

WHAT DO PEOPLE WITH DISABILITIES AND OLDER PEOPLE THINK ABOUT THE TRAINING OF THE PERSONAL CARE GIVERS? A TRANSNATIONAL STUDY

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ABSTRACT

The aim of this study is to investigate the profile of the Personal Care Givers (PCGs), for the preparation of the basic training curriculum, who are serving for the older people and the people with disabilities (PwD) among the selected European countries. A total of 276 questionnaires were completed by respondents living in Flanders (Belgium), Bulgaria, Germany and Turkey, online or during an interview/focus group. All the questionnaires were completed by the participants online in those EU countries who took part in this study. Concerning the demographics of the beneficiaries, there were respondents exceeded 75 years of age (34.8%) and there was equal representation of the two genders. The 67.0% of the respondents encountered motor disabilities, while 27.9% stated that they encountered problems with vision, 24.9% with hearing, 15% encounter intellectual disabilities and 19.3% suffer from chronic diseases. While most of the respondents (84%) need assistance at home, they also highlighted the need of assistance in the workplace, in education, as well as in vocational rehabilitation. 35% of the respondents stated that they need assistance in at community. The results are extremely encouraging for the development of the personal care giver (PCG) training curriculum and material, since people from target groups identified that the preferred methods for training cover all areas that the selected EU countries plan to address. Together with the training modules that are already in practice by vocational and educational training (VET) centers, which were identified during the desktop research, the research's results will work as a guide for the production of the study's outcomes.

Key words: Care giver, older people, disability

ENGELLİ VE YAŞLI KİŞİLER KİŞİSEL BAKIM VERENLERİN EĞİTİLMESİ İLE İLGİLİ NE DÜŞÜNÜRLER: ULUSLARARASI BİR ÇALIŞMA ÖZET

Bu çalışmanın amacı, seçilmiş Avrupa ülkelerinde kişisel bakım verenlerin (KBV) genel profilinin araştırılması ve hazırlanacak eğitim müfredatına temel oluşturmasıdır. Belçika, Bulgaristan, Almanya ve Türkiye'de yaşayan toplam 276 anket çevrimiçi veya yüz yüze olarak tamamlandı. Avrupa Birliği ülkelerindeki tüm anketler çevrimiçi olarak uygulandı. Yararlanıcıların demografik verilerine bakıldığında, 75 yaşını geçenlerin (%34,8) de yer aldığı ve her iki cinsiyetin eşit şekilde yer aldıkları görüldü. Cevap verenlerin %67,0'si fiziksel engelliysen, %27,9'u görme, 24,9'u işitme %15'i bilişsel ve %19,3'ü kronik hastalığa sahipti. Katılımcıların %84'ü evde bakıma ihtiyaç duyarken, birçoğunun iş ortamında, eğitim aldıkları yerlerde ve meşguliyet merkezlerinde yardıma ihtiyaçları olduğu tespit edildi. %35 katılımcı toplum içerisinde desteğe ihtiyacı olduğunu bildirdi. Ortaya çıkan sonuçlar, bakım verenlerin ihtiyaçlarını ortaya koyarak, seçilen Avrupa Birliği ülkelerinde geliştirilmesi gereken eğitim müfredatının içeriğinin belirlenmesinde çok önemli veriler ortaya koymuştur. Mesleki eğitim merkezlerinde hâlihazırda vergilemekte olan eğitimlerin değerlendirilmesine fırsat vererek önemli veriler ortaya koymuştur.

Anahtar kelimeler: Bakım veren, yaşlı, engel

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INTRODUCTION

The personal care givers (PCGs), provide basic health care and / or supports the work of the health care professionals in hospitals for further treatment (medical and rehabilitation facilities, specialized institutions for social services, medical and residential care) in the community (hospices for the terminally ill at home, in residential care for elderly people and homes for people with disabilities (PwDs). Care is provided to patients recovering from the acute stage of the disease, and people with disabilities in compliance with treatment plans prepared by medical professionals.

In their work, caregivers observe the rules of good practice and should follow prescription of the medical specialist or social worker to meet universal (basic) needs that are common to all and necessary to sustain life and health. Patient care should be aimed primarily at providing good physical and socio-psychological condition

An estimated 45 million people in Europe (15% of the EU population) have a long-standing health problem or disability (1). Seventy percent of them will be over 60 by 2020 (2). Elderly people and PwDs and especially those with mobility & sensory impairment depend considerably on PCGs. Personal assistance is in fact the key for the self-determination of PwDs (3,4).

