Original Article

Clinical and Epidemiological Profile of Patients and Sociodemographic Profile of Caregivers and Volunteers from the Greek Home Health Care Project «ΑΚΕΣΩ-Ι»

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Abstract

Background: The knowledge of the profile of home health care patients is required to ensure the optimal planning of the care provided, the best organization and management of home health care (HHC) services around one country.
Objective: The aim of this paper was to describe the demographic and clinical profile of users of HHC services in Greece, and the sociodemographic profile of the informal caregivers and the volunteers, during the "ΑΚΕΣΩ-Ι" project.
Methods & Materials: In this cross-sectional study the sample consisted of patients who received HHC services in 3 major cities in Greece during a 20-month period. Variables of the study were patients', caregivers' and volunteers' sociodemographic characteristics and patients' clinical characteristics.
Results: Patients were over 65 (80.71%) and female (68.37%). Nearly half of the patients (46.8%) received care for medical problems, and 83.82% were insured. The informal caregivers were female (93%), middle and older adults, had a Bachelor's degree, and 52% of them were employed. Half of the volunteers were older adults, females (91%), with secondary level of education (48%) and employed (50%).
Conclusions: This is the first study in Greece, which provides a population-based profile of the users' characteristics, and the profile of informal caregivers and volunteers of formal HHC services. The findings highlight a significant number of key changes in the organization and operation of HHC services which can motivate policy makers to make sound decisions.

Key words: ΑΚΕΣΩ-Ι project, home health care, home care, home health care patient, informal caregiver, volunteer, Greece

Abbreviations: HHC Home Health Care, PHC Primary Health Care, HRC Hellenic Red Cross

Introduction

The economic crisis that started in Greece in 2010 and continues to date has a negative impact on health and care. Studies noticed a decrease in health self-assessment (Zavras et al., 2016) and the trends in health (Vandoros et al., 2013), while showing increasing unmet needs of users (Kentikelenis et al., 2011) and deterioration of the access to healthcare services (Drydakis, 2015). Financial recession also affects negatively many dimensions of health and health care (mental health, suicides, public health expenditure and management, health care

workforce and services, pharmaceutical market, research) (Simou & Koutsogeorgou, 2014). Users out-of-pocket contribution, provision of care and efficiency issues are also deteriorated (Kaitelidou & Kouli, 2012). The most common causes of morbidity in primary health care (PHC) are circulatory and metabolic diseases, endocrine, musculoskeletal and respiratory diseases (Minas et al., 2010). A highly promising and growing sector is HHC. Many factors, such as patient profile, service tools, social and political priorities increase the need for formal HHC services (Tarricone & Tsouros, 2008). The reform in Greek health care system must emphasize in the PHC development under the values of patient centered care, the continuity and integrated approach and the need for most cost-effective use of resources (Tsiachristas, et al., 2015). The HHC emerges as an imperative need, which satisfied all the above conditions and necessities.

