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Assistive technologies for children with cognitive and/or motor disabilities: a diagnosis of the training needs of informal caregivers

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Abstract - Assistive technologies promote communication, personal independence as well as the inclusion of children with cognitive or motor disabilities. Despite the human and material resources available, the implementation of assistive technologies in many family settings is still a struggling task. With the present study we seek to survey information and training needs of informal caregivers related to the use of assistive technologies at home, so as to, in the near future, try to meet them. Therefore, we are conducting a focus group on that topic with therapists, special education teachers and an educational psychologist and analyzing the content of the discussion. The data gives a perspective on (i) how thorough informal caregivers' knowledge of what assistive technologies and their advantages are, (ii) difficulties reported by informal caregivers when using them with their children, (iii) reasons that may lead them to the abandonment of assistive technology devices, (iv) how they can develop their skills and use the technology more effectively and (v) how information on assistive technologies can be made available to them. Therefore, the full aim of this research is to contribute to reducing technology abandonment and to enhancing its use in the family setting by children with cognitive and/or motor limitations. Some preliminary results are put forward.

Keywords - Assistive technologies; cognitive and motor disabilities; informal caregivers; family setting; focus group.

I. INTRODUCTION

This study places a strong focus on the importance of using assistive technologies (AT) to promote the global development of students with disabilities at cognitive and/or motor level. Moreover, it is intended to reflect on the factors leading to the technology dropout by the users, a phenomenon named in the literature as *assistive technology abandonment* [1]–[3]. This abandonment of AT devices is a worldwide, worrying reality. This is widely documented in the literature, where it is strongly sustained the need for improved research on the theme of AT use in the family setting.

Within an action research methodology, our aim is to study that specific context and intervene with the purpose of instilling change and improvement in the practices and therefore contributing to reducing the problem of technology abandonment. In this manner the first step is to diagnose information and training needs of the informal caregivers. The present study is intended to answer one of the sub questions of the main research: What are the training needs of informal caregivers to enhance the use of AT? Therefore, our objective is to identify the training needs of informal caregivers of children with cognitive and/or motor limitations who use AT. Informal caregivers are said to be the parents, siblings, grandparents, nannies, maids, that is to say everyone likely to interact with the student at home.

To achieve our objective, as an initial step we have conducted a focus group with education and rehabilitation professionals. The qualitative analysis of the data gathered will contribute to a proposal of improvement of practices namely a parental training project on the use of AT, to be implemented throughout 2019.

The literature review in this paper focuses on AT and the tendency to abandon it. The methodology section clarifies the nature of this study, its planning, data gathering techniques and instruments. Finally, there is a description of the results achieved with the focus group and some conclusions are withdrawn.

II. CONTEXTUALIZATION AND METHODOLOGY

A. State of the art

The social movements in the second half of the XX century made society more aware of the needs of people with disabilities. The awareness that the latter can actively participate in society with devices to help them fulfil their daily tasks led to the emergence of assistive technologies [4]. These researchers stress that AT refers not only to the devices chosen on the grounds of the previous evaluation of the user's needs, but also on the importance to provide training on the device, technical support, planning an intervention and assessing it [4].

There is an emphasis on the functional skills of disabled students and on the importance of using appropriate strategies and abilities likely to lead to successful fulfilling of activities in different contexts [5]. Therefore, AT refers to a set of devices, services, strategies and practices designed and applied to reduce the limitations faced by disabled people, to improve their functionality and quality of life, enhancing their autonomy in everyday tasks and active participation in society [4], [6]. The World Report on Disability [7] describes several practical examples that if AT are adjusted to the user and his/her environment, they are likely to be powerful tools to increase independence and improve participation. In fact, AT can help in oral and written communication, reading, seeing, hearing and mobility, since there is a wide variety of devices to compensate for all types of limitations.

