT on users' caregivers.

Outcome Domains

The content of the 22 studies is mapped in Table 4 according to the outcomes of AT provision and the stressors that are involved as depicted in the conceptual framework of Demers et al.¹⁶ Hours of care provision was the most frequently documented caregiver outcomes. We identified eight outcomes related to primary stressors, two related to secondary stressors, and four related to general outcomes (three pertaining to psychological health and one to participation). Two outcomes that were not included in the framework were identified: vigilance concerning the recipient's well-being, and concern about stigma associated with using a device. Most studies reported beneficial outcomes of AT use for caregivers in terms of decreased primary stressors. Some negative outcomes included caregiver injury, caregiver worry about user injury, frustration with having to cue the user, and stigma and accessibility issues that jointly affect users and their caregivers.

Discussion

To our knowledge this is the first systematic review to explore the impact of AT on user's informal caregivers specifically.

Evidence of the Effectiveness of AT in Relation to Caregiver Outcomes

None of the 22 reviewed studies supplied more than a low level of evidence regarding the impact of AT on users' informal caregivers. Quantitative studies were primarily descriptive in nature and the four intervention studies^{33,39,44,45} used a pre-post design without a control group. The highest-level qualitative studies^{30, 40-42} described shared pathways or meaning among participants, but none offered extensive description of experiential variation among participants or provided dense explanatory description.

Overall, there seems to be a trend towards positive outcomes for caregivers. This might reflect a publication bias, as studies with positive findings are more likely to be published;⁴⁷ however, we were unable to identify any unpublished reports (containing either positive or negative findings) by contacting researchers who had published in this area, so publication bias seems an unlikely explanation for this trend. ATs, like most innovations, are intended to create favorable outcomes; however, negative, unintended consequences may also occur.^{48, 49} Negative outcomes, including caregiver frustration, worry, and injury, were more often identified in caregiver-directed surveys and in exploratory investigations using qualitative/mixed methods designs. Although not discounting caregiver injury as being a seriously negative outcome, it should be noted that similar injuries may occur in the absence of device use. Outcomes such as frustration and worry might not seem severe, but they may contribute to caregiver distress and ultimately lead to burnout.^{3,4}

Impact of Assistive Technology by Device Type

The studies included in this review evaluated a variety of AT. A substantial proportion focused on individuals who used several different types of AT, making it difficult to determine the impact of any one of them. At the same time, such studies have ecological validity because many individuals living in the community use multiple ATs.^{50, 51}

There may be issues with the increased need for assistance that stem from the use of more complex AT that include moving parts.^{11, 31, 39} In this regard, wheelchairs appeared to be especially likely to produce mixed benefits for caregivers, as they facilitated transportation on one hand, but were associated with increased hours of care and injuries on the other hand.³⁵ That may be attributable to the size and visibility of this AT, to difficulties transporting them, and to environmental accessibility issues associated with their use.⁵²⁻⁵⁴ Other types of AT appeared to yield generally positive outcomes, although caregiver complaints were noted about the need to provide verbal cueing when cognitive AT was used.^{32, 43}

Methodological Limitations of Included Studies

Many of the survey studies necessarily received low ratings because of their failure to control for extraneous variables. Most of the intervention studies received low ratings because they did not employ a comparison group and had very small sample sizes. None measured the frequency with which AT were used or accounted for opportunities for their appropriate use. In contrast, the qualitative studies had generally higher ratings than the quantitative studies; however, this likely reflects the fact that different rating systems were used to evaluate the two types of studies. Given that no qualitative studies adequately described the relationship between participants and researchers, this does call into question the authenticity of their findings, that is, the degree to which they fairly and accurately described participants' experiences.⁵⁵

Published research in this area exhibits a number of deficiencies. Principal among them is inadequately describing the characteristics of interventions. These include the types of AT provided, their appropriateness for meeting the user's and caregiver's needs (in terms of abilities and environmental fit), the extent to which both parties were involved in device selection, the training that both received in the AT's use, and measurements of that usage. That information is needed both for interpreting the findings of AT outcomes studies and for replicating them.⁵⁶ Most of these studies offered little treatment theory to explain the causally active ingredients of the interventions provided, also making it difficult to interpret their findings.⁵⁶

There are several areas that require additional documentation to develop a better understanding of the effect on AT on user's caregivers. Co-intervention is a serious confounding influence that needs to be documented to help attribute caregiver outcomes to the devices provided. Relatively few studies examined the relationship among AT use and informal and formal caregiving (formal caregiving might be expected to substitute for some informal caregiving). Pharmaceutical interventions and rehabilitation programs might also affect AT use and informal caregiving. Seasonal variation is another potential confounding variable because some AT such as mobility AT may be used differently in summer than in

winter. Finally, without documenting the characteristics of those lost to follow up it raises that possibility that those who participated are different from those who did not.

