Swiss Agency for Development and Cooperation (SDC)

HEALTH FOR ALL PROJECT

Assessment of Quality of Life and Home Based Care (HBC) needs in Dibër, Fier, Durres and Shkoder regions, Albania

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Final report

15 May 2024

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Financed by the Swiss Agency for Development and Cooperation

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ACKNOWLEDGEMENTS

Swiss TPH would like to express its gratitude to the entire HAP team for the overall technical assistance and organisation of the survey. We would like to thank the IPSOS data collection company for implementing the survey according to the defined terms of reference and for the good collaboration throughout. Special thanks to the collaborating health centers and respective health care staff for facilitating the survey implementation. Last but not least, our special words of gratitude are expressed towards the survey participants, including the patients and their family members for sharing their insights and valuable time with us.

ABBREVIATIONS

GHC	Global Health Composite
HAP	Health for All Project
HBC	Home Based Care
IQR	Interquartile Range
MHC	Mental Health Composite
MOHSP	Ministry of Health and Social Protection
NCD	Non-Communicable Diseases
LEK	Albanian Lek
PCA	Principal Component Analysis
PCS	Physical Health Composite
USD	United States Dollar
QoL	Quality of Life
VR-12	Veterans RAND 12 Item Health Survey
WHO	World Health Organization

GLOSSARY

Karnofsky Performance Scale	The Karnofsky Performance Scale measures symptom related limitations of activity, self-care, and self-determination and allows to classify patients as to their functional impairment (see Annex 9.1). Through the Karnofsky Performance Scale, patients were assessed and rated ranging from 'Able to carry on normal activity and to work; no special care needed' (value between 80 and 100) to 'Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly' (value between 10 and 40) and finally 'death' (value 0).
Proxy (respondent)	A person close to the patient, who is aware of what is going on in the patients' household and with the patients' health in particular. The proxy can be a family member that lives in the same household with the patient or not. In the case where the proxy respondent is not living in the household, she/he should be well aware of the happenings of the household as well as the patients' health.
Health care assistance at home	Health care assistance at home is if someone – excluding family members – is visiting a patients' home to care for her/his health needs.
Home based care	Home based care refers to the intervention of the HAP2 project and includes – as opposed to health care assistance at home – more services and service provision by nurses specifically trained for home based care within the HAP2 project.
Wealth index	Households are given scores based on the number and kinds of consumer goods they own, ranging from a television to a bicycle or car and housing characteristics. These scores are derived using principal component analysis. Wealth quartiles are compiled by assigning the household score to each usual (de jure) household and then dividing the distribution into four equal categories.
Quality of life	An individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [1]. In this study, quality of life is measured through the VR-12 tool measuring physical and mental health items.

PART I

Assessment of Quality of Life and Home Based Care (HBC) needs in **Dibër and Fier** regions

EXECUTIVE SUMMARY

In the frame of the Health for All Project phase 2 (HAP2), home based care (HBC) services are offered since July 2021 in selected health centers in Dibër and Fier regions of Albania. HBC targets patients that are unable to care for themselves and require special care and assistance equivalent of institutional or hospital care (e.g. home-bound, bed-bound, chronically ill, palliative, elderly, etc.). The HAP HBC intervention is implemented in 8 health centers, 4 in Dibër and 4 in Fier.

In order to measure the potential impact of the intervention, a cross-sectional baseline survey was conducted before implementation in September 2021 and two years into implementation, in October 2023, using the same methods and tools. The surveys assessed the health status, access to care, costs of health care, care provided by family members, health care assistance at home and quality of life (QoL) for patients eligible for HBC in the 8 health centers in Dibër and Fier. For comparison and to measure the impact of the intervention, another 8 health centres (4 in Dibër and 4 in Fier) with similar characteristics as those covered under intervention were selected as control.

For both eligibility for HBC as well as eligibility for study inclusion, a Karnofsky Performance Scale score of 40 or lower was considered as eligibility criteria. This score means that the patient is 'disabled, requires special care and assistance'. Thus, all eligible HBC patients served by the selected health centers were invited to participate in the survey. A questionnaire interview was conducted with consenting patients. The interview was conducted with the patient, a proxy respondent (familiar with the patients' health needs) or a combination of both. The questionnaire covered: (i) socio-demographic and household characteristics; (ii) health status; (iii) access to care; (iv) costs of health care; (v) care provided by family members; (vi) health care assistance at home; (vii) and QoL.

Of an estimated 527 eligible patients in Diber and Fier, 450 were included in the study (85.4% recruitment rate; 2021: 82.8%). Overall, 162 patients were from Diber, 288 from Fier (total in these two regions: 450). In Fier and Diber regions, 40.9% of patients were from the intervention group (2021: 48.5%) and 59.1% from the control group (2021: 51.5%).

Overall, for 33.3% of interviews it was the patient responding her-/himself to the interviewer (2021: 33.7%), for 43.6% (2021: 47.6%) of interviews it was the proxy who responded and for 23.1% (2021: 18.7%) of interviews it was both together.

The main findings, separated for (i) 2023 in Diber and Fier; (ii) the changes between 2021 and 2023 in Diber and Fier are shown in Table 1 below.

Table 1: Summary findings in Diber and Fier, 2021 and 2023

Section	Main findings
Patient and household characteristics	**2023 in Diber and Fier** • Mean age was 70.0 years. • Nearly half (46.0%) were married and 17.8% widowed. • About a quarter did not have any education or only Kindergarten (24.9%). About a third (28.4%) attained primary school level and another quarter (27.8%) attained secondary school level. 14.7% went to high school, and 3.2% to college or university, including technical university. • None of the patients lived alone but 121 patients (27.0%) lived in a 2-person household. The rest lived in a household with more than 2 people.
	2021 – 2023 in Diber and Fier • The study population in Diber and Fier was similar in 2021 and 2023 in terms of age, marital status and educational backgrounds.
Health issues	**2023 in Diber and Fier**

Section	Main findings

	• A total of 937 health problems, largely chronic, were reported by the 450 patients, most prevalent of all reported issues were:
	  ○ Diseases of the circulatory system: 86.2%
	  ○ Diseases of the nervous system: 40.4%
	  ○ Endocrine, nutritional and metabolic diseases: 20.7%
	  ○ Diseases of the eye and adnexa: 17.3%
	• 69.6% of patients reported multiple health problems.

	2021 – 2023 in Diber and Fier
	• The pattern of health issues reported differed in 2021 and 2023 as follows:
	  ○ A strong increase in circulatory system issues (from 15.0% to 86.2%).
	  ○ A slight increase of nervous system issues (from 33.5% to 40.4%).
	  ○ Whilst diseases of the musculoskeletal system and connective tissue were reported by a quarter in 2021 (26.8%), they were reported by 5.6% in 2023.
	• The percentage reporting endocrine, nutritional and metabolic diseases remained stable (19.6% and 20.7%, respectively).
	• Importantly, as these are self-reported health issues, this increase might be partly explained reporting biases, e.g. underreporting in 2021, or increased awareness in 2023.
	• The proportion of patients reported to be entirely bed-bound increased from 16.5% (95% CI 13.2-20.2%) in 2021 to 22.0% (95% CI 18.3-26.1%) in 2023.

Access to health care	**2023 in Diber and Fier** • Only 8.9% of patients reported to be able to ever visit the health center without assistance. More than two thirds of the patients (72.9%; 2021: 61.2%) experienced barriers to visit the health center in the two months preceding the survey.
	2021 – 2023 in Diber and Fier • In 2021, for more than half (55.7%) of the patients, their health status did not allow them to ever visit the health center. *However, numbers are not comparable to 2023 as the questions were asked differently.* • In 2023, more than two thirds of patients (36.2%; 95%CI 31.8-40.9%) were both bed-bound and could not afford transport to go to the health facility, which was significantly higher than in 2021 (21.4%; 95%CI 17.7-25.4%). • The proportion of patients who are bed-bound and can't afford to take the transport increased from 21.4% in 2021 to 36.2% in 2023.
Costs of health care	**2023 in Diber and Fier** • For 82.0% of patients, health care costs resulted from buying drugs/medications, for 33.8% from medical tests, for 23.6% from transportation to the health centre and for 20.2% from consumables. • Respondents self-reported to have spent a median of 13,068 LEK or 130 USD on health care costs excluding hospitalisations in the 2 months preceding the survey.
	2021 – 2023 in Diber and Fier • Drugs/medication were the main cost driver in both years (84.6% and 82.0%, respectively). • Costs for ''transport for health care assistance at home' has decreased from 3,500 LEK in 2021 to 2,178 LEK in 2023. This cost applies when a HBC nurse is called to the home beyond the routine services and visits, e.g. for emergencies. • Considering the inflation rate, median self-reported health care costs (excluding hospitalisations) in the 2 months preceding the survey increased from 12,000 LEK to 13,068 LEK.
Care and support provided by family members	**2023 in Diber and Fier** • Out of the 450 patients, 413 (91.8%) received also care and support from family members. • This rate did not differ significantly between the intervention group (88.6%; 95% CI 83.1-92.8%) and the control group (94.0%; 95% CI 90.4-96.5%). • Of those 413 patients with care from family members, in-laws were most frequently involved in care taking (35.6%), followed by children (30.2%) and spouses (29.1%). • All family members combined, invested on average 19.7 hours per day (including all hours from all family members) for the care and support of the bed / home-bound patient.