It is important to stress the idea that each user is unique in his/her needs so, when selecting an AT device, it is essential to assess his/her functional, physical, cognitive and sensorial abilities, identify the activities and the context where they will be performed [6].

The students addressed in this study will be children with cognitive/intellectual limitations, described in the literature as individuals whose intellectual performance and adaptive behavior causes them to face global problems in academic and social learning [8], [9]. We have also included children with motor limitations, whose physical skills have been altered, causing them exhibit manual or mobility incapacities [8], [9]. Both populations tend to have communication constraints, which is particularly important in view of their functional limitations, and the advantages of applying communication strategies supported by AT. Nonetheless, the success of an alternative and augmentative communication system largely depends on the involvement of parents or other informal caregivers. Therefore, it is important not to restrict the use of a communication system to the school or the therapeutic setting, but to create opportunities that allow its use at home [10]. Indeed, it is vital to include the child's family in the process, since it is the main vehicle to have the AT device transposed to other more regular and lasting contexts of life [11]. The literature places strong emphasis on the relevance of the family setting to enhance the use of AT by children with limitations.

Users´ tendency to quit using AT is a reality widely felt by teachers, rehabilitation technicians and health professionals. It is important to understand the motivations behind the user's decision to reach for AT, since that may help teachers and rehabilitation professionals to design and implement effective interventions against AT abandonment [12]. Some factors are said to be related to acceptance or rejection of AT devices: not taking into consideration the user´s opinion when selecting the AT; low performance of the device; changes in the user's needs and priorities [13]. Results in these researchers' study pointed to the need to reinforce the user's involvement and identify his/her needs in the long term, so as to increase satisfaction and reduce abandonment [13].

Therefore, Brotherson, Cook and Parette suggested creating a parental training program to promote the use of AT [14]. One must bear in mind that the family setting is the children's first and main learning environment and it contributes decisively to developing skills. Besides, considering the family culture, resources and family interactions is essential for a successful introduction of AT at home [14]. The state of the art in this field of research reveals that despite the fact that the need to invest in the family setting is mentioned in the literature, in Portugal there are no validated parental training programs for AT use at home. At an international level it is possible to find "Assistive Technology – a parent's guide" which specifically focuses on AT for individuals with learning limitations [15]. The "Assistive Technology – Pointers for parents" addressed to parents and informal caregivers, published by the Wyoming Institute for Disabilities, provides practical advice for parents to enable them to actively participate in the process [16].

B. Nature of the investigation

This is an exploratory, descriptive study, with a qualitative approach. Such approach explores the characteristics of individuals and situations, placing emphasis on processes and meanings that are neither measurable nor experimentally examinable [17], [18]. It is our goal to get a comprehensive and holistic understanding of the problem in its historical, socioeconomic and cultural background and interpret it through an inferential and inductive process [17]. Indeed, in a qualitative approach, the focus is on the process, since the purpose is to understand, interpret and find meanings [19].

The main investigation qualifies as action-research, for the investigator has a participative role and aims at gaining knowledge to understand the context and intervene with the final purpose of contributing to solve a problem. The nature of this research follows an inductive model but aims to go beyond the descriptive level [20]. In this case, there is the need to study the family setting and intervene so as to instill change and improve practices. So, the purpose is to identify the training needs of informal caregivers and to develop, make available and evaluate a training program validated and adjusted to their needs.

Given the research questions, the objectives to be accomplished and the qualitative and descriptive methodology, this study fits in the interpretative paradigm, also known as naturalist or qualitative [20].

Since the critical dimension of action research methodology is to solve problems diagnosed in specific situations, in this case the lack of skills of informal caregivers to use AT in the family setting, it involves changes in people and institutions aiming at better living conditions and full participation of all [21]. In this case the aim is to introduce change in the context and in the participants, addressing the needs identified and improving the interactions between the informal caregivers and the children using AT.