European people with disabilities (especially those with mobility impairments) depend heavily on PCGs. While this assistance is crucial in ensuring a daily quality of life (assisting with basic tasks such as getting dressed, eating, taking a bath/shower), it is still quantitatively and qualitatively a huge problem (5,6). Few PCGs get a proper training, if any, while such formal training hardly exists in EU countries. Most PCGs are low skilled, have

to be trained on the field, thus making it a very laborious and at the same time a tricky “adventure” for people with disabilities, but equally for e.g. older people who make use of them (7-9).

Raising competence levels of these low-skilled people to be benefit of care recipients. This aim is at the core of this study. It aims to ensure that vocation and education centers (VET) centers can offer such training anywhere anytime, for low-skilled people (without jobs), or people that want to extend their service provision (independent nurses, caretakers, etc.). According to the competencies, it is proposed to prepare blended training approaches such as simulation both via video and animations, audio, textual training format, including hands-on practicing in to follow up of this study.

In this respect we have conducted an online survey and a state of the art analysis in order to identify the needs of the beneficiaries (PCGs, PwDs), to obtain a good perception of the need for adjustments in existing PCG training practices to enable the trainees and beneficiaries to achieve success, to define a set of learning activities appropriate to, and usable across, the range of user need, to gain familiarity with the nature and potential value of adjustments in training methods and in their learning strategies to meet their needs, to identify and highlight similarities and differences between national contexts in the selected countries. The survey questions are prepared according to the needs of the PCG training by a consensus of all partners. The selected countries are as follows; Flanders (Belgium), Bulgaria, Greece, Germany and Turkey. All the questions translated into the language of the partner countries.

In this paper, the research and analysis is of crucial importance as it provides for the (EU) countries with the information

needed in order for them to develop a basic curriculum for training the PCGs for the elderly and PwDs. A dedicated PCG curriculum and relevant training material for different disabilities (including those associated with aging), applicable in every country in the EU and beyond, provided under a creative commons and in accordance with transparency of qualifications and competences and ECVET; an innovative online and mobile training platform, with a gaming component that allow for an interactive learning experience anytime anywhere (PC, smart phone and tablet PC -both Android- based online learning platform/application), multilingual, and provided freely to everybody as well as the VET centers and stakeholders; piloting with end-users (low skilled people, care workers) and beneficiaries (PwDs and OP) in Flanders (Belgium), Bulgaria, Germany and Turkey. A portal that bring together relevant information and services on personal assistance, as well as host a community for PCG trainers, learners and beneficiaries will be prepared according to the result of the survey. This is the first and only study that reveals the current situation about PCGs in the selected EU countries.

MATERIAL AND METHOD

In order to address the goals of the training, a combination of methods was used. The main research instruments were the online questionnaires which were used to collect mostly quantitative data (10). These questionnaires also formed the basis for face to face/phone interviews, which mostly focused on qualitative data. The selected EU countries are also conducted desk research (11), collecting information about the current situation with PCG services in their countries. The participants are selected from the nursing homes and Daily care institutions who accepted to participate in the study. Written informed

consent has been obtained from each participant and the study done within the ethical standards of the Declaration of Helsinki.

A questionnaire was designed to be short (about 20 questions) with simple and clear questions for the PwDs and older people. The inclusion criteria was to have at least 24 points from mini mental test for the older people. The questionnaire was used as the main research instrument for this research. All the questionnaires were completed by the participants online in those EU countries who took part in this study. Some questions were open ended to reveal all the problems and to find out suitable solutions where possible at the end of the study.

The questionnaires were accessible mostly online (Survey Monkey was used), but taking into consideration that among the population, there are people with disabilities and OP who might encounter difficulties in accessing the survey, there were also alternative solutions, such as personal interviews, focus groups, etc.

Some questions were used to gather information of a personal nature and might be upsetting for some people. Therefore, they have been introduced very carefully in a later section of the questionnaire, in a way that does not discourage respondents at the beginning of the survey. Furthermore, the questions were grouped thematically in logical sections in order for the respondents to focus on their context and avoid misunderstandings. Five persons were responsible about the survey in every country. Face to face questionnaires were done by health care professionals in all countries.