Many studies' findings about caregiver outcomes were based on the reports and judgments of care recipients and not those of the caregivers themselves. Proxy measurements of subjective caregiver-related outcomes are likely to be of questionable accuracy. Caregiver and AT user reports of more objective constructs such as the frequency of care provision may also be discrepant. Furthermore, few studies examined the outcomes of AT provision separately and concurrently for users and their informal caregivers. Consequently, the impacts of AT use on individuals in these two roles cannot be compared. This is important, because some AT may benefit caregivers and assistance users alike, while other AT may benefit caregivers and assistance users differentially. Like much research on factors influencing either caregiver outcomes⁵⁷ or AT outcomes,⁵⁶ most of the studies that were reviewed were atheoretical and not hypothesis driven, making it difficult to advance research in this area. Furthermore, the failure of many studies to provide an explicit definition of informal caregivers makes comparisons across studies problematic. For example, studies that include both co-resident and extra-resident caregivers versus co-resident caregivers alone may yield different outcomes because of different demands associated with the two roles.⁵⁸

Outcome Domains

From the standpoint of the framework by Demers et al.,¹⁶ the preponderance of studies focused on the effects of AT use on the primary stressors experienced by caregivers. The most frequently measured stressor was hours of care. Fewer studies examined the impact of AT use on secondary stressors such as role overload and elective use of time. Outcomes involving psychological health were studied while effects on physical health and quality of life were generally neglected. It is important to document the impact of AT on stressors as well as outcomes, so that the effects of AT provision can be fully understood.

Research Gaps

There are many gaps in this research area, one regarding the populations studied. Most of the available research has focused on caregivers of older adult AT users. The caregivers of users in younger age groups well may experience different outcomes. Furthermore, despite the prevalence of disability in non-Western countries and projections of a dramatic increase in its prevalence,⁵⁹ the impact of AT on informal caregivers in these areas is unknown. It has been argued that the gendered nature of caregiving, wherein women provide the majority of care, contributes to different outcomes being experienced by male and female caregivers.² However, none of the studies examined that possibility.

Research is also limited in terms of the AT that have been evaluated and economic evaluations of their effectiveness. Although it is infeasible to study impacts of the over 40,000 specific products that are available,⁶⁰ more research is needed of caregiver outcomes associated with the use of particular, broadly defined categories of devices such as AT for daily living, mobility AT, and environmental adaptations. This is important because different categories of devices may produce different outcomes. This is suggested, for example, by the findings that compared the impact of wheelchairs versus ambulation aids on hours of

caregiving. Furthermore, without examining the cost-benefit of various forms of AT interventions on user's caregivers, an understanding of the overall utility of these devices cannot be determined.

Future Research

To date, most research in this area has used exploratory designs, a strategy that is appropriate in view of the current level of knowledge. The majority of quantitative studies used cross-sectional survey methods. Additional hypothesis-driven exploratory research is needed to identify active ingredients that appear to contribute to caregiver outcomes. Promising candidates will then need to be confirmed by well-controlled experimental studies, RCTs foremost among them.⁶¹ Qualitative methods can be embedded in those studies to examine how interventions were implemented and perceived^{62, 63} and to provide multiple perspectives on observed outcomes so they can be understood more completely.^{64, 65}

National population surveys (cf., ^{11, 13, 27, 28}) offer the possibility of having demographically representative findings. However, the available survey-based studies have inferred the impact of AT use on caregivers from users' responses to very few queries, principally dealing with the number of hours of assistance they received. Outcomes have been neglected that are likely to be important to caregivers, e.g., the amount of physical demands on them, injury risk, psychological stress, and some of the positive aspects of caregiving that have been documented including companionship and satisfaction with providing help.⁶⁶ Future population-based surveys that encompass the perspective of both AT users and their informal caregivers and that contain more detailed queries about caregiver demands will be especially valuable.