HHC in Greece: a brief review: HHC services in Greece are part of the PHC. Their first reference dates in 1982 by the law which established the National Health System (NHS). After then, there were many other references on Greek legislation but none of them have been accomplished. There are well developed free of charge public HHC services only for cancer patients in the capital, showing inequality in access. HHC services are provided by non-governmental organizations, mainly in the capital, usually targeted at specific patients. There are some developed private HHC services, but high costs decrease their accessibility. There is also the "Help at Home" program, which provides social and home care rather than nursing care at home. There is also provision the new Local Health Units (TOMY) (Law 4486/2017), to provide HHC but the operation of these Units is at an early stage and there is no data yet on the services provided and their effectiveness (Adamakidou & Kalokairinou, 2017). It is important to mention that there is no public concern for reimbursement of HHC services by the main insurance institution (EOPPY), as in contrast with other European countries (Genet at al., 2011). During the austerity, an ambitious government effort to develop HHC services across the country and for all patients in need through a pilot project was organized (Adamakidou & Kalokairinou, 2017). Unfortunately, the end of the project, which means discontinuation of guidance, support and control, has resulted in weakening or stopping the efforts of development. A special interest was also found for the HHC through the implementation of funded projects. These projects led to the development of HHC protocols, the identification of the educational needs of patients, caregivers, health professionals (Pierrakos et al., 2016), the conduct of training in HHC for nurses', caregivers and volunteers (ΑΚΕΣΩ-I, ΑΚΕΣΩ-II), the development of an e-health record (ΑΚΕΣΩ-I, Pierrakos et al., 2016). Data concerning HHC are focused mainly on patient satisfaction (Kouli et al., 2013, Zagga, 2012), nurses' ability to evaluate patients' quality of life (Adamakidou et al., 2015), team members' roles at home (Adamakidou et al., 2020) and cost of HHC services (Kouli, Patiraki, et al., 2013). Unfortunately, there is no evidence on the clinical and epidemiological profile of users, as well as of caregivers and volunteers in HHC, like in other countries (Genet et al., 2011).

The "ΑΚΕΣΩ-I" project: A corporation with Hellenic Red Cross HHC services : Hellenic Red Cross (HRC), as a member of the International Red Cross and Red Crescent Movement, has been offering humanitarian aid since 1877 in Greece. Since 1985, in Athens, the multidisciplinary team has provided free residential care to patients. Over the last decade, HHC services has an annual average of more than 700 users (HRC, 2007). Close associates of health professionals are the informal caregivers who are trained to provide quality care and are empowered to maintain their personal physical and psychosocial health. The HRC in Athens maintains a register of 50 volunteers formally trained to contribute to care (e.g. personal hygiene, feeding, entertainment, escorting to other health services, etc.). "ΑΚΕΣΩ-I" project was planned and implemented during the economic crisis. The title of the project was "*Development of an integrated post – hospital health care system of patients from vulnerable social groups. Networking of hospitals and PHC services with Nursing Volunteers of the HRC with General Hospitals and Local governments"*.The aim of this innovative project was to create HHC services for People from Vulnerable Social Groups with better use of the available resources. It was based on networking and collaboration between Public Health Units, the respective services of the HRC and Local Government with the ultimate goal of promoting HHC. The main objectives of the project were: a)

the provision of HHC services to patients in need b) the interconnection of public General Hospitals and HHC services of the HRC Nursing, c) the training and certification of nurses in HHC, d) the training and utilization of volunteers, e) the training of caregivers, f) informing and raising the awareness of the community in order to come closer to the institution and benefits of HHC services, g) the development of patients' e-health records for HHC services, and h) the accreditation of HHC services in the three cities.The project was a cooperation of the Laboratory of Community Nursing of the Nursing Department of National and Kapodistrian University of Athens (NKUA) and three Departments of HRC. One department was in the capital Athens, where HHC services were well-staffed and with great history. The second department was in Thessaloniki the second biggest city in Greece where HHC services were understaffed, so during the project, more health professionals were hired. The third was in Ioannina, where HHC services was organized and operated from scratch. This particular city was chosen because in Ioannina there is the University Hospital, which made patients referrals to the HHC service (Figure 1). The project lasted from May 2013 until December 2015 (20 months).