C. Planning of the investigation

In the first step, based on the literature review on this subject, we have conducted a survey of the training needs, limitations and resources of the informal caregivers of children who use assistive technology. The final aim is to conceive and implement a parental training program and reflect on its results. The methodological steps of this investigation project are described next.

The decision to hold a focus group relies on two identifying characteristics of this technique of data gathering: the interactions arising inside the group are the main source of information or data collection, and this method focuses on a specific topic about which participants have experience or knowledge [20].

The focus group technique is commonly used in qualitative studies [22], [23]. The possibility to watch a large quantity of interactions and to gather a large amount of data about a theme in a short period of time are said to be the main advantages of holding a focus group [24]–[26]. Moreover, the data is directly targeted to the researchers´ interests. On the other hand, the fact that a focus group is driven by the researcher´s interests may pose as a weakness of this data collecting method because there is the concern that the moderator will influence the group´s interactions so as to maintain the interview´s focus [24]. Besides speech itself, non-verbal behaviors of the participants (tone, gestures, emotion) can also provide relevant data in a focus group [27]. In this particular study, data transcription comprised mostly linguistic features, even though some participants´ gestures were registered, mostly to reinforce their answers.

The purpose of this focus group was to explore the perceptions, experience and meanings that different professionals have on AT knowledge of users' parents. The first phase consisted in determining the purpose of the focus group interview, selecting an appropriate sample and draw up a script/guideline. The concepts or questions to be investigated were previously defined and clarified since these would determine the participants' selection, the kind of questions to ask during the session and the type of analysis to carry out afterwards [22].

Sampling is said to be a major key to the success of focus groups [24]. These participants were brought together because the topics are closely related to their professional experience. Another important point is the homogeneity of the group elements (being in touch with children with cognitive and/or motor disabilities) which fosters the integration of the participants within the group, but there should be some variation allowing contrasting opinions. The decision as to the number of participants in the focus group depends on the objectives predefined for the study. So, based on the review of the literature [20], [22], [27], [28] we decided to include six participants. Therefore, we have selected different professionals: two teachers, three therapists and a psychologist [28].

Carrying out this focus group required the previous elaboration and validation of a script/guideline containing open questions, using plain language and encouraging lines of thought besides those initially planned [22]. During the discussion, participants were stimulated to spontaneously share their personal experience, ideas and feelings in an open atmosphere. The role of the moderator was essential to conduct the focus group: posing the questions, keeping the discussion flowing and enabling group members to participate fully [22], [23]. The researcher acted as the moderator in this focus group, being well aware of the dynamics so as not to bias the interventions, either consciously or unconsciously. Indeed, the fact that focus groups are driven by the researcher´s interests raises the concern that the interviewer will influence the group´s interactions [28]. The moderator of this focus group directed the discussion and encouraged interaction in a non-threatening, emphatic atmosphere. Therefore, the discussion took place in a comfortable and ensuring classroom environment at the University, without noise or other inhibitors of communication.

Besides the importance of the quality of the personal relationship between the researcher and the focus group members, there are important aspects concerning validity, reliability and ethics. There was careful attention to ethical issues during the process: participants were informed of the purpose of the study, gave their informed consent including permission for video recording and were made aware of the need to maintain confidentiality about the content of the session [23], [27], [29].

This focus group session took place on 11th January 2019, lasted for about 90 minutes and was video recorded. Afterwards, the transcription of the discussions was sent to the participants so that they could check, correct or confirm their contribution to the discussion. This procedure of sending the text to the participants for validation is a way to ensure the desired quality of the study [20].

The following step was the analysis and interpretation of the data content. We adopted the content analysis technique within the methodologies in social research [30]. Content analysis allows progress in capturing the meaning of the discourse through its classification in categories and subcategories and coding. The coding process respected the fundamental rules: exclusivity, homogeneity, pertinence, objectivity, completeness and productivity [17]. This procedure was validated by two external researchers so as to ensure the reliability of the analysis [26]. The procedure was supported by webQDA, a web-based software aimed at researchers who need to analyze qualitative data (either text, image, video or audio sources) individually or collaboratively.

