How to measure the impact of assistive technology solutions on the person's quality of life?

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ABSTRACT

This paper reports the findings of a study that developed a standardized method to measure the outcome of assistive technology solutions. Here the term "assistive technology solution" or "AT solution" is used to describe any intervention involving assistive technology products and environmental adaptations to address a person's individual problems related to disability in daily life, education, work, leisure and social life. A literature review was carried out in order to identify validated outcome measures, applicable to any kind of AT solutions. Eight instruments were identified as able to capture the impact of AT solutions in real-life context; three of them (KWAZO, IPPA and QUEST) were chosen to measure the outcome of the intervention for 34 subjects. KWAZO investigated the user's perception about the quality of the AT service delivery process. IPPA assessed the perceived effectiveness of the AT solution provided. QUEST measured the individual's satisfaction with each AT equipment provided. The findings are described in this article. This standardized method for outcome measurement proved to be applicable in clinical practice.

CCS CONCEPTS

• **Human-centered computing** → Accessibility → Accessibility technologies • **Applied computing** → Life and medical sciences → Consumer health

KEYWORDS

Assistive technology, participation, quality of life, AT outcome assessment

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1 Background

AT intervention is the phase of the rehabilitation programme when barriers to participation present in the living environment are faced and appropriate AT solutions are assessed, acquired and provided.

There is growing awareness about the impact assistive technology products and environmental adaptations (overall referred to as "AT solutions") can have in the daily lives of persons with disabilities. The World Health Organization (WHO) stated in a recent resolution [1] that "*assistive technology enables and promotes the inclusion, participation and engagement of persons with disabilities, ageing populations and people with co-morbidities in the family, community and all areas of society, including the political, economic and social spheres*". Examples of assistive technology products are wheelchairs, special keyboards for IT access, communication aids, etc. Environmental adaptations consist of those changes made to living environments that increase their accessibility.

As AT solutions are key enablers to participation, it is essential that persons with disabilities have access to them; in fact all countries that adopted the United Nations Convention on the Rights of Persons with Disabilities (CRPD) have taken a commitment to ensure "*availability, knowledge and use*" of quality assistive technology at an affordable cost [2].

As a result of the collaborative work done within the WHO's GATE initiative (Global Collaboration on Assistive Technology), a position paper was published on the "state of the science" view of AT users stating that "*measuring the personal impact and outcomes of AT in the lives of users is essential in identifying and analyzing need, meaningful planning, matching (unmet) need to appropriate AT solutions, optimizing usage and participation".* The position papers also states that "*… it is also critical in demonstrating fundamental and added value that technologies offer, quantifying this impact and informing funding decisions.*" [3].

In order to create evidence of the impact of assistive technology and environmental adaptations on users' and their caregivers' daily life, internationally validated AT interventions

outcome measures must be available, sustainable and globally used.

As Andrich et al. stated in 2013 [4], AT interventions outcome measures should investigate at least three dimensions:

- **effectiveness** (adherence to the established objectives);
- **usefulness** (the extent to which the AT solution is perceived as being useful in improving the quality of life);
- **efficiency** (the extent to which the economic investment was worth the achievement of effectiveness and usefulness).

Effectiveness, within the ICF framework [5], can be assessed through changes in functioning. When introducing environmental facilitators, changes in performance (i.e. functioning in real-life context) should be detected: if a person experiences participation restrictions in certain areas (communication, mobility or self-care or education or work or social life) the introduction of an environmental facilitator such as an AT solution is expected to improve performance in those areas [6]. Of course, "*from the user's perspective, the ultimate outcome is an improvement in the quality of life*" [7]; however, this is a fuzzy, aggregate and multi-dimensional concept that is highly subject to personal values and cultural factors [8], and may not even be measurable because it is unclear whether detected changes should be attributed to the AT solution or other reasons.

Usefulness is another important dimension. As a matter of fact, observing the achievement of certain goals (e.g., the increased performance in moving about at home) is not enough; it is also necessary to know the user's perception of how **useful** the assistive solution was in improving his or her independence, personal wellbeing, family relationships, etc. [9].

Concerning **efficiency**, the purchase price of an assistive product is not a meaningful indicator of the cost of an intervention; also costs related to maintenance, repairs, human assistance and related services should be accounted over time to calculate the exact investment [10].

Nowadays, instruments are available to assess these dimensions. The outcome assessment must be made after a period of time the AT solution has been introduced, so that the person's "system" (including personal, family, occupational and environmental factors) has reached a new balanced situation [11].