Section	Main findings

	2021 – 2023 in Diber and Fier
	• The proportion of patients receiving care and support from family members remained similar and high over the years (92.7% in 2021 and 91.8% in 2023).
	• In both survey years, more than half of the patients receive support from family members (i) in implementing of doctor's prescriptions, care and treatment; (ii) financial support; (iii) hygiene; and (iv) checking blood pressure. The burden of health care provided by family members (=time effort) has increased but was spread over fewer family members in 2023:
	  ○ Whilst in 2021, on average, about 2.3 family members supported the patients' care in a household (range 1-7), this was 1.4 in 2023 (range 1-4).
	  ○ On average, family members invested 19.7 hours per day for the care and support of the bed / home-bound patient in 2023. This is an increase of 4.1 hours compared to 2021 (15.6 hours per day).

Health care assistance at home	**2023 in Diber and Fier** • About half of the respondents (223; 49.6%) were aware, that health care assistance at home exists as a service provided by health centres. • In 2023, this awareness was significantly higher in the intervention group (70.1%; 95% CI 62.9-76.6%) than the control group (35.4%; 95% CI 29.6-41.4%; p<0.001). • Among those aware, most heard about this service from their nurse (89.7%) and/or their doctor (60.1%), respectively. • A total of 372 (82.4%; 95% CI 78.6-85.8%) reported to have ever asked for health care assistance at home and 329 (73.1%; 95% CI 68.7-77.2%) have already received some sort of health care assistance at home in the past. • 220 (48.9%; 95% CI 59.7-68.7%) patients reported to receive health care assistance at home at the time of the survey. In turn, 230 (51.1%) patients did not receive health care assistance at home. Among those, 100 (82.6%) reported that they would like to receive medical assistance now or in the future. • The frequencies of the need for care ('every day', 'once' or 'several times a week') were higher than what was actually received at the time of the survey.

	2021 – 2023 in Diber and Fier
	• The results indicated a marked increase in the intervention group on awareness of health care assistance at home as a service and communication thereof from health staff to their patients:
	  ○ Whilst in 2021, awareness about health care assistance at home was similar in the comparison and the control groups, this significantly was significantly higher in the intervention group in 2023.
	  ○ The proportion of patients who heard about the service from their nurse and doctor increased markedly between 2021 (66.0% and 39.3%, respectively) and 2023 (89.7% and 60.1%, respectively).
	  ○ Indeed in 2023, hearing from the nurse as well as from the doctor was higher in in the intervention group than in the control group (93.8% vs. 84.0%; p=0.018, and 70.5% vs. 45.7%; p<0.001, respectively).
	• The results indicate an increased demand and previous use of health care assistance at home, especially in the intervention group:
	  ○ In 2023, 82.4% (95% CI 78.6-85.8%) have ever asked for health care assistance at home, compared to 66.1% (95% CI 51.5-70.4%) in 2021 (p<0.001.
	  ○ In 2023, significantly more patients reported to ever have asked for health care assistance at home in the intervention group (93.5%; 95% CI 88.9-96.6%) than in the control group (74.8%; 95% CI 69.1-79.9%; p<0.001).
	  ○ In 2023, 73.1% (95% CI 68.7-77.2%) have reported to have already received some sort of health care assistance at home in the past, compared to 64.5% (95% CI 59.9-68.9%) in 2021.
	  ○ In 2023, significantly more patients reported to ever have received health care assistance at home in the intervention group (84.8%; 95% CI 78.8-89.6%) than in the control group (65.0%; 95% CI 59.0-70.8%; p<0.001).
	• Interestingly, the proportion of patients receiving health care assistance at home at the time of the survey was significantly less than in 2023 (48.9%; 95% CI 59.7-68.7%) compared to 2021 (64.3%; 95% CI 59.7-68.7%).
	• However, whilst in 2021, there was no significant difference in the current service use between the intervention group and the control group, in 2023, current service

Section	Main findings
	use was significantly higher (p<0.001) in the intervention group (64.7%; 95% CI 57.3-71.6%) than in the control group (38.0%; 95% CI 32.1-44.1%).
Quality of life	**2023 in Diber and Fier** • The physical health composite (PHC), mental health composite (MHC) and general health composite (GHC) scores for all patients as well as the scores for specific patient sub-groups (stratified by sex, region, intervention and wealth quantile) were all categorized as 'low'. 'Low' means that these were scores that are obtained by 20% or less of the respective normative population, thus are in the lowest quintile of a normative population. These individuals experience physical and mental health symptoms that impede life functioning, which is explained by the general health status of the patients (bed-ridden or home-bound) and at the same time, the inclusion criteria in the study.
	2021 – 2023 in Diber and Fier • For both 2021 and 2023, and all regions, overall scores and scores for specific subgroups (sex, region, intervention and wealth quartile) were all categorized as 'low'. • Overall, no significant changes or differences were found between the years or different stratification groups. • There seems to be no gender-specific differences. • In 2023, Diber showed slightly higher QoL scores than Fier, which was the opposite in 2021. • The intervention group showed higher QoL scores in 2023, which was the opposite in 2021. • The wealthiest quantile has highest QoL scores throughout. • No real change in QoL was detected since the implementation of HBC, which is to be expected in this specific study population (bed-ridden or home-bound).

In conclusion:

- Intrinsic to the study eligibility and inclusion criteria, the surveyed population had high burden of chronic diseases. Self-reported prevalences of these increased overall between 2021 and 2023. The proportion of patients entirely bed-bound increased slightly from 16.5% in 2021 to 22.0% in 2023.
- The burden of health care provision by family members remains high and even increased since 2021, potentially also due to the increased burden of disease.
- Generally, awareness, demand and previous use of health care assistance at home, or HBC, has increased between 2021 and 2023 and importantly, were consistently higher in the intervention group than in the control group. These findings suggest an impact of HAP's HBC intervention.
- Whilst QoL scores were consistently 'low' (all years, regions, intervention groups or wealth quartile), the intervention group showed higher QoL scores in 2023, which was in contrast to 2021. However, no change in QoL since the implementation of HBC was expected in this specific study population.

1. INTRODUCTION

The Health for All Project (HAP1) Phase 1 implemented between 2015 and 2019, aimed to increase the health of the Albanian population, including the most vulnerable, by improving primary health care (PHC) services and health promotion activities [2]. The HAP Phase 2 (HAP2) project was being implemented between 2019 and 2023 with the overall goal that the Albanian population benefits from better health thanks to improved PHC services. This goal was extended to HAP Consolidation Phase implemented between 2023 and 2027, including extending an inclusive primary health care system.

1.1 Need for medical home care service

Patients that are home- or bed-bound (chronically ill, need palliative, elderly, etc.) are one of the most vulnerable population groups in terms of health needs. A 2018 cross-sectional household survey on "Access to Health Services" carried out in Dibër and Fier regions by the HAP provided relevant information about the situation of non-communicable diseases (NCDs) in these two regions [3]. Among self-reported chronically ill patients, the NCD profile was as follows: hypertension (62%), heart problems (35%), rheumatism (35%) and diabetes (20%). The main challenges of the people affected by NCDs were their needs for continuous care and frequent access to health care.

Furthermore, there is currently an increase of elderly people and a decrease of the fertility rate in Albania. In addition, many young Albanians are leaving the country for economic reasons. These demographic changes are affecting the types of services, frequency of health care seeking, and access. More elderly are living alone, without support of their family members, more elderly are suffering from chronic non-communicable diseases, for which access to health services is not easy and available and need more care at home. To better understand these challenges, HAP conducted a qualitative study in 2019/2020 in Dibër and Fier regions aiming to:

1. identify the services that can be provided on a pilot basis by the PHC teams in close collaboration with social services of municipalities, in Dibër and Fier; and
2. suggest potential models of HBC services for urban and rural areas, including types of services, resources, skills, or groups to be served.