The types of questions that were used were Multiple Choices: Questions that provide two or more specific responses from which respondents have to choose; Rating Scales

with 5 alternatives: Provide an indication of the respondent’s opinion on a statement; Open Ended questions: The responders were required to write their own answer or comment on the question.

RESULTS

A total of 276 questionnaires were completed by respondents living in Flanders (Belgium) (n: 70), Bulgaria (n: 54), Germany (n: 65) and Turkey (n: 87), online or during an interview/focus group. All questionnaires were available into the own language of the country. According to the responses the numbers of participants were 276 PwDs and older people. They consisted of people with mobility impairments, people with visual impairments, and people with hearing impairments, people with intellectual impairments, people with chronic diseases,

people with complex diseases and older people. The stakeholders consisted of 120 family members of PwDs or older people and 98 care centres, VET centres and employment centres that wanted to provide PCG training.

Their participation in the survey helped the partners to collect information on current PCG practices, on the needs of PwDs that need to be addressed by professionals and on the types of training that would be beneficial for PCGs. This will also identify the current situation with PCGs in each country, the qualifications for becoming a PCG and the different policies across the selected countries. Concerning the demographics of the beneficiaries, there were respondents exceeded 75 years of age (34.8%) and there was equal representation of the two genders (Figure 1-2).

Figure 1: Age of the participants

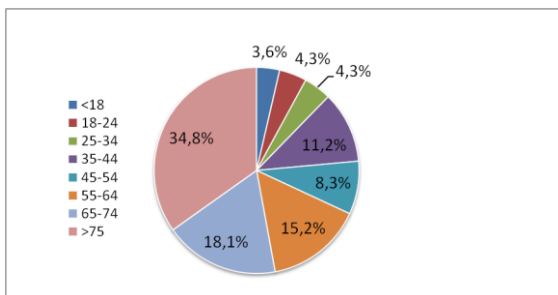
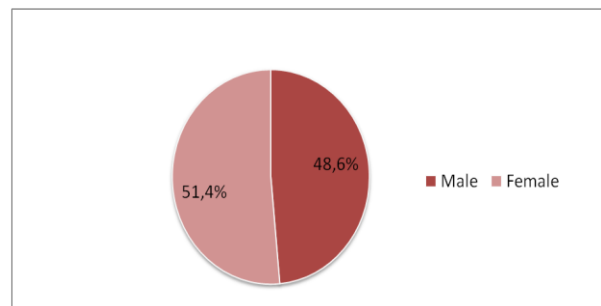


Figure 2: Gender of the participants

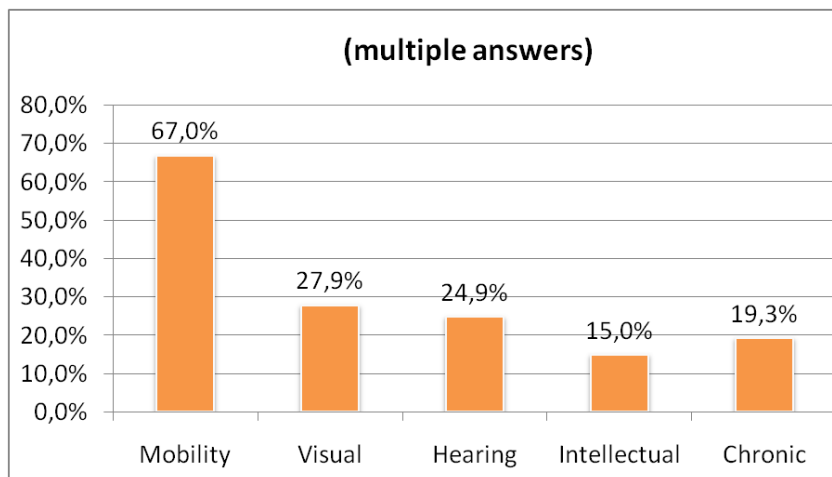


The 67.0% of the respondents encountered motor disabilities, while 27.9% stated that they encountered problems with vision, 24.9% with hearing, 15% encounter intellectual disabilities and 19.3% suffer from chronic diseases. Please note that the

respondents could provide more than one answer, if they encountered a combination of challenges, a so called “complex disability) (Figure 3). The respective rates in each country are indicated in the Table 1.