Limitations

Four limitations of this review should be noted. First, the inclusion of additional grey literature such as conference abstracts and technical reports that were not indexed electronically might have identified additional relevant research. Second, our search did not identify any relevant studies prior to 1994. This may reflect the decreased electronic coverage of older publications and inconsistent use of the term assistive technology, which was only formalized in 1988.⁶ Third, the quality of evidence of quantitatively designed studies could only be compared indirectly with that of qualitatively designed ones because different systems were used for those appraisals. Finally, although the CASP and Downs and Fawcett appraisal systems are a useful way to make comparisons across studies, caution needs to be used in interpreting the total scores, as this assumes that each item is equally important. For this reason, we have provided the scores for each item for all of the included studies.

Recommendations

Given the importance of informal caregivers on those they care for, their integral role within the healthcare system, and the need to facilitate their continued provision of informal care, our review results in 12 recommendations for future research regarding caregiver outcomes attributable to AT use.

1. Like studies ^{11,16, 26–28,40, 43} the research should be informed theoretically so that models and theories can advance as empirical knowledge grows.⁶⁷
2. Like studies ^{11,27–28,37,41,43}, reports should clearly indicate how the role of caregiver was operationally defined.
3. Unlike all of the intervention studies included in the review, study reports should supply a) information about the bases for device recommendations (if any were made), b) unequivocal designations of the AT that were used, c) descriptions of any device training that was provided, and d) documentation about co-interventions (formal caregiving, pharmaceutical interventions, rehabilitation services).⁵⁵
4. Unlike all of the studies included in the review, AT use should be measured in terms of where, when, how, and how often AT was used, and whether or not they were used in conjunction with caregiver assistance.
5. Like studies ^{30,36,41} AT intervention outcomes should be assessed multidimensionally, including those accruing to AT users as distinct from those accruing to their caregivers.¹⁵
6. Like studies ^{35,44} diverse subjective aspects of caregiving should be measured, such as fatigue, burden, and personal satisfaction.¹⁵
7. Like studies ^{16,30,33,36–37,39–44} data pertaining to subjective caregiver outcomes should be elicited from caregivers themselves, rather than from AT users.
8. Like studies,^{32,37,39,40,45} exploratory research should be expanded to provide a better understanding of how different types of ATs impact on users and their informal caregivers.
9. Unlike the studies in the review, longitudinal studies should be conducted to foster knowledge about how caregiver outcomes vary over time.
10. More robust experimental designs should be employed for confirming putative causal linkages between aspects of AT use and caregiver outcomes.
11. Unlike the studies in the review, the effects of individual differences among caregivers should be investigated, including their sex, age, ethnicity, and health status.
12. Unlike the studies in the review, future research should look at a diversity of AT interventions in respect to a variety of user populations, and some of those studies should include benefit-cost analyses to determine the relative value of various caregiver outcomes.⁶⁷

Conclusion

This systematic review of the outcomes of AT for users' informal caregivers identified 22 relevant studies. Despite the health effects of care provision on informal caregivers and their economic impact, the evidence provided by these studies is limited because of the relatively weak study designs that were used and methodological limitations. Further research is

necessary to explore how AT use affects informal caregivers, and to make stronger inferences about the determinants that are involved. This research needs to include a greater variety of AT users, informal caregivers, and AT. These studies will highlight ways that AT interventions can be improved so that they are associated with beneficial outcomes for both users and their informal caregivers.

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Table 1

Study Design, Theoretical Basis, Participant Demographics, AT Provided, Caregiver Outcomes, Location and Respondent for Included Studies