In-depth interviews with health care providers were conducted to understand the needs of their patients and to understand what services could realistically be implemented in a potential home based care (HBC) pilot.

1.2 HBC intervention in HAP

Through this qualitative study, the need for medical HBC services was identified for the following patient groups:

1. Patients living in the areas served by one of the pilot health centers.
2. Patients that are unable to care for themselves and require special care and assistance equivalent of institutional or hospital care (e.g. home-bound, bed-bound, chronically ill, palliative, elderly, etc.).
3. a. Home-bound elderly: elderly that need medical attendance at home because they cannot go to the health center.
   b. Home-bound chronic patients: patients who have the presence of a chronic disease in advanced stages that needs medical attendance at home because they cannot go to the health center, including patients disabled by cerebrovascular accident, diabetes, hypertension and cancer.

Thus, since 2021, two forms of HBC have been introduced:

1. HBC services with a dedicated team organized into a HBC unit; and
2. HBC services without a dedicated team (provided by most of the nurses operating in health centers and health posts).

Initially HBC services covered a population of 66,872 inhabitants through 8 health centres in Diber and Fier regions. Thereof, 4 are in Dibër region, namely Klos, Melan, Shupenze and Komsi, and 4 are in Fier region, namely Patos, Portez, Roskovec, and Ballagat.[1]

1.3 Baseline and endline survey approach

To assess the interventions' impact, it was planned that a baseline and an endline survey are to be conducted at the start of the introduction of HBC and two years afterwards. Consequently, a baseline survey was conducted in October 2021 and a follow-up survey was conducted in October 2023.

2. GOAL AND OBJECTIVES

The overall goal of this survey was to describe the endline situation of people in need and eligible for HBC with regards to their health, their needs (health and social needs related to health) and their quality of life (QoL).

The specific objectives linked to this goal were to:

1. assess the self-reported health status;
2. describe the current access to health care with a focus on health care assistance at home;
3. assess past, current, and future use and needs of health care assistance at home and associated factors; and
4. assess the patients' perceived QoL.

In Diber and Fier, the results are compared to the 2021 baseline results to assess potential impact of the intervention and evolvement over time.

3. METHODS

3.1 Study design

The surveys were conceptualised as cross-sectional surveys based on a cluster sampling methodology at health center level. The methods and tools of the 2023 endline survey were the same as for the 2021 baseline survey. The surveys addressed the objectives as outlined in section 2 and thus established a follow-up status assessment in Fier and Diber regions. In Fier and Diber regions, the same health centers as in the 2021 baseline survey were selected (intervention and control).

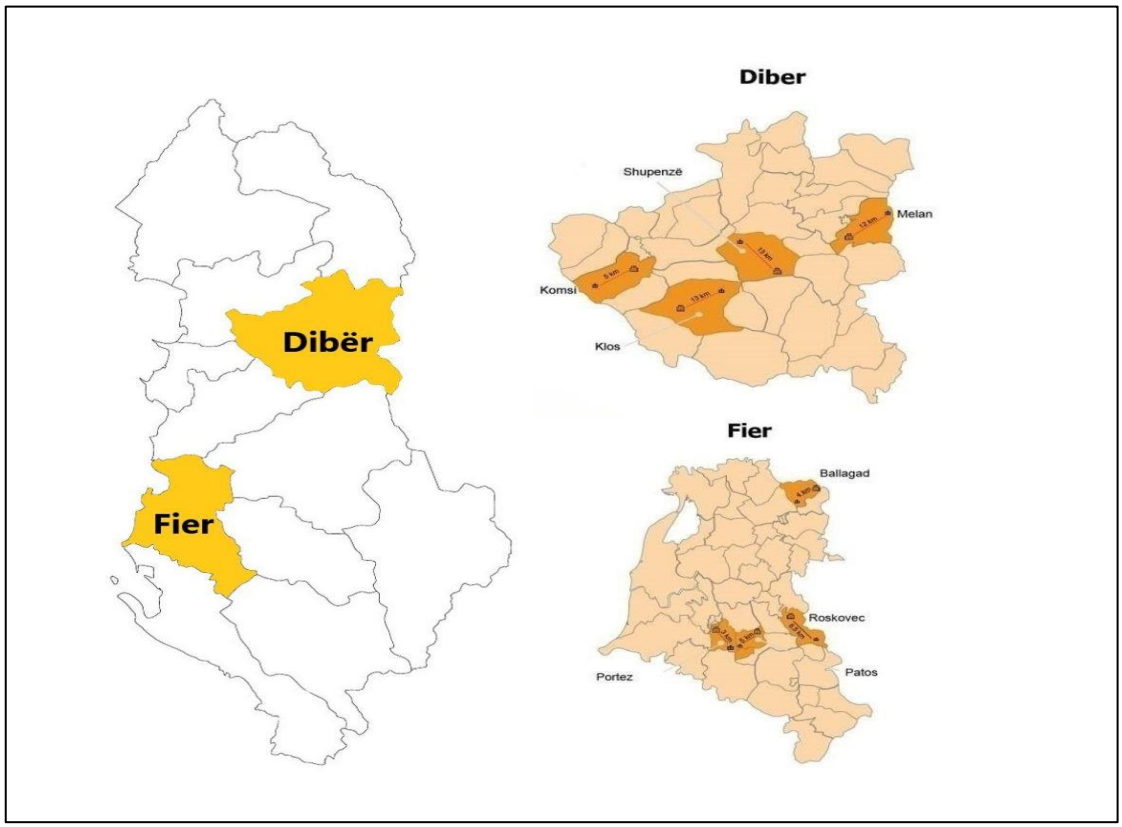
3.2 Study areas

The survey was carried out in Fier and Dibër regions (Figure 1). The HBC service package is offered since 2021 in the two regions, and is, to date, offered in 58 health centers in across the two regions.

[1] HAP2 piloted the home-based care in 9 health centers including Frakull health center in Fier region. However, the baseline was conducted in 8, because one health center joined the pilot interventions later. The endline will be conducted in the same areas where the baseline was conducted.

The current study is conducted in the 8 health centers in Diber and Fier already included in the 2021 survey, namely in Klos, Melan, Shupenze, Komsi in Dibër region and in Patos, Portez, Roskovec, and Ballagat in Fier region.

Figure 1: Diber and Fier study areas



3.3 Study population

The survey targeted people in need for HBC services in the catchment areas of the selected health centers (see section 3.4 below).

In order to identify the eligible population – for both HBC services and survey inclusion – in each health center, the Karnofsky Performance Scale was used [4]. This scale measures symptom related limitations of activity, self-care, and self-determination and allows to classify patients as to their functional impairment (see Annex 9.1). Through the Karnofsky Performance Scale, patients were assessed and rated ranging from 'Able to carry on normal activity and to work; no special care needed' (value between 80 and 100) to 'Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly' (value between 10 and 40) and finally 'death' (value 0). For all potentially eligible patients (e.g. home-bound, bed-bound, chronically ill, palliative, elderly, etc.) registered at the selected health centers, family doctors and family nurses assessed and calculated the Karnofsky Performance Scale score.

A Karnofsky Performance Scale score of 40 or lower was considered as eligibility criteria. This cut-off was chosen because a score of 40 means 'Disabled, requires special care and assistance' and scores between 10 and 40 generally mean 'Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly'. Thus, these patients fit the need for HBC.

Patient inclusion criteria were:

- Fulfil the eligibility criteria; and

- Willingness to provide written informed consent to participate in the study by the patient or the proxy respondent.

Patient exclusion criteria were:

- Any of the inclusion criteria not met; or
- No willingness to provide written informed consent to participate in the study by the patient or the proxy respondent; or
- Unavailability or inability of both the patient and the proxy to be interviewed.

3.4 Sampling strategy and sample size

The study population was selected in a two-stage sampling process, namely:

1. selection of the health centres; and
2. inclusion of all eligible patients.

Based on the Karnofsky Performance Scale score, the eligible population in these health centers amounted to 228 persons, which were all to be included in the study.

Table 2: Catchment population and estimated eligible population by health center, Diber and Fier, 2023

Region	Municipality	Health center	Catchment population	Administrative category	Eligible population
Dibër	Dibër	Shupenze	5'500	Rural	19
	Dibër	Melan	3'800	Rural	9
	Burrel	Komsi	6'000	Rural	14
	Klos	Klos	10'000	Urban/Periurban	35
Subtotal					***77***
Fier	Roskovec	Roskovec	7'800	Urban/Periurban	17
	Fier	Portez	5'000	Rural	37
	Lushnje	Ballagat	3'600	Rural	24
	Patos	Patos	25'172	Urban/Periurban	73
Subtotal					**151**
Total					**228**

To be able to better analyse the effects of the intervention in the two regions, it was considered beneficial to add a control group to the sample. This allowed to measure the effects of the intervention not only over time in the intervention health centers, but also between intervention and non-intervention health centers.