Published studies concerning the application of outcome measures following prosthetic interventions relate to small samples of users and specific AT classes.

2 Method

2.1 Literature review

Starting from the seminal work published by Gelderblom in 2002 [12] and Fuhrer in 2003 [9], a systematic review was carried out of the scientific papers published in the following years on AT outcome measurement. The objective was to identify instruments for the measure of outcome of individual AT interventions, applicable to any kind of assistive products. 53 papers were identified and reviewed, overall describing 86 instruments: 37 were found to be related to the outcome of the whole rehabilitation process rather than to AT purposely, 41 were restricted to specific categories of AT products. Only five were found to be applicable to any AT products: **FIATS** [13], **IPPA** [14], **PIADS** [15], **QUEST** [16], and **SCAI** [17]. In addition, three further measures were found that can add useful information on the quality of the AT intervention (**KWAZO** [18], **SATS** [19]) and the individual predisposition to AT use (**ATD-PA** [20]).

2.2 Participants

The study involved eight rehabilitation Centres, located in various Italian regions. Each Centre has an AT assessment unit (SIVA) staffed with therapists with expertise on AT and supported by a central bioengineering unit specializing in ICT assistive technology (SIVALab). 23 professionals were involved as experimenters in the study, including medical doctors (physiatrists), physiotherapists, occupational therapists, speech therapists and biomedical engineers.

Each Centre was asked to consecutively enroll - among the served population - a number of clients who underwent AT interventions and for whom the assessment process was reported using the template for tracking AT interventions. No limitations were established in relation to age, gender or pathology. The only requirement was the need of significant AT interventions addressing heavy restrictions in one or more of the following areas: communication (ICF d3), mobility (ICF d4), self care (ICF d5) and domestic life (ICF d6). Only users who signed informed consent were included. Overall, the outcome of the interventions was measured for 34 patients and interviews started after receiving clearance by the Ethical Committee.

2.3 Materials

The template for tracking the individual AT intervention was based on international literature analysis, experience of previous projects and consultation with all professionals involved in the study. It was shaped as a fillable-PDF file, developed by means of a commercially available software (Adobe LiveCycle Designer©) in such a way to make data extraction possible for aggregate processing (first in XML and in turn imported to MS Excel © file according to purposely-defined schemas).

The template was composed of five sections: 1) contact data, 2) Assessment Report, 3) Verification Report, 4) Follow-up Report, and 5) statistical data.

The Verification and Follow-up sections included three of the outcome measurement instruments resulting from the described literature review; this choice was a compromise between the need to investigate as much outcome dimensions as possible and the need to ensure sustainability in clinical practice:

- **KWAZO** ("Kwaliteit van Zorg" i.e. "Quality in care") measures the user's satisfaction with the assessment and provision process; it consists of seven items (accessibility, information, coordination, competence, efficiency, user

influence, instructions), each to be rated 1 ("unsatisfied") to 5 ("very satisfied"). It must be administered at Verification.

- **IPPA** (Individual Prioritized Problems Assessment) measures the perceived effectiveness, based on seven self-defined "problems" which the user expects to solve thanks to the new assistive solution. At Verification, the user is asked to rate 1 to 5 ("not really important" to "very important") the importance of each problem ("*how much is it important to solve this problem for you, in your life*") and the difficulty experienced (1 to 5 i.e. "none" to "insurmountable") with that problem ("*how difficult is it for you now, before having the new assistive solution*"). At Follow-up, the question about difficulty is administered again ("*how would you score the difficulty you have with that problem now, with the new AT solution*"). The difference between the first-interview overall score (IPPA1) and the second-interview overall score (IPPA2) returns the IPPA indicator.
- **QUEST 2.0** (Quebec User Evaluation of Satisfaction with AT) - to be administered at Follow-up - measures the user satisfaction with each product (8 items) and the related services (4 items); each item is rated 1 to 5 ("totally unsatisfied" to "very satisfied").

The Verification report is structured as follows.