Reference	Study Design/Theoretical Basis or Hypotheses (Y/N)	AT User Demographics	Caregiver Demographics/Definition(Y/N)	Type of AT	Caregiver Outcomes	Region	Perspective
Mobility AT							
Allen et al. 2001 ²⁷	S*/Y	N=9,230 reporting limitations in both mobility & activities of daily living, 63% female, mean age of 62 yr.	NR/Y	Wheel-chairs, walkers, canes, crutches	Use of canes & crutches, ↓ number of hours of informal care & wheelchair use, ↑ hours of informal care	NA	A
Allen et al., 2006 ²⁸	S*/Y	N=899 using a wheelchair in previous two weeks; 62% female, mean age of 67 yr.	NR/Y	Home modifications for wheelchairs	Inverse relationship noted between number of home modifications & hours of unpaid help	NA	A
Boss & Finlayson, 2000 ³⁰	QI/N	N=7 individuals with multiple sclerosis using powered mobility, 29% male, mean age of 49 yr.	N=4, spouses, 50% female, mean age of 57 yr./N	Powered mobility	↓ dependence on caregivers & ↑ worries about safety	NA	B
Demers et al., 2009 ¹⁶	QI/Y	NR Individuals using powered mobility	N=19, 57% female, mean age of 53 yr., all relatives/N	Powered mobility	↓ anxiety, ↓ assistance, ↓ physical effort, ↓ worries about safety, ↑ free time, ↑ participation in personal & shared activities, & ↑ quality of relationship with user	NA	C
Frank et al., 2000 ³⁴	S/N	N=113 prescribed powered mobility mean age of 46 yr.	N=94, 51% spouses, 32% parents, & 16% others, Sex NR/N	Powered mobility	86% felt the chair made life for caregivers easier by letting the user go out alone, ↓ number of transfers & ↓ need for pushing	E	A
Frank et al., 2010 ³⁵	QI/N	N=64 prescribed powered mobility, 50% male, mean age of 46 yr.	N=80, 39% parents, 28% spouses, 15% siblings, 18% other/N	Powered mobility	44% of users reported on burden of care related to device use. 39% reported ↓ physical burden .44% noted practical problems for carers in term of size & weight of devices, transportation, & curbs & slopes. 19% reported concerns about safety	E	A
Kirby et al., 1994 ³⁸	S/N	N=577 community dwelling wheelchair users, 57% male, mean age of 44 yr.	NR/N	Manual wheelchairs	One caregiver was injured.	NA	A
Rudman et al., 2005 ⁴¹	QI/N	N=16 with stroke, 75% male, mean age of 76 yr.	N=15, 87% co-resident spouses, 87% female, mean age of 68 yr./Y	Manual wheelchairs	Wheelchair became incorporated into daily life. Accessibility & transportation issues sometimes restricted activities & ↓spontaneity	NA	B
Medic-Alert or Cognitive AT							
Baruch et al., 2004 ²⁹	CS/N	One woman in her 80's with balance & memory problems	Son/N	Night-day reminder system	Night time phone calls to son went from 12 to 0 per night	E	R
Cahill et al., 2007 ³³	MM I/N	N=20 with dementia, 35% male, most between the ages of 70–80 yr.	N=20, 25% male, most between ages 34–51 & 61–75 yr./N	Five different types of devices	All caregivers reported finding the devices useful. Many had to prompt the user to use the device	E	C
Garceau et al., 2007 ³⁶	FG/Y	N=4 without cognitive impairment & with mobility or cardiovascular problems, 100% female, mean age of 77 yr.	N=6, 50% female, 50% daughters, mean age of 62 yr./N	Medic-alert device	↑ sense of security & ↓ sense of burden reported	NA	B
Starkhammar & Nygård, 2008 ⁴²	QI + O/N	N=9 with memory problems, 33% male, mean age of 80 yr.	N=5, 40% male, 40% spouses, 60% daughters/N	Stove timer	↓ worries about safety, but frustration noted when the device was engaged while caregivers were cooking	E	C
Topo et al., 2007 ⁴³	MM I/Y	N=50 with dementia, 38% male, most 80–90 yr. of age	N=50, 22% male, 49–58 yr. of age/Y	most Night & day calendar	Caregivers received ↓ questions & phone calls about time orientation, but some were frustrated	E	C