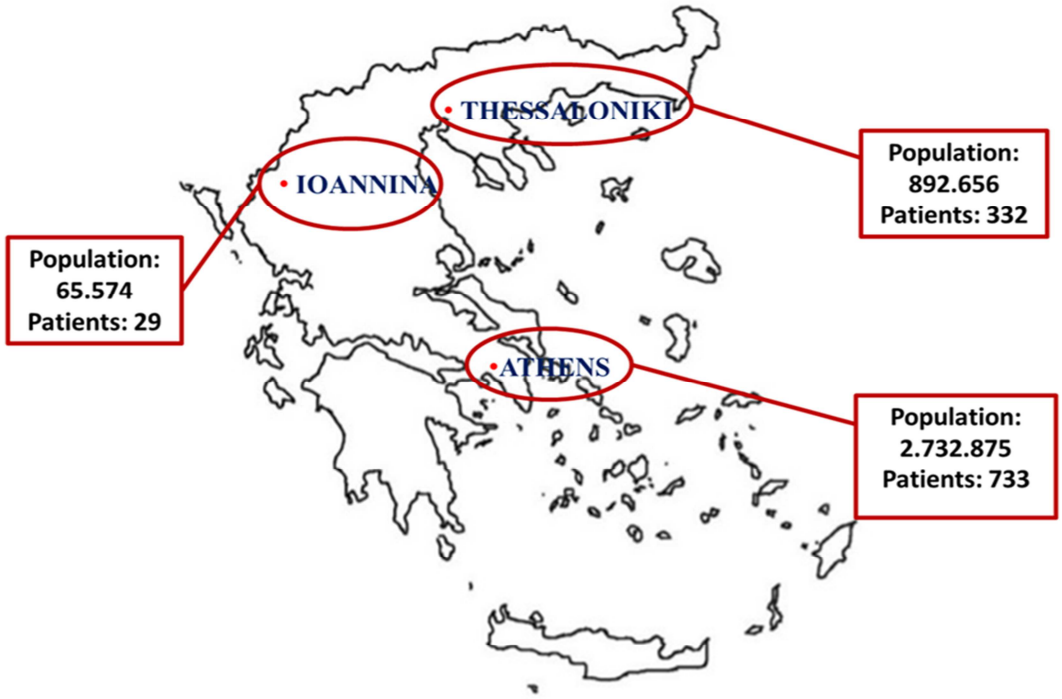

Figure 1. Map of the home health care services of the "ΑΚΕΣΩ-Ι" project (cities, population and patients).

Nowadays, HHC in Greece is in slow and steady development. The Greek literature on this topic is few and fragmented. There is a knowledge gap regarding the profile of HHC services users. First data on their profile is required to ensure the optinal planning of the care provided, the best organization of HHC services and their management around the country. There is also a lack of knowledge on the profile of caregivers and volunteers.

Purpose of the study: The aim of this paper was to describe the demographic and clinical profile of HHC services users in Greece and the sociodemographic profile of informal caregivers and volunteers during the "ΑΚΕΣΩ-Ι" project.

Methodology: This is a descriptive cross-sectional study, based on data collected from the medical records of 1,094 patients who received HHC, 86 informal caregivers and 99 volunteers. The interdisciplinary team (nurse, physician, physiotherapist) in each city was responsible for completing the patients' e-file. Data from new patient admissions during the project were included. There was none exclusion of the patient records. The information of the caregivers' and volunteers' profile was selected during a training program. Carers were caregivers of the patients who participated in the program. Volunteers came from the HRC volunteer register in all three cities. Both indicated their interest in participating in a training program.The variables of the study were patients' sociodemographic characteristics (gender, age and social fund), patients' clinical characteristics (disease category, the outcome at the end of care/project) and caregivers and volunteers sociodemographic characteristics (gender, age, education and occupation). Data collected in excel sheets and descriptive analysis was conducted. The project was approved by the Committee of the HRC, the Committee on Ethics of the Nursing Department of NKUA. It was also approved and funded by the National Committee for the management of European Funds and received the codes MIS:376390 and MIS:374850.

Results

Patients' descriptive statistics in each city, are presented in Table 1. A total of 1,094 patients received HHC. The majority of users were over 65 (80.71%) and female (68.37%). Nearly half (46.8%) received care for medical problems, and 83.82% were insured. Descriptive statistics of 86 informal caregivers are shown in Table 2. Most of them were female (93%), had a Bachelor's degree, almost one in three were 40-54 years old and one in three was 55-64 and 52% were employed.Descriptive statistics of 99 volunteers are shown in Table 3. Half of them were at the age between 55-64 years (51%), most of them were female (91%), with secondary level of education (48%) and 50% were employed.