Given the main research question (How to promote the use of assistive technology in the family setting) and the literature review, the following dimensions of analysis were defined: (i) skills of the informal caregivers and contexts of AT usage, (ii) obstacles to the use of AT in the family setting, and (iii) training needs of the informal caregivers.

The theoretical framework or the state of the art also allowed us to define six a priori categories of analysis: (i) knowledge of informal caregivers about AT and its advantages, (ii) reasons for giving continuity to the training at home, (iii) difficulties faced by informal caregivers in using AT, (iv) reasons for AT abandonment, (v) requirements for a better use of AT by informal caregivers, and (vi) training informal caregivers on AT.

The following step consisted in repeated and active reading of the data corpus (the written transcription of the focus group) and deciding on the unit of analysis [23], [30]. In this case, the unit of analysis ranged from parts of sentences to whole sentences. Thereafter, a careful and active reading allowed us to define the empirical/inferential sub-categories of analysis shown in table I [17]. Thereafter we proceeded with the coding of the text references into these categories and subcategories.

TABLE I. INTERNAL CONSISTENCY OF THE ANALYSIS

Categories	Sub-categories
Knowledge of informal caregivers about AT and its advantages	Lack of knowledge
	Partial knowledge
	Technologies known by informal caregivers
Reasons for giving continuity to the training at home	Involvement and responsibility of all interveners
	Widespread use of AT in all contexts
	Motivation and awareness of the advantages
Difficulties faced by informal caregivers in using AT	Delay in obtaining results
	Personal limitations and/or self-indulgence
	Material and technical limitations
	Time constraints
Reasons for abandoning AT in the home setting	Lack of material conditions
	Shortage of time
	Lack of articulation between professionals
	Unawareness of the need to use AT
Requirements for a better use of AT by informal caregivers	Articulation
	Information search to meet specific needs
	Ease and desire to search for information
	Better research and access to information
	Encouragement and advice by professionals
	Ways to make information available
	Training
Training informal caregivers on AT	Setting
	Schedule
	Method

III. DESCRIPTION OF RESULTS

Within the first dimension of analysis, in order to assess the skills of the informal caregivers in using AT and the context of usage, the focus group participants were asked if informal caregivers know what AT are, why they should be used, which AT devices they would be able to identify and indicate their purpose. Their answers allowed us to create two categories of analysis: lack of knowledge and partial knowledge. The majority of the references coded in this category (68%) point towards lack of knowledge. It is said that "*most of them don't know what AT is, their lack of knowledge", "they find it hard to understand", "they probably don't know", "they aren't aware of the functions", "they are completely unfamiliar with it"*. Only 22% of the references refer to partial knowledge in terms of "*at least they have got some idea of what it is", "perhaps they are starting to realize", "they are already familiar with some things"*.

Concerning the next category - AT devices known by informal caregivers - participants mentioned that parents are usually acquainted with technologies for mobility and daily life activities, that is to say, that compensate for immediate difficulties/needs. They also mention a growing familiarity with augmentative and alternative communication aids on tablets or computers, even though other informal caregivers are only familiar with communication tables without the multimedia resource.

As far as the next category is concerned, based on the common group opinion that teachers and therapists shouldn't be the only ones training the use of AT devices, some justifications are presented in favor of giving continuity to the training at home. An analysis of the references allowed us to divide the reasons into three subcategories as shown in table 1.

The most frequently referred subcategory - Involvement and responsibility of all interveners - applies to the need to involve and assign responsibility to everyone who interacts with the child (teachers, therapists, relatives, tutors). This idea is evident in references such as *"parents must give continuity to the training at home", "it should be shared responsibility", "the family should be part of the training", "for the family spends long regular periods of time with the child"*.