- Inventory of assistive products acquired and environmental adaptations actually carried out, for each item: short description, supplier, ISO assistive product code, brand, model, link to the product record in the national assistive products database, purchase price, amount paid by the user in case the funding body could not pay for all the price
- Remarks on the quality of the provision (as observed by the verificator)
- Possible difficulties experienced (as reported by the user and/or the caregiver)
- KWAZO questionnaire on the quality of the provision process
- IPPA1 questionnaire on the expectations with the new AT solution

The Follow-up Report is structured as follows:

- Inventory of assistive products and environmental adaptations in use (for each item: months of actual use so far; average hours/week of use, either independently or with human assistance; number of critical events, if any; cost incurred for maintenance / management / repairs); amount paid by the user, if any; overall user's and caregiver's satisfaction (1 to 5 i.e. "totally unsatisfied" to "very satisfied")
- Observation of the equipment while in use (by the inspector)
- Possible difficulties experienced (as reported by the user and/or the caregiver)
- IPPA2 questionnaire on perceived effectiveness (IPPA score)
- QUEST questionnaire of satisfaction with each AT product

2.4 Procedure

The Verification and Follow-up phases were carried out by the professionals of the SIVA units coordinated and supported by the principal investigator, with 34 participants (aged 5 to 83, average 44,9, median 46,5), respectively after the assistive solution was acquired, and after 3 months of use. For participants having a primary caregiver, the outcome measurement instruments were administered also to their caregiver, or only to the caregiver in case of inability to understand the questions. In both cases, the caregivers were asked to express their personal view, not to guess the participant's view.

3 Results

The assistive solutions actually acquired were related to mobility (56%), communication (15%), domestic life (10%) and personal care (7%). The distribution of the categories of AT products among the sample reflects that of the entire population of users who undergo AT interventions within the SIVA centers. All participants had assistive solutions composed of more than one assistive product (103 products, for 34 people). The most recurring devices were seating units (n=23), manual wheelchairs (n=20) and powered wheelchairs (n=10); other categories of products were pressure-sores prevention aids, walkers, lower limb prostheses, communicators, communication software, computer access peripherals and stair climbers (see Fig. 1).

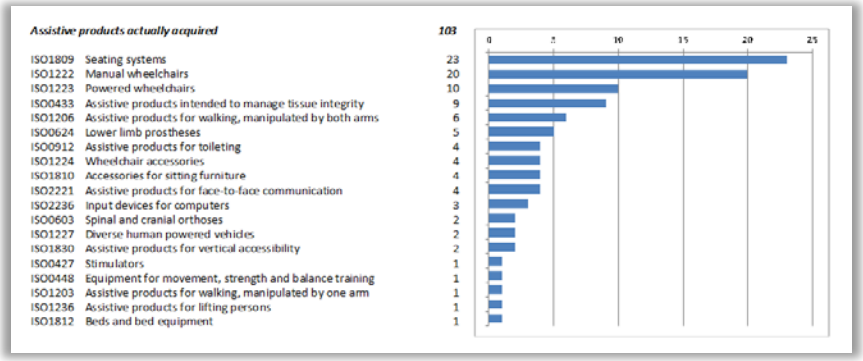

Figure 1: Assistive products actually acquired by the participants in the study

The overall purchase price of the solutions acquired ranged from no cost (solutions composed of free software) to very high cost (70.314 €), with 6.041 € as average. In most cases the assistive solution was totally reimbursed by the National Health Service (NHS). However, 11 users had to contribute partly or totally out of their pocket (seven over 5.000 €), as some devices were not eligible for NHS provision.

Overall, KWAZO revealed high satisfaction with the quality of the service (average score: 4,63 by users, 4,60 by caregivers) provided by the different subjects (such as AT evaluation centers, AT providers, financing authorities) involved in the provision process; only 3 users and 3 caregivers expressed scores lower than 4, due to a perceived unsatisfactory coordination among all professionals involved.

IPPA indicated that the interventions were in most cases effective (average scores +4,79 by users, +6,64 by caregivers), in other words they brought about a positive change in the person's life in relation to the problems indicated by each respondent. However, in two cases IPPA was negative (-6,14 by a user, -0,83 by a caregiver) and in other two cases it was null, which raised the question as whether the assistive solution had damaged the person's life or any unforeseen external circumstances had made the assistive solution ineffective: in both cases a worsening of the clinical status had occurred, which required re-assessment.

These results are shown in Table 2, which indicates, for each user, the assistive solution acquired, its overall purchase price, the user's and/or the caregiver's IPPA scores. The table is sorted in descending IPPA score (IPPA1-IPPA2, IPPA1: first interview at Verification; IPPA2: second interview at Follow-up), the last column represents the average between the user's and the caregiver's IPPA scores.