Table 1 Descriptive characteristics of patients received home health care in each city

	ATHENS	**THESSALONIKI**	**IOANNINA**	**TOTAL**
	n (%)	n (%)	n (%)	n (%)
Patients	733 (67%)	332 (30%)	29 (3%)	1,094 (100%)
Age				
≤ 39 years	18 (1.65%)	7 (0.64%)	0 (0%)	25 (2.29%)
40-54 years	40 (3.66%)	27 (2.47%)	8 (0.73%)	75 (6.86%)
55-64 years	48 (4.39%)	60 (5.48%)	3 (0.27%)	111 (10.14%)
≥ 65 years	627 (57.31%)	238 (21.76%)	18 (1.65%)	883 (80.71%)
Gender				
Men	219 (20.01%)	115 (10.51%)	12 (1.1%)	346 (31.63%)
Women	514 (46.98%)	217 (19.83%)	17 (1.55%)	748 (68.37%)
Disease				
Medical	341 (31.17%)	152 (13.89%)	19 (1.73%)	512 (46.8%)
Orthopedic	276 (25.23%)	81 (7.40%)	1 (0.09%)	358 (32.72%)
Neurological	92 (8.40%)	58 (5.30%)	9 (0.82%)	159 (14.53%)
Surgical	24 (2.19%)	41 (3.74%)	0 (0%)	65 (5.95%)

Insurance				
Public Insurance	692 (63.25%)	201 (18.37%)	24 (2.19%)	917 (83.82%)
No Insurance	18 (1.64%)	61 (5.57%)	1 (0.1%)	80 (7.31%)
Social Welfare/Indigent	12 (1.09%)	40 (3.65%)	0 (0%)	52 (4.76%)
Other Type	11 (1.01%)	30 (2.74%)	4 (0.36%)	45 (4.11%)
Patient's outcomes				
Healed	212 (19.37%)	70 (6.39%)	2 (0.18%)	284 (25.96%)
Improved	68 (6.21%)	73 (6.67%)	7 (0.64%)	148 (13.53%)
Stable	350 (32%)	117 (10.69%)	4 (0.36%)	471 (43.05%)
Deaths (at home or in an institution)	92 (8.41%)	72 (6.58%)	16 (1.46%)	180 (16.45%)
Institutionalization (Hospital or Rehabilitation Center or Nursing Home)	11 (1.01%)	0 (0%)	0 (0%)	11 (1.01%)

Table 2 Informal caregivers sociodemographic characteristics in each city

	ATHENS	THESSALONIKI	IOANNINA	TOTAL
	n (%)	n (%)	n (%)	n (%)
Informal caregivers	29 (34%)	30 (35%)	27 (31%)	86 (100%)
Age				
≤ 39 years	4 (4.65%)	6 (6.97%)	8 (9.3%)	18 (21%)
40-54 years	12 (13.95%)	15 (17.44%)	3 (3.48%)	30 (35%)
55-64 years	12 (13.95%)	7 (8.13%)	11(12.79%)	30 (35%)
≥ 65 years	1 (1.16%)	2 (2.32%)	5 (5.81%)	8 (9%)
Gender				
Men	3 (3.48%)	2 (2.32%)	1 (1.46%)	6 (7%)
Women	26 (30.23%)	28 (32.55%)	26 (30.23%)	80 (93%)
Education				
Primary	0 (0%)	0 (0%)	3 (3.48%)	3 (4%)
Secondary	10 (11.62%)	12 (13.95%)	12 (13.95%)	34 (40%)
Bachelor	15 (17.43)	10 (11.62)	10 (11.62)	35 (40%)
Master or Doctoral	4 (4.65%)	8 (9.30%)	2 (2.32%)	14 (16%)
Occupation				
Employed	17 (19.75%)	16 (18.58%)	12 (14.88%)	45 (52%)
Pensioner	6 (6.97%)	4 (4.65%)	3 (3.48%)	13 (15%)
Other	6 (6.97%)	10 (11.62%)	12 (13.95%)	28 (33%)