Based on various considerations (see the below assumptions) of different elements influencing sampling for the control group, 8 health centres with similar characteristics as those covered under intervention (around 3 urban health centers and 5 rural health centres) were selected (Table 3).

Assumptions:

- Coefficient of variation of 0.78 within the study population;
- Loss of follow-up of 5-10% from baseline to the follow-up study;
- Baseline – follow-up correlation of 0.5;
- Population standard deviation of 10.7 (from KOSCO);
- Intraclass correlation of 0.013 (best estimate from KOSCO);
- Minimum detectable intervention effect size (in RAND-12 points):
    - 5% loss to follow-up: 3.36
    - 10% loss to follow-up 3.42

Table 3. Estimated sample size of intervention and control groups by region and health center, Diber and Fier, 2023

Region	Intervention health center	No of patients	Control health center	No of patients	Total
Dibër	Shupenze	19	Lis	15	***163***
	Melan	9	Gjorice	10	
	Komsi	14	Suc	19	
	Klos	35	Maqellare	42	
Subtotal 1		***77***		***86***	
Fier	Roskovec	17	Aranitas	40	***345***
	Portez	37	Divjake	27	
	Ballagat	24	Fier. No 3	80	
	Patos	73	Kuman	47	
Subtotal 2		***151***		***194***	
Total		**228**		**280**	**508**

3.5 Data collection

3.5.1 Approach

In a first step, the nurses from the selected health centers contacted the eligible patients and/or a proxy. At this first interaction, the survey and its purpose were explained, and permission was sought to visit the patients' household.

If permission was granted, in a second step, the study enumerators visited the patients' homes for the administration of the questionnaire interview. The enumerator presented her-/himself and the survey and its purpose were explained once more to the patient and – if present – the proxy respondent. The study information was also provided in written form to each patient and household. Last, the patient or proxy provided written informed consent before commencement of the questionnaire interview.

In cases where patients were not reached by nurses over phone, the enumerators were visiting a patient's home directly.

3.5.2 Training of enumerators, field work and quality assurance

A three-day training was conducted with 18 enumerators plus 3 back-ups. The training included a pre-test in health centers not included in the main survey. The pre-test allowed to make final adaptations and corrections to the questionnaire.

The data collection was conducted between 12 and 31 October 2023. Enumerator teams worked in parallel in the four survey regions.

Three supervisors were responsible for running daily quality control of field work. The supervisors supported data collection and facilitated communication with the respective health centers staff, participating in selected individual interviews checking consistencies of the process, etc. The daily supervision was supported by data quality control reports provided by Swiss TPH, leading to immediate corrective measures.

3.5.3 Questionnaire interview

An electronic questionnaire was used to collect data through a face-to-face interview. Whenever possible, the interview was conducted with the patient her-/himself. However, in cases where

interaction with the patient was limited or impossible, the interview was conducted with a proxy respondent or with the support of such a proxy respondent.

The questionnaire covered the topics listed in Table 4.

Table 4: Content of the questionnaire

Section	Topics covered
Patient and household characteristics	• Demographic data • Household composition • Housing conditions • Household incomes • Household assets
Health status	• Health issues relevant to the study population and health care assistance at home
Access to health care	• Access and barriers • Cost and affordability
Costs of health care	• Costs of health care in the 2 months preceding the survey, including hospitalisation costs
Care and support provided by family members	• Family members involved in care • Types of care and support provided • Time expenditure for care and support provided
Health care assistance at home	• Awareness and availability • Expectations and needs • Past, current and future use • Types of services provided • Satisfaction • Staff • Costs

Quality of life	• Veterans RAND 12 Item Health Survey (VR-12)
	  ○ General health (1 question)
	  ○ Physical functioning (2 questions)
	  ○ Bodily pain (1 question)
	  ○ Role limitations due to physical health problems (2 questions)
	  ○ Mental health (3 questions)
	  ○ Social functioning (1 question)
	  ○ Role limitations due to emotional health problems (1 question)
	  ○ Vitality / energy-fatigue (1 question)
	• Other QoL questions

The health-related change in QoL as results of an intervention, treatment or service is used by many clinical and public health studies. The Veterans RAND 12 Item Health Survey (VR-12) tool was used in this study. The VR-12 has proven to give comparable QoL results as the SF-12 questionnaire, which has been used in other Balkan countries with similar contexts as Albania [5].

3.6 Data management and analysis

Questionnaire data was registered using electronic data capture with tablets using Open Data Kit (ODK) software. Data was submitted to the server of Swiss TPH in Basel, Switzerland, on a daily basis. No identifying data was available in the electronic dataset but a unique ID was linked to the paper-based informed consent sheets signed by the respondents and kept securely by HAP. Only study investigators from Swiss TPH and HAP had access to the database.

Descriptive analyses were performed and stratifications between sub-groups were computed where considered meaningful. The following stratifications are considered: region/qark, intervention group (intervention vs. control), wealth quantile, and survey year. Continuous

variables are transformed into categorical variables as needed. 95% confidence intervals (CIs) are only displayed where relevant, indicating statistically significant difference.

Data analyses was carried out using STATA.

3.6.1 Household wealth

An inventory of household assets and amenities, similar to the one developed by the Demographic and Health Survey (DHS), was used to measure levels of household wealth and poverty, respectively [6]. The measure used a reduced set of inventory items: materials of floors, roof and walls; type of cooking fuel and ownership of key household assets (i.e., mobile phone, television, refrigerator, bicycle, motorbike, car, computer, washing machine, heater and oven). Principal component analysis (PCA) was used to create a single dimension asset score. Household wealth quartiles were then computed based on the first principal component of the PCA [7]. Household wealth quartiles were: poorest, second, third, wealthiest.

The PCA analysis was conducted both in 2021 and 2023, utilizing identical assets for comparison. Consequently, the 2021 households served as the baseline, against which the 2023 PCA scores were measured. Despite including partly different households in 2021 and 2023, the asset-based wealth scores allow for a comparison of household wealth between the two years.

3.6.2 Health care cost

To determine the central tendency of the health care costs, the median and associated interquartile range (IQR) were analysed. As the health care costs are expected to be non-normally distributed (e.g. most pay less, few pay more), the median measure is chosen as it is less influenced by outliners and skewed data (i.e. non-normally distributed). The median describes the value separating the higher half from the lower half of the data points. The IQR describes the spread of the data/cost around the median, and we list the range from the 25th to the 75th percentile of the data.

Inflation was considered as follows: 2021 was taken as the reference value; and inflation rates considered were 8.9% depreciation between 2021 and 2022 (inflation rate for 2023 was not available at the time or the report writing).[2] In addition, annual average exchange rates were applied for 2022 and 2023.

3.6.3 Quality of life

The VR-12 tool allows for the computation of three measures: (i) Physical Health Composite (PHC); (ii) Mental Health Composite (MHC); and (iii) Global Health Composite (GHC). The goal of the VR-12 is to provide an aggregate-level analysis of these composite scores. The tool contains 12 questions (called 'items'), where 6 items contribute to each the PHC and MHC and all 12 items contribute to the GHC. Thus, the GHC can be viewed as a 'thermometer' of general health [8]. The VR-12 tool is shown in Annex 4 in section 9.2.

Methods, scaling, scoring, scores, weights and intercept values, interpretation and other relevant details for the calculation and analysis of the VR-12 are provided in Hays' manual entitled 'RAND-36 Health Status Inventory', specifically Appendix E [8].

For our study population, age-based scores were applied to categorize individuals into their normative age groups for comparison with the QoL reference population (normalised US

[2] https://www.worlddata.info/europe/albania/inflation-rates.php#:~:text=The%20inflation%20rate%20for%20consumer,the%20price%20increase%20was%202%2C474.13%25

population). Pre-defined age-groups are: 18-24, 25-44, 45-65 and ≥65 years [8]. 16 individuals below 18 years of age were excluded from the QoL analysis as no reference values exist.

PHC, MHC and GHC score interpretation is shown in Table 5. The following principles are applied [8]:

- **Low T scores** are defined as T scores obtained by approximately 20% or less of the normative group.
- **The clinical cut score** is defined as the point that optimally differentiates those in an independently defined criterion group as low on the criterion from those defined as high on the criterion.
- **High T scores** are defined as scores >50 and obtained by approximately 50% or more of the normative non-clinical sample.