The second most addressed reason for using AT in the family setting - Widespread use of AT in all contexts – is justified by the advantages of using AT not only at school or in therapy but also at home, because, as the focus group argues, *"it is designed for functionality at school, at home and in other life contexts", "at home there are also communication needs, not just at school", "besides, there are routines that only happen at home", "it is important to embed the use in their daily routines at home too"*.

The third reason - Motivation and awareness of the advantages – is justified with the fact that giving continuity to the training of AT at home makes the child more motivated to use it and aware of its advantages, as the focus group outlined: *"make the child feel that using the AT device will facilitate her life", "it aims for the autonomy of both the child and the parents"*.

As to the difficulties faced by informal caregivers in using AT, the references codified in this category point mostly to the delay in obtaining results since training a skill using an AT device sometimes takes a long time to produce results, because, as the focus group stresses, *"these children take their time to give some kind of response", "it takes a long time", "often the results are not immediate", "the search for the most immediate"*.

To address situations deriving from caregivers´ lack of digital literacy to solve technical problems or their lack of proactivity to seek specialized support, we created the subcategory Personal limitations and/or self-indulgence. As far as personal limitations are concerned, it is mentioned in references that *"there's a lot of people who still don't have skills to use a computer", "aren't used to using a computer", "they don't know how to access and how to help", "sometimes it is hard for them to use devices and figure out how to do it"*. On the other hand, the above mentioned self-indulgence or lack of proactivity is evident in references such as *"There is free software and they don't use it", "they have access to technology and don't use it", "Even if they have technicians available, they don't address them", "there are training sessions and few parents attend", "Parents can come and ask us for training but very few do"*.

Another limitation mentioned by informal caregivers, though with less references, has to do with time constraints. Their work schedule, their children's therapies and the household tasks leave them little or no time available, as shown in these references: *"families have such time restraints", "lack of time available", "it is complicated because it takes time"*. Informal caregivers´ difficulties in using AT are also noticeable in situations where they lack material resources, technical issues, e.g. internet connection, lack of technical support. This subcategory – material and technical limitations – is the less referenced. Nevertheless, it is referenced that *"there are children who haven't got a computer at home", "who don't have internet"*. Portability is also said to be an issue, even though not as much as in the past: *"they say laptops are not that easy because you have to take them out of the bag, put them on the table, open and close them, and there are often updates running"*. Nevertheless, it is stressed as very positive that *"from the moment the app for tablet and smartphone was made available, it came up as a huge help"*. It should be noted that the subcategories "Time constraints" and "Material & technical limitations" are the ones with the least references, which is in line with the results in the data regarding reasons for abandoning AT in the home setting.

Indeed, the second most mentioned reason for AT abandonment - Lack of articulation between professionals – is a subcategory concerning situations deriving from the absence of communication between teachers and therapists. This often results in a gap between the AT used by the children and his/her real needs, which is illustrated in references such as: *"the lack of communication between professionals", "there are no moments together to reflect", "in my practice I see communication tables that don't exactly meet that child's needs", "there is a gap here because implementation should have been done differently"*. And the most mentioned category - Unawareness of the need to use AT – refers to lack of motivation to use AT as a result of not realizing the need to use the AT device. In this regard there are references such as *"the matter of realizing the need of that technology", "it is as if they don't understand the need to use it", "the children themselves abandon it if they don't feel the need"*.

In the next category - Requirements for a better use of AT by informal caregivers -, the focus group stressed once more the need of articulation between all participants to enhance the use of AT devices. This is clear in references such as *"to be a job well-done it has to be articulated", "to have everyone present and reflect, to reassess the implementation", "in these meetings one could talk and pose doubts", "in an articulated way, to have specific answers for each student"*.