Table 3 Volunteers sociodemographic characteristics in each city

	ATHENS	THESSALONIKI	IOANNINA	TOTAL
	n (%)	n (%)	n (%)	n (%)
Volunteers	46 (47%)	30 (30%)	23 (23%)	99 (100%)
Age				
≤ 39 years	6 (6.06 %)	3 (3.03%)	4 (4.04%)	13 (13%)
40-54 years	13 (13.13%)	4 (4.04%)	4 (4.04%)	21 (21%)
55-64 years	23 (23.23%)	17 (17.17%)	10 (10.10%)	50 (51%)
≥ 65 years	4 (4.04%)	6 (6.06%)	5 (5.05%)	15 (15%)
Gender				
Men	5 (5.05%)	3 (3.03%)	1 (1.01%)	9 (9%)
Women	41 (41.41%)	27 (27.27%)	22 (22.22%)	90 (91%)
Education				
Primary	0 (0%)	1 (1.01%)	1 (1.01%)	2 (2%)
Secondary	20 (20.20%)	19 (19.19%)	8 (8.08%)	47 (48%)
Bachelor	21 (21.21)	7 (7.07)	11 (11.11)	39 (39%)
Master or Doctoral	5 (5.05%)	3 (3.03%)	3 (3.03%)	11 (11%)
Occupation				
Employed	26 (26.26%)	16 (16.16%)	8 (8.08%)	50 (50%)
Pensioners	12 (12.12%)	8 (8.08%)	7 (7.07%)	27 (28%)
Other (Unemployed/Students)	8 (8.08%)	6 (6.06%)	8 (8.08%)	22 (22%)

Discussion

This is the first population-based study in Greece in which findings highlight the clinical and demographic characteristics of HHC services users. It also describes the sociodemographic profile of informal caregivers and HRC volunteers. Greek literature does not provide any kind of this information.

HHC users: The age of the majority of the sample confirms the trend of demographic aging in Greece (Eurostat, 2018). The age and gender profile are similar to the population profile of other studies (Genet et al., 2011; Martin et al., 1993). In addition, it indicates this age group as the main user of HHC services. During the 20 months of the project, 1,094 patients benefited. The actual needs for HHC are much larger and equally important. The HRC HHC services can serve only geographically accessible users and not users from all over the city. Almost half of the patients received care for medical problems, which is in agreement with other studies (Xiao et al., 2017; Yeh & Chen., 2003). This is an expected assumption given the age of users and the fact that cardiovascular diseases and cancer are the leading causes of death in Greece (Economou et al., 2017). The small number of users in the provincial city of Ioannina is due to objective difficulties encountered by healthcare professionals in finding patients. Difficulties related to either the users themselves (lack of knowledge of the service, population concerns for HHC, strong physician- and hospital-centered concept of Greek citizens for care) or the physician's community responsibility for reporting patients to HHC services (reservations for HHC, physician- and hospital-centered conception of the medical community and health system in general (Economou et al 2017)). Similarly, a study in Iran (Shahsavari et al., 2018) showed that the lack of confidence in community structures and in non-medical healthcare professionals emerges as a strong barrier to the development of HHC services (Heydari et al., 2016). Ilinca et al. (2015) point out that failure to change the views for the formal

caregivers is a strong barrier to deinstitutionalization.