Table 5: Quality of life score interpretation [8]

	PHC		MHC		GHC	
	T score	Interpretation	T score	Interpretation	T score	Interpretation
Low	≤42	Perceived physical health problems are impeding life functioning	≤38	Individuals has psychological symptoms that might impede life functioning	≤42	Perceived health problems are impeding life functioning
Clinical cut score	47		41		50	
High	>53	Individuals are less likely to have physical health problems that impede life functioning.	>53	Individuals are not likely to have psychological problems that impede life functioning	>52	Individuals have normal or better global health functioning

The PHC, MHC and GHC can be used for tracking clinical change and see if an individual has benefited from an intervention. Thus, the PHC, MHC and GHC scores can be compared in the population to the baseline survey to measure the impact of the HAP2 HBC intervention for the two pilot regions.

3.7 Ethical considerations

The study protocol, including informed consent and the questionnaire tool, was submitted for ethical clearance and authorization to the Albanian Ministry of Health and Social Protection. Ethical clearance to conduct the study was obtained (Reference No: 633/20, dated 25.08.2023).

Before the interview, the respondents were given detailed information about the purpose of the study and the extent of their involvement. It was emphasised, that the participation is entirely confidential and voluntary and that the respondents may withdraw the participation at any time. Written informed consent was obtained from each participant (i.e. patient or where applicable, the proxy respondent).

Each patient was assigned a unique ID. The unique ID was used both on the informed consent sheet signed by the respondent as well as in the electronic questionnaire for ethical clearance documentation. No identifying information was recorded in the electronic questionnaire form.

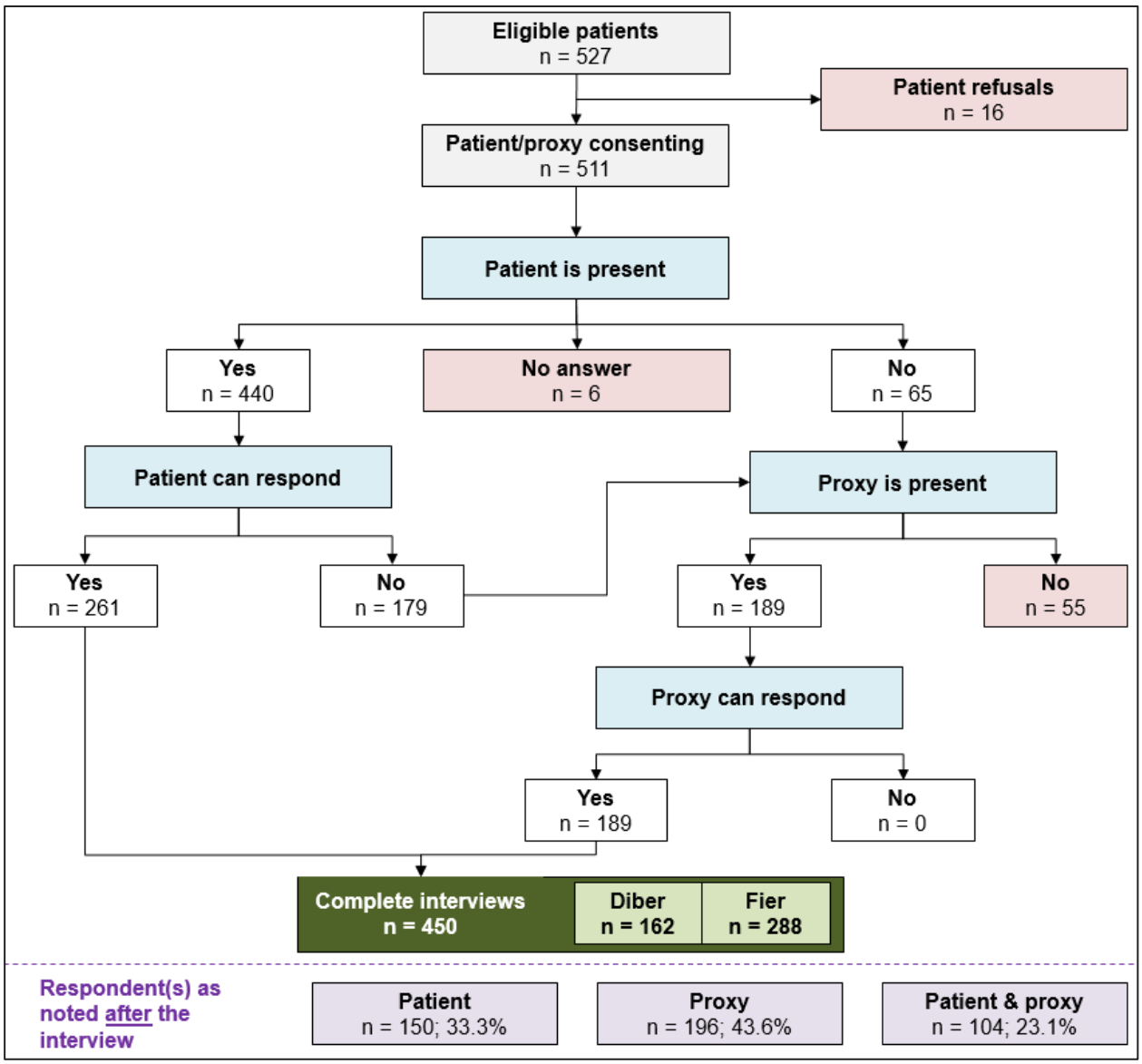
4. RESULTS

4.1 Study population

Figure 2 shows the flowchart of the study respondents (patients and proxy). Overall, 527 persons were registered as eligible for the study and approached by the data collection team. Thereof, 16 have refused to participate in the study already at contact stage, resulting in a 3.0% refusal rate, compared to 5.6% in 2021.

Finally, 450 persons were consenting to participate in the study and completed interviews, thus similarly to the 454 complete interviews in 2021. Moreover, 162 (36.0%) were from Dibër and 288 (64.0%) from Fier (178/39.2% and 276/60.8% in 2021, respectively).

Figure 2: Respondent flowchart, Diber and Fier, 2023



At the start of the interview, 261 of patients reported to be able to respond themselves to the questionnaire and for 189 of interviews the proxy was the designated respondent. At the end of the interview, the interviewer was noting down (again) who finally was the person that was responding. For 150 of interviews, it was the patient her-/himself alone (33.3%), for 196 (43.6%) of interviews it was the proxy and for 104 (23.1%) of interviews it was both together. Thus, often, it was required that household members 'supported' the patient in answering the questions. These respondent patterns were very similar to 2021 (33.7%, 47.6% and 18.7%, respectively).

For the 189 patients where a proxy was responding to the questionnaire, the proxy respondents were in most cases a son- or daughter-in-law (25.4%), followed by a parent (20.1%) and the patient's children (18.5%) (Table 6). The same four proxy respondent categories were most frequent in 2021 but with marginal differences in the proportions.

Table 6: Proxy respondents, Diber and Fier, 2021 and 2023

	2021		2023	
Proxy relationship to the patient	**n**	**%**	**n**	**%**
Son / daughter	42	22.3	35	18.5
Parent	39	20.7	38	20.1
Spouse / partner	34	18.1	23	12.2
Son- / daughter-in-law	29	15.4	48	25.4
Head of household	15	8.0	10	5.3
Sister / brother	10	5.3	7	3.7
Sister- / brother-in-law	8	4.3	0	0.0
Grandchild	4	2.1	4	2.1
Grandparent	2	1.1	2	1.1
Other relative	2	1.1	8	4.2
Other	2	1.1	9	4.8
Parent-in-law	1	0.5	3	1.6
Total	**188**	**100.0**	**189**	**100.0**

Overall, the total number of interviews per year, intervention vs. control group, region and health center are shown in Table 7.

Table 7: Number of respondents by health center, Diber and Fier, 2021 and 2023

	Intervention			Control			Total	
		2021	2023		2021	2023	2021	2023
Dibër	Shupenze	32	14	Lis	14	**16**		
	Melan	18	9	Gjorice	10	9		
	Komsi	16	10	Suc	17	20	**178**	**162**
	Klos	32	40	Maqellare	39	44		
Subtotal		***98***	***73***		***80***	***89***		
Fier	Roskovec	13	12	Aranitas	37	**33**		
	Portez	35	29	Divjake	21	27		
	Ballagat	19	23	Fier No. 3	56	73	**276**	**288**
	Patos	55	47	Kuman	40	44		
Subtotal		***122***	***111***		***154***	***177***		
Total		**220**	**184**		**234**	**266**	**454**	**450**

4.2 Patient characteristics

Patient characteristics are shown in Table 8. In Diber and Fier overall, 58.6% of patients were female (55.5% in 2021) and 41.4% were male (44.5% in 2021). Similar to 2021, in Fier, the proportion of female patients was higher (64.9% in 2023 and 58.7% in 2021) than in Diber (53.1% in 2023 and 50.6% in 2021).