Table 1: Type of disabilities per country

	Flanders (Belgium)	Bulgaria	Germany	Turkey
Mobility	71.4%	39.3%	100%	61.3%
Visual	25.0%	7.1%	92.0%	20.7%
Hearing	7.1%	10.7%	92.0%	20.7%
Intellectual	3.6%	17.9%	16.0%	15.3%
Chronic	14.3%	10.7%	60.0%	12.0%

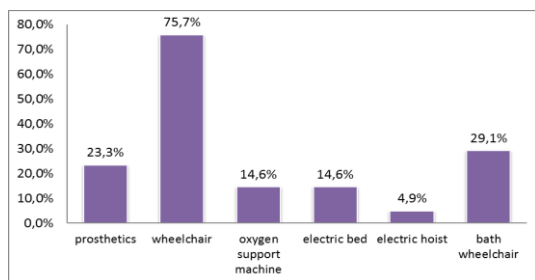
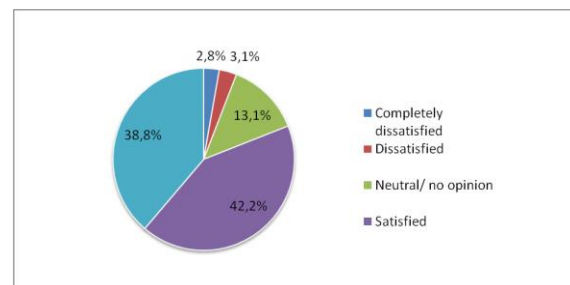
Figure 3: Types of the disabilities

While most of the respondents (84%) need assistance at home, they also highlighted the need of assistance in the workplace, in education, as well as in vocational rehabilitation. 35% of the respondents stated that they need assistance in the public space (Table 2). Some respondents noted the need for sign language support and assistance for reading information

online. Six out of ten respondents use some kind of technological support or/and assistance device (wheelchair 75%, bath wheelchair 29%, etc) (Figure 4). The aforementioned needs are addressed by professionals (59.1%) or family members (40.9%). On the other hand, in Germany 80% use professionals as care givers. In Flanders (Belgium) and Turkey the respective rate is 60% and in Bulgaria 58.3%.

Table 2: Areas of the assistance needed for the elderly and the PwDs

	Flanders (Belgium)	Bulgaria	Germany	Turkey
Home	61.9%	85.7%	100%	84.5%
Work	19.0%	21.4%	0.0%	6.1%
School	0.0%	28.6%	0.0%	7.4%
Public space	71.4%	85.7%	88.0%	40.5%

Figure 4: Support or/and assistance device used**Figure 5:** Satisfaction with PCG services

The survey respondents are in general satisfied with the PCG services they receive. In detail: 81% are either satisfied or completely satisfied, while 13.1% are neutral and 5.9% are dissatisfied/completely dissatisfied (Figure 5).

For Flanders (Belgium) the hours range from 2 hours per week up to full time care and the cost ranges from 15 Euros per week to 625 Euros. Some respondents did however indicate much higher amounts in other questions. For Bulgaria the hours range from 10-40 per week and the cost is between 50-150 Euros per week. For Germany, the cost ranges from 12 Euros (28%) up to 50 Euros (8%) per week. 28% say they cannot spend any amount. In

Turkey the cost ranges from 30 to 750 Turkish liras per week (10-260 Euros/week). It is important to note here that 48.8% of the respondents said that they need a 24h support / in house PCG.

As indicated by the respondents, most PCGs have completed basic education. Cases of PCGs that work as volunteers, without having completed mandatory education have also been reported. The 51.4% of the respondent state that they have not received any training related to providing assistance to PwDs and older people.

When asked about what type of extra training they would like their PCG to receive, the majority of the 219 (57 skipped the question) respondents (163)

selected basic psychological support. The second most popular option understood a disability (143) and third was practical approaches in daily care with examples

(140). The answers in detail are provided in the Table 3 (please note that respondents were able to indicate more than one option).