The focus group also reinforced the need for more information on AT. In that sense, Caregivers´ motivation to search for information that meets their needs, in order to solve practical problems of their child, is a subcategory visible in these references: "*It is according to their child's needs that they learn", "as the needs come up, they go on searching", "these parents´ knowledge is closely related to the needs that occur", "most of them need very practical, useful information"*. In this regard, the subcategory "Ease and desire to search for information" seems important to us, for there are parents who take the initiative to seek for information and do it easily, as revealed in some references: *"I have also met some parents who research on their own initiative", "there are parents who are eager for knowledge and like to search for information online", "people who find it easy to access the internet and search"*. On the other hand, there is a significant number of references showing the difficulties faced by many informal caregivers in information search or in handling the information they find online or provided by the therapists. Therefore, in this subcategory - better research and access to information -, we coded references such as *"they have difficulty to access information, to search", "parents find it hard to access information and to search on their own", "I think it is too much information for them to manage", "they get lost in the information"*.

It is worth highlighting that many informal caregivers need to be encouraged and guided by the technicians in their search for information, so the subcategory "need of encouragement and advice by technicians" is also mentioned: *"many parents need to be encouraged, guided and encouraged", "they go on to investigate, read and try to understand through us and sometimes they even question", "they rely a lot on therapists and teachers"*. Questioned about how information on AT could be made available to informal caregivers, the focus group referred that these usually search online for information about similar cases in a local online forum and talk in blogs to other parents who have children with similar problems.

Training was also considered an essential condition to develop informal caregivers´ skills in using AT. So, the last category approached in the focus group regarded the method of training addressed to informal caregivers, namely where, when and how to conduct such training. In relation to the best location for parental training, all participants in this focus group indicated the home setting: *"preferably at home, in their environment, it would be the ideal for them", "in order to be a specific answer for that student", "only showing and working in the context and the parent seeing that the child actually gives feedback, will we be able to take advantage of AT"*. As to the preferential schedule for training addressed to informal caregivers, the general opinion of the group is that it should be at the end of the day, when parents are at home. However, some obstacles are pointed out as well, such as "*that will demand that a set of people are available at a certain place and time, which is not easy", "everything would be extra in terms of time", "there's a shortage of time available to make it possible"*.

As to the ideal method, the group was a clear advocate of face to face training rather than online: *"there are usually better results when we are face-to-face and not online"*. One of the possibilities mentioned was implementing mutual help groups with mediators, in which caregivers share information, experiences and difficulties. One participant suggested *"maybe even a parent could help train other parents by sharing his/her experience", "it is essential that they see how it works, that it is practical and beneficial for the whole family", "parents would see how it works, and realize that there is a way. That it is functional and there are children who use it", "Of course there would be a technician mediating the group"*. It is worth emphasizing the suggestion given in one of the references: *"I think it should be carried out in* *stages: first there would be training on how to implement it for the first time, then there would be an experimental period, then we would meet again, and parents would report the obstacles they faced".*

IV. CONCLUSION

There were clear advantages in conducting this focus group, for it gave important contributions to the diagnosis of the needs of informal caregivers who use AT. In terms of knowledge of what AT is and its purposes, informal caregivers are said to have a striking lack of knowledge on the subject. They are said to have only partial knowledge of AT, mostly devices aimed at mobility and daily life activities that address immediate needs. The general opinion that parents should use AT devices at home is mostly based on the need to involve and hold them responsible, but also to generalize their use in all life contexts and increase the motivation and awareness of their advantages. Nevertheless, the focus group reported some serious obstacles to AT usage by parents. The most striking is the delay in obtaining results, followed by parents´ personal limitations and some self-indulgence. Time/availability is also said to pose a problem and it is said to be one of the reasons for AT abandonment. But the most mentioned reasons are unawareness of the need to use AT and lack of articulation between professionals.

Articulation is said to be an essential requirement to improve the use of AT by informal caregivers, as well as information. The data stress the need to improve parental research skills and access to information. Training is also highlighted, and the home setting is said to be the best location for parental training, at the end of the day and in group, so that parents can share experiences and help each other.

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