Mean age was 70.0 years (±19.6 standard deviation (SD), thus, similar to 2021 (68.8 years ±20.9 SD). Mean age in women was 73.9 years (2021: 72.1 years) vs. 63.9 years in men (2021: 64.4 years). In Diber, mean age was 67.5 years (2021: 65.7 years) and in Fier, mean age was 71.4

years (2021: 70.6 years). Thus, in both survey years, patients in Fier were slightly older on average. Mean age in intervention vs. control group was very similar (70.2 vs. 69.8 years, respectively). In terms of age categories, the majorities in both years were in the >65 years age category (70.4% in 2023 and 69.6% in 2023.

As in 2021, most of the patients in Diber and Fier were married (46.0% in 2023 vs. 46.7% in 2021) and about a third was widowed (35.8% in 2023 vs. 31.7% in 2021). Overall, 24.0% of patients reported to not have had any education, compared to 24.9% in 2023. Across the survey years, this proportion decreased in Diber from 32.0% to 23.5% but increased slightly in Fier from 20.3% to 24.3%. This high percentage might be explained by several factors, including the old age of many patients or the physical and mental handicaps of the patients that might have restrained these individuals from attending school. In general, changes over the survey years for the different groups (regions or intervention/control) were marginal.

Table 8: Patient characteristics (%), Diber and Fier, 2021 and 2023

	Dibër		Fier		Intervention		Control		Total	
	2021	2023	2021	2023	2021	2023	2021	2023	2021	2023
Sex										
Female	50.6	53.1	58.7	64.9	55.9	58.2	55.1	62.4	55.5	60.7
Male	49.4	46.9	41.3	35.1	44.1	41.8	44.9	37.6	44.5	39.3
Age in years										
<18 years	4.6	1.9	2.9	2.8	3.7	0.6	3.5	3.8	3.6	2.5
18-24 years	5.8	1.8	1.5	1.1	4.2	1.1	2.2	1.5	3.1	1.3
25-44 years	8.0	12.4	5.8	6.3	8.3	6.2	5.2	8.7	6.7	8.5
45-65 years	20.1	21.0	15.0	15.3	18.0	22.9	16.0	13.5	17.0	17.4
> 65 years	61.5	63.0	74.8	74.6	65.9	67.2	73.2	72.6	69.6	70.4
Mean age in years	65.7	67.5	70.6	71.4	67.2	70.2	70.1	69.8	68.8	70.0
Marital status										
Married	38.8	45.7	51.8	46.2	43.2	43.5	50.0	47.7	46.7	46.0
Divorced	0.6	0.0	0.0	0.4	0.5	0.5	0.0	0.0	0.2	0.2
Separated	0.0	0.0	0.4	0.4	0.5	0.5	0.0	0.0	0.2	0.2
Widow/er	34.8	32.7	31.9	37.5	34.6	39.7	31.6	33.1	33.0	35.8
Single	25.8	21.6	15.9	15.6	21.4	15.8	18.4	19.2	19.8	17.8
Educational attainment										
None	32.0	23.5	20.3	24.3	26.8	22.8	23.8	24.8	24.9	24.0
Pre-school, Kindergarten	1.1	0.6	1.1	1.0	1.8	0.5	0.4	1.1	1.1	0.9
Primary (grade 1-5)	33.2	29.0	27.9	28.1	31.4	29.4	28.6	27.8	30.0	28.4
Secondary (grade 6-9)	21.9	37.7	30.1	22.2	25.9	29.9	27.8	26.3	26.9	27.8
High school	9.0	4.9	14.5	20.1	10.5	14.7	14.1	14.7	12.3	14.7
College, Technical University	0.6	1.9	2.2	1.4	1.8	2.2	1.3	1.1	1.5	1.6
University	1.7	0.6	4.0	2.1	1.8	0.0	4.3	2.6	0.2	1.6

Overall, no major study population differences were observed for the patient population in terms of the assessed background characteristics (sex, age, marital status and educational attainment) in:

- the Diber vs. Fier in 2023;
- the Diber and Fier between 2021 and 2023; and

- the health centers offering HBC (i.e. intervention) and the health centers not offering HBC (i.e. control) in 2023.

4.3 Household characteristics

4.3.1 Household composition

In Fier and Diber, none of the patients lived alone but 121 patients (27.0%) lived in a 2-person household (2021: 26.2%). Thereof, 79 (65.3%) lived with their spouse, which was considerably less than in 2021 (81.5%). Another 17.4% lived with another, non-relative (2021: 7.5%) and 11.4% lived with a child (2021:11.0%). According to the Albania DHS, the proportion of 2-person households was 26.4% in rural and 29.1% in urban households [6]. In turn, 73.0% of patients lived in a household with more than 2 people (2021: 73.8%).

Overall, 53.6% lived with their spouse, which was considerably less than in 2021 (85.2%). Further, 50.7% were living with their child(ren), 38.4% with in-law(s), 21.3% parent(s), 15.8% with grandchild(ren), 11.6% with niece(s) or nephew(s) and 10.0% with sibling(s). Of note, the exact number of household members was not recorded.

4.3.2 Housing conditions

Housing structures, i.e. materials of the floor, walls and the roof, for all four regions surveyed in 2023 are shown in Table 40 in annex 9.3.

Overall, housing conditions in Fier and Diber remained similar to 2021. In Diber, the typical houses were having ceramic tiles as floors (72.8%), covered adobe as walls (57.4%) and ceramic tiles as roofs (90.7%). In Fier, houses were similar but more often with reinforced concrete as roofs.

4.3.3 Household income

Households stated their main sources of income, whereby all existing sources were mentioned. In the surveyed households, the majority had income from pension funds (93.3%; Figure 3). This was similar as in 2021 (92.7%). In Dibër, the proportion of households gaining income was higher than in Fier for several sources, namely salary from irregular income, social aid and farming and livestock keeping. The intervention and control groups had similar proportions for all income sources.

Figure 3: Household income, Diber and Fier, 2023

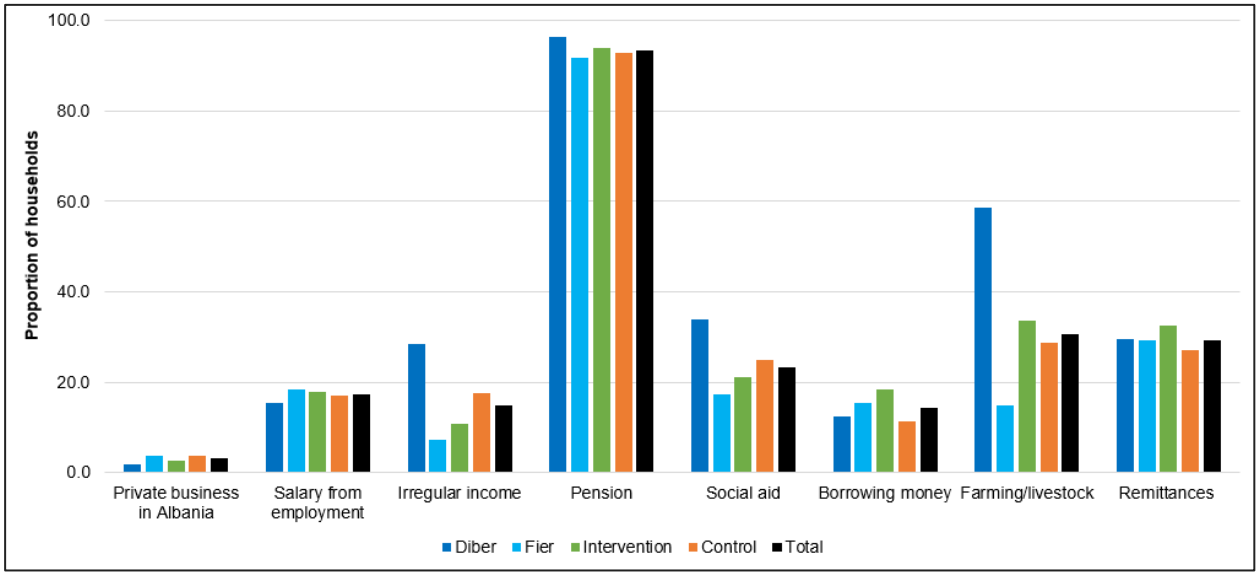
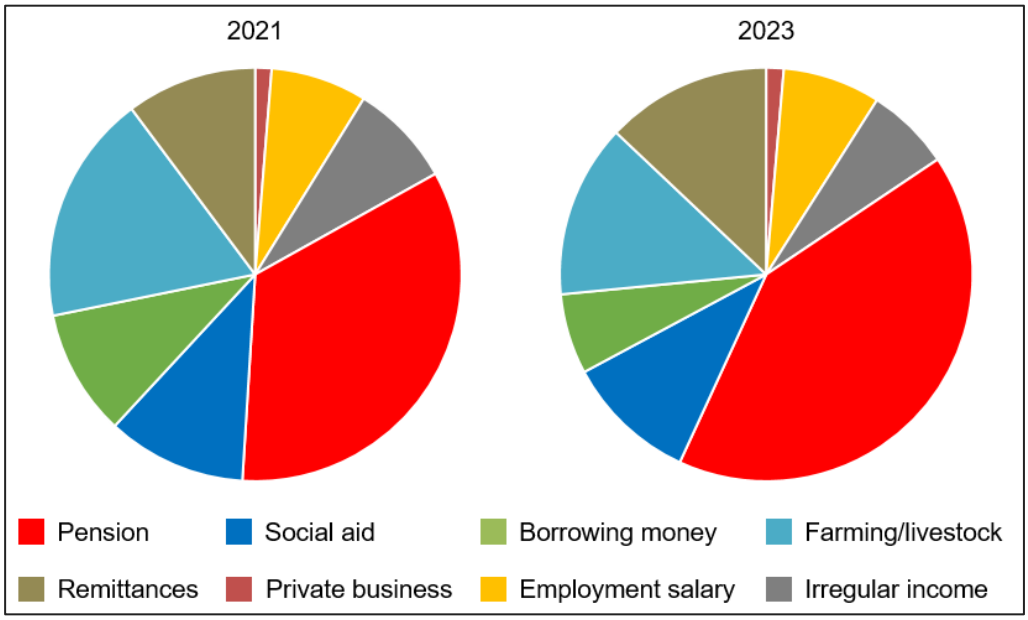