Table 3: Type of desired extra training areas

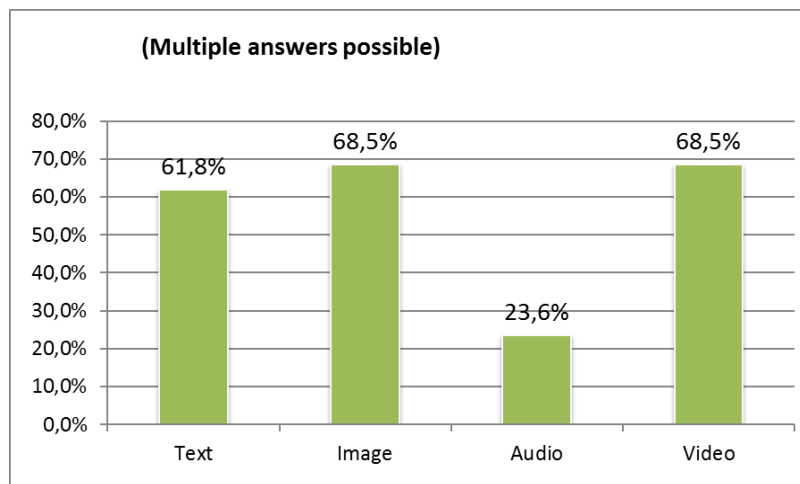
Answer Options	Flanders (Belgium)	Bulgaria	Germany	Turkey	Answers in English	Total
Basic psychological support	5	6	24	122	6	163
Understanding a disability	10	12	25	92	4	143
interpersonal communication skills	5	8	25	97	5	140
Practical approaches in daily care (examples)	11	8	25	64	4	112
Types of technical assistance devices	4	5	24	67	2	102
Examples on care per disability	5	9	25	57	2	98
Environmental challenges/accessibility issues	9	3	23	58	1	94

The 37% of PwDs and older people replied that their PCGs is not a member of the legal workforce (with social insurance, license, etc). This could indicate that they either use family members, volunteers, or employ a person unofficially. In more detail, the respective rate in each country is as follows: Flanders (Belgium); 33%, Bulgaria; 57%; Germany; 80% and Turkey; 27%.

When asked about their training preferences, PCGs are divided between a broad (50.6%) and a specific (49.4%) training program. Concerning the issues on which they would like to receive extra training is given at the Table 4. Most of the respondents seem to prefer a combined training provided by both online resources and face to face activities or using printed material. Some users stress the need for practical exercises as well (Figure 6).

Table 4: Type of training preferences

Answer Options	Flanders (Belgium)	Bulgaria	Germany	Turkey	Total
Practical approaches in daily care (examples)	3	19	25	18	65
Understanding a disability	2	16	26	18	62
Interpersonal communication skills	5	14	26	13	58
Examples on care per disability	3	18	24	12	57
Basic psychological support	7	1	25	18	51
Environmental challenges/accessibility issues	3	8	24	9	44
Types of technical assistance devices	6	8	0	15	29

Figure 6: Preferred course material format

DISCUSSION

Analysis of quantitative data and of the qualitative extracted information from the questionnaires/interviews, as well as desktop research findings provide the selected EU countries as well as the others, with a comprehensive description of the current PCG practices and the beneficiary's

needs. These data are of crucial importance for all EU countries. The results of the study show that, there is a need for establishing a standardised curriculum for PCGs serving for PwD and older people in EU countries.

A broad definition of a personal caregiver for people with disabilities and older

people could be that of the employed professional who addresses the needs of people who are in one or more ways incapable of personal care tasks (12). The PCG profession is formally described only in Bulgaria (among the selected countries). Therefore, there are a lot of different definitions given for the role in each country. There are differences concerning what a personal care giver can and cannot do, and his/her working conditions and the required training¹²).

In Flanders (Belgium) there is no special training necessary for a "personal assistant" to work. There is however a list of requirements (competences, skills, personal characteristics, and working conditions) that the Flemish employment agency expects from candidate PCGs, but these are merely recommendations. There is a personal assistance budget (PAB), part of which is used to pay the salary of a PCG. The PAB holder can employ personnel to perform a variety of tasks to assist in the organization of his / her daily life. A PCG cannot do activities that fall under "performing therapies" (13)

In Bulgaria the profession of PCG is formally described and graduation from a PCG VET course is required. The caregiver provides basic health care and/or supports the work of health care professionals in hospitals, in the community and/or at home. The services offered cover a wide range of activities (from assisting with mobility and hygiene to providing entertainment and emotional support), with the main goal of improving the patient's quality of life -always working under the guidance of doctors or health care specialists. Caring for the elderly, sick and disabled persons in the home environment is implemented under national and European projects (14).