Table 2 – AT solution, cost and IPPA scores

Age	Sex	Assistive Solution	Total price	IPPA user	IPPA caregiver	IPPA aver.
34	M	Highchair, seating system	4.165		20,00	20,00
45	M	Wheelchair, home adaptations	16.100		15,00	15,00
43	M	Pw.wheelchair, home adaptations	70.314	11,87		11,87
71	F	Wheelchair, seating system	1.635	11,00		11,00
20	M	Spinal orthosis	636		10,00	10,00
21	M	Symbolic communication device	1.560		10,00	10,00
67	F	Pw wheelchair, seating system	4.694	9,38		9,38
12	F	Highchair, wheelchair, seating unit	5.041		9,29	9,29
5	M	Tilting wheelchair, seating system	4.567		8,86	8,86
8	F	Wheelchair	1.882		8,67	8,67
49	F	Pw.wheelchair, seating system	4.506	8,31		8,31
70	M	Pw.wheelchair (tilting, adj.backrest)	3.000	8,29		8,29
33	F	Symbolic communication device	2.236		8,00	8,00
42	M	Wheelchair, seating system, ramp	2.270	0,10	15,50	7,80
55	M	Trackball, access interfaces	286	7,33		7,33
74	M	Manual wheelchair, cushion, tripod	1.221	6,29		6,29
68	F	Pw.wheelchair, seating system	11.641		4,86	4,86
61	F	One side drive wheelchair, cushion	500	3,87	5,83	4,85
38	M	Wheelchair, seating system	1.601	11,45	-2,00	4,73
11	M	Wheelchair, seating system	3.452	4,71		4,71
66	F	Electronic knee, walker	13.353	3,86		3,86
73	F	Leg prosthesis, wheelchair, walker	6.170	3,29		3,29
34	F	Pw.wheelchair, seating system	4.945	3,29		3,29
58	M	Leg prosthesis, wheelchair, walker	4.151		3,14	3,14
83	F	Powered wheelchair, seating system	3.145	3,00		3,00
60	M	Functional electrical stimulator	400	2,43		2,43
24	F	Walker	2.028		2,40	2,40
48	M	Walker, I-phone vocal assistant	74	1,71	0,83	1,27
45	F	Hip prosthesis, wheelchair	9.770	1,14		1,14
66	M	Wheelchair, seating system, hoist	2.921	0,57		0,57
12	M	Tablet PC, communication software	1.231		0,00	0,00
53	F	Highchair, seating system	0		0,00	0,00
7	F	Folding pushchair, seating system	1.089		-0,83	-0,83
71	M	Pw.wheelchair, home adaptations	14.804	-6,14		-6,14
		Average >>	6.041	4,79	6,64	

QUEST indicated high satisfaction with most devices acquired, by either users (average product score 4,46, average service score 4,49) or caregivers (average product score 4,62, average service score 4,58). Only one product was judged totally unsatisfactory.

4 Discussion

The project led to a set of outcome measures applicable in clinical practice and to the first set of outcome data ever available in our Institution for actual use in clinical practice. Now the method is being implemented in the daily routine of all rehabilitation centres of the Institution.

KWAZO proved useful to capture the user's perception about the quality of the process. Possible low scores related to any of the eight indicators help identify and correct possible inconsistencies that may occur when several professionals, departments of agencies are involved in the process.

IPPA proved useful to describe the perceived effectiveness of the AT solution provided; negative IPPA scores are clear alerts that the user needs to be contacted again to check what happened and - if possible - undertake corrective interventions; near-to-zero (<1) IPPA scores also suggest to check whether the assistive solution has proved ineffective or brought about positive effects in relation to some problems and negative effects in relation to others.

Likewise, possible low **QUEST** scores (<3) alert that the related products had critical problems and corrective actions may be required, in order to increase the assistive solution effectiveness.

4.1 Study limitations

Due to organizational reasons (the recruitment of participants was possible only among the patients accessing the AT services within a limited time window), the inclusion criteria had to be necessarily broad, in terms of either clinical conditions or assistive solutions. The data gathered in the study so far are not yet sufficient to infer relations among the person's clinical-functional status, the assistive products, their effectiveness and their costs.

5 Conclusions

Despite the above-mentioned limitations, the Study was able to develop and fine-tune a sustainable method that allows measuring AT interventions outcome in a standardized manner. The interventions tracking system is being implemented in centres' information system. Research involving higher-level analysis will be possible as the database gradually grows.

The method also allows to easily detect possible critical events that may compromise the effectiveness of the assistive solution, and to understand which corrective actions are needed in those cases. As a matter of fact, looking after the client along the whole intervention is of paramount importance, as many unexpected events may happen for which the user needs help.

AT interventions outcome measures are instruments of significant importance to higher the appropriateness of interventions themselves and necessary to demonstrate their positive impact.

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