Figure 4 shows the overall relative proportions of income sources in Fier and Diber in 2021 and 2023 (sources sum up to over 100% as multiple sources of income are possible). The proportion of patients relying on pension funds has increased between 2021 and 2023. In turn, less patients relied on farming/livestock income, remittances and from borrowing money.

Figure 4: Household income sources by year, Diber and Fier, 2021 and 2023

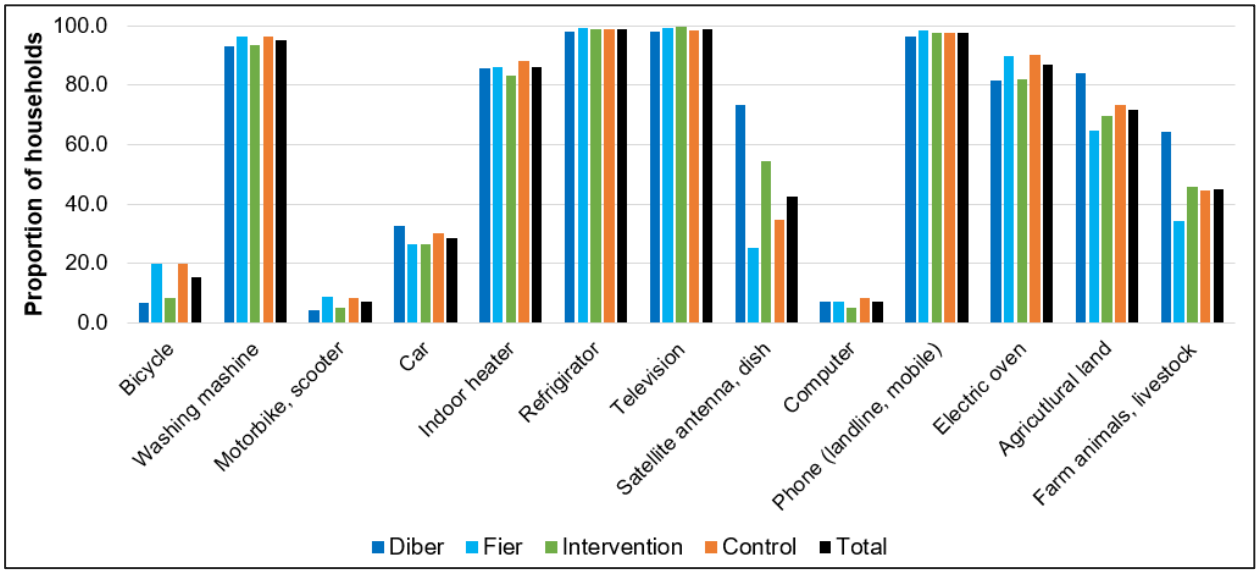


4.3.4 Household assets and wealth quartiles

The possession of household assets per region and group is shown in Figure 5. Across all subgroups, households were well equipped with washing machines, indoor heaters, refrigerators, televisions, phones and electric ovens. Less than 30% had transportation vehicles such as bicycles, motorbikes or cars. Differences between regions were mainly concerning the possession of satellite antennas/dishes (73.5% in Dibër vs. 25.4% in Fier), agricultural land (84.0% in Dibër vs. 64.9% in Fier) and livestock (64.2% in Dibër vs. 34.4% in Fier). Overall, the control group had slightly higher levels of possession for most the surveyed assets than the intervention group.

Between 2021 and 2023, the possession of household assets has changed only marginally. Exception was the satellite antennas/dishes (decreases across all groups).

Figure 5: Household assets, Diber and Fier, 2023



Wealth quartiles by year, region and intervention control group are shown in Table 9. As described in the methods, 2021 households are considered the baseline, against which the 2023 wealth scores were measured.

In 2023, in Diber, most patients were in the second (40.4%) and third (29.8%) quartile. In Fier, however, most were in the poorest quartile (41.2%). Importantly, in Fier, there was a significant increase of the proportion of patients in the poorest wealth quartile and in turn a decrease in the wealthiest quartile.

Wealth quartile distribution in the intervention vs. control group were comparable in 2021. In 2023, however, there was more patients in the intervention group in the second quartile as compared to the control group. In turn, the control group had slightly more patients in the third and wealthiest quartile.

Table 9: Wealth quartiles, Diber and Fier, 2021 and 2023

	Dibër		Fier		Intervention		Control		Total	
	n	%	n	%	n	%	n	%	n	%
2023										
Poorest	35	21.7	117	41.2	62	34.1	90	34.2	152	34.2
Second	65	40.4	63	22.2	63	34.6	65	24.7	128	28.8
Third	48	29.8	57	20.1	37	20.3	68	25.9	105	23.5
Wealthiest	13	8.1	47	16.6	20	11.0	40	15.2	60	13.5
2021										
Poorest	64	36.2	49	17.9	63	28.8	50	21.6	133	25.1
Second	60	33.9	53	19.3	53	24.2	60	25.9	113	25.1
Third	34	19.2	89	32.5	57	26.0	66	28.5	123	27.3
Wealthiest	19	10.7	83	30.3	46	21.0	56	24.1	102	22.5

4.4 Patient's health problems

Table 10 and Figure 6 show the health issues reported by patients, in terms of frequency and proportion of all problems reported. Of note, these are self-reported health issues by the patient or the proxy, where the accuracy of the diagnosis and/or the medical terminology was not verified and where issues were summarized into ICD-10 classification. However, some respondents' answers were medically unclear and did not allow precise classification.