Reference	Study Design/Theoretical Basis or Hypotheses (Y/N)	AT User Demographics	Caregiver Demographics/Definition(Y/N)	Type of AT	Caregiver Outcomes	Region	Perspective
Vincent et al., 2006 ⁴⁴	I/N	N=38 "frail" older adults, 92% female, mean age of 81 yr.	N=38, 76% children, 71% female/N	Medic-alert device	because they needed to remind the user to use the device Significant improvements noted in 3 of 5 dimensions of caregiver burden: daily support provided, concern about user well-being, & caregiver effort	NA	C
Three or more Devices							
Agree et al., 2005 ¹³	S*/N	N=4,008 adults age 65 yr. who reported 1 ADL limitation, 64% female, 58% age 75+ yr.	NR/N	Devices primarily for mobility & bathing	↓ hours of informal care with AT associated, especially for persons who are unmarried, better educated, with better cognitive skills	NA	A
Agree et al., 2000 ¹¹	S*/Y	N=10,028 adults age 65+ yr. with a disability	NR/Y	Various (e.g., for mobility, dressing, & bathing)	Results were highly task specific, ↓ informal care when simple devices were used	NA	A
Brown & Mulley, 1997 ³¹	CS/N	80 year old woman with multiple sclerosis & an 85 year old man	80 year old husband & a daughter/N	Homemade assistive devices	Two caregivers were injured using the devices	NA	R
Chen et al. 2000 ³²	S/N	N=20, 40% female, mean age 74 yr.	N=20, 80% spouses, 20% children, 75% female, mean age 67 yr./N	Various (e.g., for mobility, dressing, & bathing)	Most used the devices when caregiving (59%), ↓ assistance provided (59%)	NA	A
Kane et al., 2001 ³⁷	S/N	N=30 with moderate disability (age 60 yr.)	N=30, 73% female, mean age 65 yr., 29 relatives, 66% spouses/Y	Various (e.g., for mobility, dressing, & bathing)	Most agreed AT made it easier to assist the care recipient	NA	C
Nochajski et al., 1996 ³⁹	I+ CS/N	N=20 with cognitive impairment, mean age of 79 yr.	N=17, 8 spouses, 6 children, 3 others; mean age of 62 yr./N	Mobility, personal care, sensory & cognitive functioning	↓ need for assistance & ↑ efficiency of care	NA	C
Pettersson et al., 2005 ⁴⁰	QI/Y	N=12 with stroke requiring help everyday with personal or instrumental activities	N=12 spouses, 10 female, median age of 75 yr./N	Mobility, personal care, housekeeping, & home modifications	Facilitated residential living, but sometimes caused 1) anxiety about possible injury, 2) accessibility problems, & 3) concern about social stigma	E	C
Yang et al., 1997 ⁴⁵	I/N	N=7 with cognitive impairment, 43% male, mean age of 80 yr.	N=8, 75% female, mean age of 62 yr., all relatives/N	Mobility, personal care, sensory, environmental & cognitive functioning	Devices reported to assist care providers, ↓ stress reported by 3 caregivers	NA	C

Abbreviation for column 1: CS, = case studies, FG= Focus Group, I= Intervention Study, MM= mixed methods, N=no, NR= not reported, O= Observations, QI= Qualitative Interviews, S= Survey, Y=yes *Based on nationally representative 1994–95 United States National Health Interview Survey data; Abbreviations for column 2: yr.=years; Abbreviations for column 6: ↓= decreased, ↑= increased; Abbreviations for column 7: E=Europe, NA=North America, Abbreviations for column 8: A= AT User, B= both(AT User and caregiver), C=caregiver, R= researcher

Table 2
Methodological Quality (Downs and Black criteria) and Level of Evidence (Centre for Evidence Based Medicine) of Quantitative Data