Even though most of the patients were insured, the Public Insurance Fund (EOPPY) does not cover HHC. The percentages of uninsured and people in poverty were 7.31% and 4.76% respectively. Given that a large percentage of the population (23.6% in 2016) is currently living in the poverty line (Economou et al 2017); the rates could be much higher! It is also worth noting that the absence of costing healthcare providers procedures and processes in Greece, a weakness of the Greek health care system (Adamakidou & Kalokairinou 2017), may exacerbate economic exploitation in the provision nursing care at home. On the other hand, reimbursement for specific and limited number of services seems to be a disadvantage for the users' satisfaction (Yeh & Chen 2003). Consequently, the reimbursement of the HHC services by the insurance fund (Shahsavari et al., 2018; Heydari et al. 2016) and well-organized HHC services (vanCampen & Woittiez 2003) seem to increase the chance for users to live at home. Yeh & Chen (2003) found that users who were totally dependent (Barthel Index score<5) and in a deteriorating stage of the disease, had high rates of death and institutionalization. Similarly, high mortality rates are associated with high complexity patients and aggressive characteristics of the diseases (de Boas 2015). In this study in the city of Ioannina the referrals were mainly made by the University General Hospital and the newly established HHC services served patients with severe health problems (16 out of 29 patients died). This suggests that close co-operation between HHC and secondary care services can serve sufferers, decongest the hospital from care and thus reduce the cost of care (Jones 2017). Interestingly, in this study, only one in 100 patients receiving HHC needed to be institutionalized. There is evidence of the reduction in readmission of patients receiving HHC (Jones 2017) and the fact that de-institutionalization requires collaboration with formal care in the community and informal care (Ilinca et al., 2015).

In this study the withdrawal of the patient from the service meant death or hospitalization in a hospital or a long-term care institution. The withdrawal rate (17.46%) was small compared to other studies (Xiao et al., 2018, Yeh & Chen., 2003). We did not keep data on patient's specific place of death (home or hospital). However, it is reported (Shepperd et al., 2016) that people who receive formal HHC end-of-life care are more likely to die at home. At the same time, HHC and the presence of an informal caregiver are positive prognostic factors of home death in palliative care (Gill et al., 2013).

Informal Caregivers: The role of informal caregivers in HHC is undisputed (Bliss, 2006). Our study confirms that in Greece, during the economic crisis, informal care is "female", as confirmed by other community (Mestheneos & Triantafillou, 2005) and in-hospital studies (Stavrianou et al., 2018). Informal caregivers were middle-aged and older adults which are similar to other study (Jang et al. 2012).Also, about 1 in 2 informal caregivers in this study were employed. In a previous study (Jang et al. 2012) it is reported that employed caregivers were 33.5%, the group of household wives and labor market caregivers were 64.8% and the unemployment group was 1.7%. Differentiation may be due to the fact that in the present study working spouses are usually caregivers. The economic crisis forces Greeks, even when working, to take on the caregiver role. In addition, it is reported that in southern Europe, informal care often replaces formal care (Bolin et al., 2008). Interestingly, the economic crisis has significantly increased the proportion of unemployed and student caregivers (33%) compared to the previous report (Jang et al., 2012). It was also found that 15% of caregivers were retired. The role of the caregiver does not stop with retirement in Greece as informal care is identified with emotional expression and close family relationships (Mestheneos, Triantafillou, 2005) and the revival of family solidarity during this period of austerity (Tsekeris et al., 2015). It is no coincidence that Greece has the lowest rates in Europe (<20% for the year 2016) out of a population aged 65 of older living alone (Eurostat, 2017). According to the typology of European long-term care regimes (Lamura, 2007 as mentioned in Ilinca et al., 2015), Greece belongs to the "family based" type of care regime, which is characterized by high demand for long-term care, high provision of informal care and low provision of formal care. The negative impact of the financial crisis on the formal welfare system directly affects the family-based informal welfare system (Lyberaki & Tinios, 2014). Even though, supporting family caregivers has triple beneficiaries (careers, care recipients and public finances) (Colombo et al.,

2011), there is no governmental recognition in Greece for informal caregivers (Mestheneos & Lamura, 2013) neither support as it exists in other countries (respite care, pensions, ect) (Maetens et al., 2017; Genet et al., 2011). Therefore, multidimensional support of informal caregivers in Greece is the primary responsibility of nurses (Bliss, 2006).