A general legislative framework including all possible services (caring and nursing)

does not exist in Germany. There are rules of law or directives/requirements for each service or offer. PwD and OP people do not have to pay for the PCG services because the employment is financed by different state programs and implemented by social and VET institutes.

In Turkey, since 2005 all PwDs in need of care/whether they had social insurance or not- became entitled to benefit from care services. PwDs in need, without family and social insurance, are admitted to public or private care institutions or receive care services at home. The role of the personal caregiver is partially covered by the legislation for certified caregivers employed in public and private care institutions. According to it, their main responsibility is to provide services for PwDs following the individual prescribed care program (hygiene, nutrition, etc.), to provide psychological support and inform medical staff if necessary (15,16). The responses related to the hours that the beneficiaries need support are very varied and depend both on the type of assistance needed/severity of the case, as well as the country since policies e.g. in terms of reimbursement schemes are different across all partner countries.

The fact that the majority of PwDs and older people state that they encounter mobility problems is decisive for the interpretation of other results of the survey such as their major needs. For example, the needs related to the assistance of mobility are identified as very important by the respondents. The answers collected regarding the main needs of assistance (open-ended question) were varied and depended highly on the severity of the limitations. As indicated above, in accordance with the prevailing of motor disabilities among the sample the main needs of assistance reported included help with moving around, transportation, being

lifted in the house, sitting, carrying heavy things, receiving help when travelling.

Many respondents mentioned that they needed help with their personal hygiene, eating, grooming, toilet usage and getting dressed parallel with the results of the other studies (17-19). Some also needed basic nursing services. It was also noted by some respondents that they needed help with household activities, such as shopping, cooking, cleaning, taking care of pets and maintaining the garden. An important part of the needs indicated include those related to social activities and provision of emotional support (attending public events and meeting friends, assistance in self-service restaurants, providing emotional/social support services, providing memory workout).

While most of the respondents (84%) need assistance at home, they also highlighted the need of assistance in the workplace, in education, as well as in vocational rehabilitation. The 35% of the respondents stated that they need assistance in the public space. Some respondents noted the need for sign language support and assistance for reading information online. Six out of ten respondents use some kind of technological support or/and assistance device (wheelchair 75%, bath wheelchair 29%, etc).

It should also be noted that the use or not of a professional assistant depends highly on the type of needs that has to be addressed (if for a example a case is not very severe and therefore the needs of assistance are minor, one could chose not to employ a professional PCG) and on cultural differences as well (family relations / role in each society).

In Belgium, there is no uniform reply concerning the educational background of PCGs, as no formal education exists nor is required for them in Flanders. One

respondent replied that motivation and compassion/empathy are the most important, while care giving has to be adjusted to the needs of the cared for person. The educational backgrounds are very varied with an absolute minority having indicated there was a "carer training" (volunteers with no education, basic education, teacher (small children), and technical) (2). In Bulgaria, 28.57% of the beneficiaries stated that their PCG has completed higher education and the same rate occurred for secondary education as well. Another 28.57% is not aware of the PCG's educational background, while 14.29% say that the PCG has graduated from high school. Nearly all of the PCGs in Germany have a primary education graduation (9/10 grade). As for PCG specific training: 98% respondents answered that their PCG has no specific training or qualification. Nearly all of the respondents answered that there is a specific need in the asked qualification fields /extra training. In Turkey, there is a variety of responses ranging from primary education to vocational training and graduate degrees. The majority of PwDs and OP stated that their PCG has completed secondary or primary education. Also, 60% of the respondent said their PCG has received training related to providing assistance to PwD/OP.

As a conclusion, the results are extremely encouraging for the development of the PCG training curriculum and material, since people from target groups identified that the preferred methods for training cover all areas that the selected EU countries plan to address. Together with the training modules that are already in practice by VET centres, which were identified during the desktop research, the research's results will work as a guide for the production of the study's outcomes.

The limitation of this study is the heterogeneity of the people with

disabilities. In the future studies there should be more people with different disabilities to conclude their specific needs about care givers.

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