Study	Agree 2006 ¹¹	Agree 2005 ¹³	Allen 2006 ²⁷	Allen 2001 ²⁸	Barach 2004 ²⁹	Brown 1997 ³¹	Caillit 2007 ³³	Chen 2006 ³²	Frank, 2006 ³⁴	Kam, 2001 ³⁷	Kirby 1994 ³⁸	Noshajri, 1996 ³⁹	Togo 1997 ⁴³	Vincent, 2006 ⁴⁴	Yang, 1997 ⁴⁵	
Q1: Hypothesis/objective	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1
Q2: Main outcome measures clearly described	1	1	1	1	1	0	0	1	0	1	1	1	0	1	1	1
Q3: Patient characteristics clearly described	0	0	0	0	1	1	1	1	0	1	0	1	1	1	1	1
Q4: Interventions clearly described	0	0	0	0	1	1	1	0	0	0	0	0	1	1	0	0
Q5: Distributions of confounders in each group described	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q6: Main findings clearly described	1	1	1	1	1	1	1	1	1	0	1	1	0	1	1	1
Q7: Estimates of variability for main outcomes	0	1	1	1	0	0	0	0	0	0	1	1	1	0	1	0
Q8: Adverse events reported	0	0	0	0	1	1	0	0	1	1	1	0	1	0	0	0
Q9: Characteristics of patients lost to follow up described	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q10: Actual <i>P</i> values reported	0	0	0	0	0	0	1	0	0	1	0	1	1	0	0	0
Q11: Subjects asked to participate representative of population	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Q12: Subjects who participated representative of population	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Q13: Staff, place, and facilities representative	1	1	1	1	1	0	0	0	0	0	0	0	0	0	0	0
Q14: Blinded subjects	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q15: Blinded evaluators	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q16: Any data handling mask clear	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Q17: Adjustment for different lengths of follow-up	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q18: Appropriate statistical tests	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
Q19: Compliance with intervention	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q20: Main outcome measures reliable and valid	0	0	0	0	0	0	0	1	0	1	1	1	1	1	1	1
Q21: Selection bias	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q22: Subjects in different groups recruited over same period	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q23: Randomization	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q24: Randomization concealed	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Q25: Adjustment for confounders	0	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0
Q26: Losses to follow-up accounted for	0	0	0	0	0	0	1	0	0	0	0	0	1	1	1	0
Q27: Adequate sample size	1	1	1	1	1	0	0	0	0	0	0	1	0	0	0	0
Total	9	11	11	11	7	6	7	8	5	8	10	10	9	10	10	7
Level of Evidence (Centre for Evidence Based Medicine)	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4

1= yes, 0= no or unable to determine

Table 3

Methodological Quality (CASP criteria) and Level of Evidence (Kearney's criteria) of Qualitative Data

Question	Cahill 2007 ³³	Boss 2006 ³⁰	Demers 2009 ¹⁶	Frank 2010 ³⁵	Garceau 2007 ³⁶	Petterson 2005 ⁴⁰	Rudman 2006 ⁴¹	Starkhammar 2008 ⁴²	Topo 2007 ⁴³
Q1 Was there a clear statement of the aims of the study?	1	1	1	1	1	1	1	1	1
Q2 Is qualitative methodology appropriate?	1	1	1	1	1	1	1	1	1
Q3 Was the research design appropriate to address the aims of the study? (justified)	1	1	1	1	1	1	1	1	1
Q4 Was the recruitment strategy appropriate to the aims of the research?	0	1	0	0	0	0	0	1	0
Q5 Were the data collected in a way that addressed the research issue?	0	1	1	1	1	1	1	1	0
Q6 Has the relationship between the researcher and participants been adequately considered?	0	0	0	0	0	0	0	0	0
Q7 Have ethical issues been taken into consideration?	1	1	0	1	0	0	0	1	1
Q8 Was the data analysis sufficiently rigorous?	0	1	1	1	1	1	1	1	0
Q9 Is there a clear statement of the findings?	1	1	1	1	1	1	1	1	1
Q 10 How valuable is the research	1	1	1	1	1	1	1	1	0
Total	6	9	7	8	7	7	7	9	5
Grade (Kearney's criteria)	V	III	IV	IV	V	III	III	III	V

Table 4

Categorization of the outcomes identified according to the Demers et al.¹⁶ framework for understanding outcomes for caregivers who assist AT users

	Studies
Effect on Primary Stressors	
Caregiver injury with device use	31, 38
Decreases physical effort	16, 34, 35
Assists caregiver	32, 37, 45
Increases efficiency of care provision	39, 44
Decrease in hours of care/ frequency of assistance	11, 13, 27, 28, 29,30
Increase in hours of care	27
Increased physical effort transporting the device	35
Vigilance	41
Effect on Secondary Stressors	
Increases free time for participation in personal & shared activities	16, 35, 40
Home modifications difficult to accept initially	40
Participation-Related Outcomes	
Device interferes with caregiver's activities	42
Accessibility issues may affect the caregiver's activities	37, 40, 41
Psychological Health Outcomes	
Frustration with need to provide cues to use device	33, 43
Increases sense of security/ decreases worry or stress	34, 36, 42, 44-45,
Concern about potential injury of user	16, 30, 35, 40, 41,
Concern about stigma	37, 40