Volunteers: Volunteering in the HRC HHC services in Greece is of "female gender". Volunteers demographic characteristics are consistent with other studies (Morris et al., 2017; Jenkinson et al., 2013; Planalp & Trost, 2009; Caidwell & Scott, 1994). The age of volunteers involved in health and social care is reported to decrease with the involvement of a younger population (Nayor et al, 2013). However, volunteering in palliative care refers to the involvement of an older age population (Planalp & Trost, 2009). Besides of their supportive roles (Candy et al., 2015), volunteers are also integral parts of the interdisciplinary team (Nayor et al., 2013).

In the present study, half of the volunteers were employees, while the participation of retired volunteers confirms the need to contribute and to have substantial experiences between generations (Caidwell & Scott, 1994), as well as that lifelong learning and supply has no age. There is evidence about the strengthening of care and help from informal social groups in Greece during the economic crisis (Sotiropoulos & Bourikos, 2014), as well as the great value of volunteering and the financial benefits (Nayor et al., 2013, Candy et al., 2015). According to Morris et al. (2017) volunteers are close to people and they link the hospice to the community. While volunteer involvement varies among countries in Europe, their use in home and palliative care services is the highest (Woitha et al., 2015).

Limitations: The main limitation of the study is its design, which primarily served the provision of HHC to vulnerable population groups, under the "ΑΚΕΣΩ-Ι" project and was not research. The electronic health database that was used in the 3 cities during the project was the same one that the HHC services in Athens was using throughout the years of its operation. The purpose was to redesign and create an integrated, user-friendly and fully functional database for future users. For this reason, only the descriptive variables are presented as they served the function of the HHC services. Another limitation is that the population that received HHC is not indicative of the population of the whole of Greece; it is a convenience sample as those who sought HHC from the HRC HHC services received it.

Conclusion: In this paper, data on the profile of Greek patients receiving HHC, their caregivers and volunteers involved in HHC, were presented for the first time. The findings of the project point out, firstly, the need to develop HHC services, promote their functioning and disseminate their effectiveness under a PHC-oriented health system. Secondly, the need for a change in the perceptions of the Greek population for HHC services, which can be achieved by appropriate information and confidence building. As soon as Greek citizens are informed of the availability, effectiveness and efficiency of these services, their knowledge and confidence will be increased. Thirdly, the need to change the physician's community perception for the place of care in order to trust and refer patients to the HHC. During the period of the economic crisis it must be realized that this is not a 'conflict of interests' but a common effort to continue and integrate person-centered care. At the same time, it is advisable to change the philosophy of health care by all healthcare professionals to consciously empower the user in self-care and self-management and to direct him to PHC and the use of services. Fourthly, the increase in efficiency and effectiveness can be achieved through effective networking and collaboration with secondary and tertiary healthcare services with other community services and with the utilization of family and informal caregivers. Fifthly, state care is required to cost healthcare providers procedures and processes in HHC, which will be an incentive for the use of HHC services and a disincentive for the exploitation of citizens and will improve the efficiency of the services. Sixthly, HHC is greatly supported by informal and family caregivers, state care is required for those with appropriate support services (HHC services, respite care, day care arrangements, psychological support, financial support, etc.). Lastly, the utilization of volunteers in a systematic way can increase health and social advantages and financial benefits too.

National projects like "ΑΚΕΣΩ-Ι" highlight the needs, identify ways to implement them, teach from the mistakes and successes but unfortunately are fragmented and have impaired

viability. At a national level, political and institutional decisions are required, which will prioritize and strategize the development of HHC services within the NHS for equal access to all citizens and will guarantee long-term viability, quality, efficiency, availability and accessibility of HHC services.

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