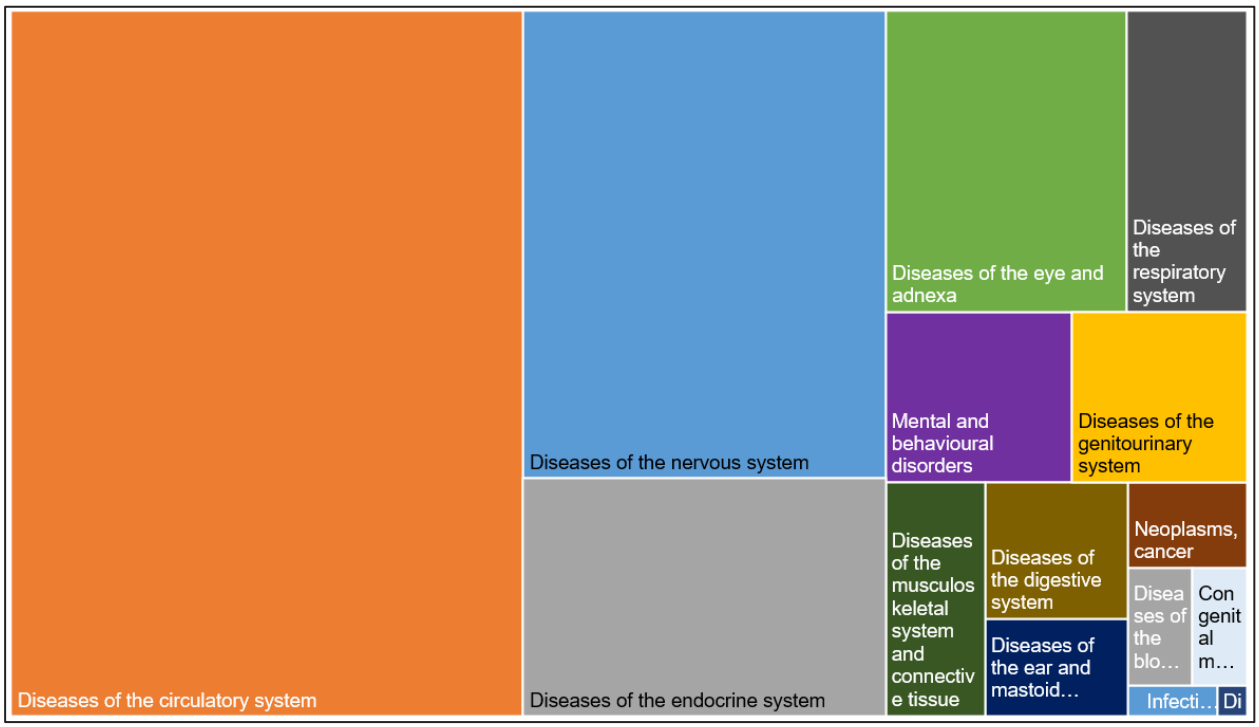
In general, the burden of disease pattern found was typical for this ageing population in the given context. In Diber and Fier in total, 937 health issues were reported by all patients. 137 patients (30.4%) reported one health problem and the remaining 69.6% reported multiple health problems. As visualised in Figure 6, diseases of the circulatory system (incl. heart issues, hypertension, etc.) were most prevalent in the study population (41.4% of all reported issues). This was followed by diseases of the nervous system (19.4%), endocrine diseases (incl. diabetes, 9.9%) and diseases of the eye and adnexa (8.3%).

Table 10: Health problems reported, Diber and Fier, 2023

ICD-10 code	Health issue	n	% of patients	% of total health issues
C00–D48	Neoplasms	11	2.4	1.2
D50–D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	8	1.8	0.9
E00–E90	Endocrine, nutritional and metabolic diseases	93	20.7	9.9
F00–F99	Mental and behavioural disorders	34	7.6	3.6
G00–G99	Diseases of the nervous system	182	40.4	19.4

H00–H59	Diseases of the eye and adnexa	78	17.3	8.3
H60–H95	Diseases of the ear and mastoid process	15	3.3	1.6
I00–I99	Diseases of the circulatory system	388	86.2	41.4
J00–J99	Diseases of the respiratory system	39	8.7	4.2
K00–K93	Diseases of the digestive system	21	4.7	2.2
L00–L99	Diseases of the skin and subcutaneous tissue	1	0.2	0.1
M00–M99	Diseases of the musculoskeletal system and connective tissue	25	5.6	2.7
N00–N99	Diseases of the genitourinary system	32	7.1	3.4
Q00–Q99	Congenital malformations, deformations, and chromosomal abnormalities	7	1.6	0.7
	Infectious and parasitic diseases	3	0.7	0.3
	Total health issues reported	**937**	**n/a**	**100.0**

Figure 6: Health issues reported, Diber and Fier, 2023



The pattern of health issues reported differed in 2021 and 2023 as follows:

- A strong increase in circulatory system issues (from 15.0% to 86.2%).
- A slight increase of nervous system issues (from 33.5% to 40.4%).
- Whilst diseases of the musculoskeletal system and connective tissue were reported by a quarter in 2021 (26.8%), they were reported by 5.6% in 2023.
- The percentage reporting endocrine, nutritional and metabolic diseases remained stable (19.6% and 20.7%, respectively).
- Importantly, as these are self-reported health issues, this increase might be partly explained reporting biases, e.g. underreporting in 2021, or increased awareness in 2023.

In the 12 months preceding the survey 5.6% n=25) patients had an operation (2021: 4.9%). Proportions were similar in Dibër and Fier (4.9% vs. 5.9%) and insignificantly different in the intervention vs. control groups (3.3% vs. 7.1%).

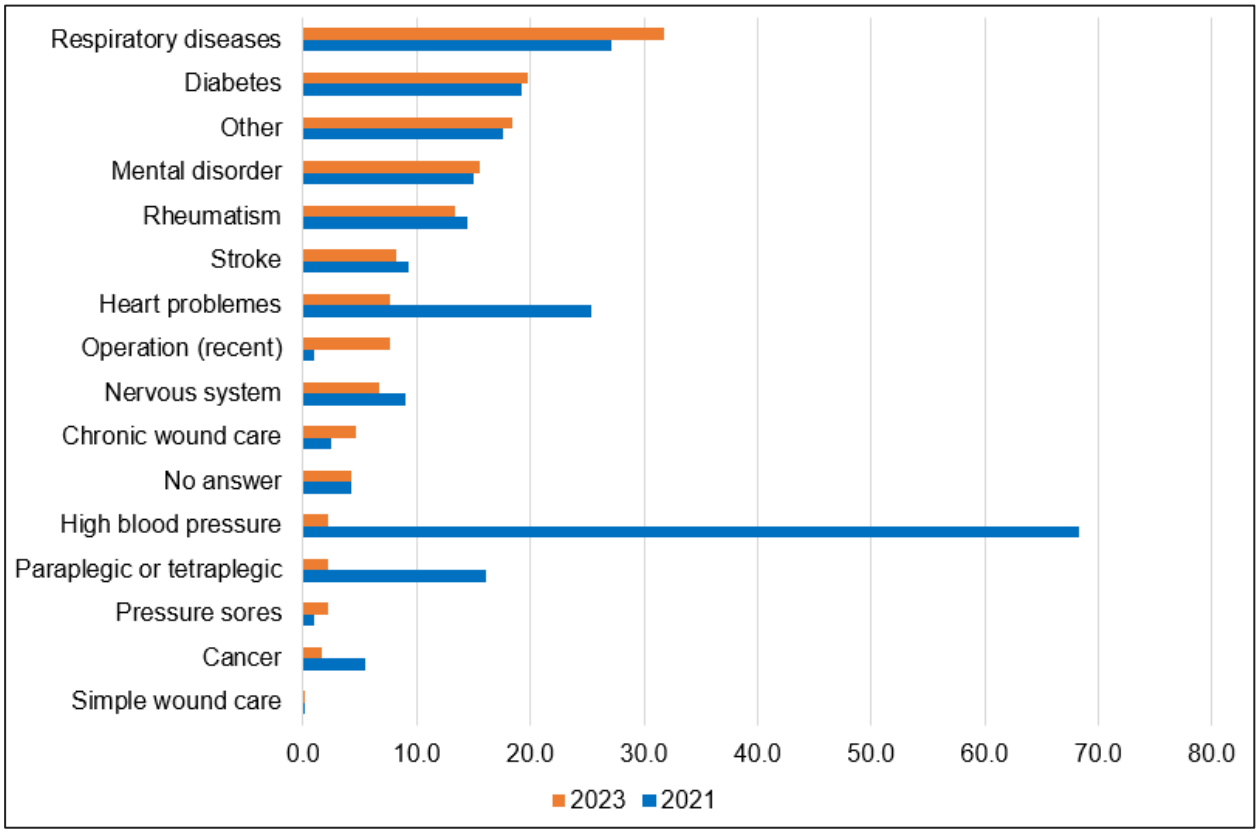
Overall, 10.7% (n=48) patients required simple wound care (2021: 11.5%) which was required every day by most patients (58.3%; n=28; 2021: 71.2%). Another 6 (12.5%) patients required

simple wound care several times a week. 10.0% (n=45) patients required chronic wound care (2021: 14.1%) which was required every day by most of them (62.2%; n=62; 2021: 73.4%).

4.5 General access to health care

Figure 7 shows health problems, for which patients would seek care but patients reportedly encounter difficulties in seeking care, for 2021 and 2023. Health care access has become more difficult for most for respiratory diseases by 4.7%. For heart problems, high blood pressure, para- or tetraplegic and cancer patients, however, health care access seems to have improved.

Figure 7: Health issues for which patients would seek care but accessibility is limited, Diber and Fier, 2021 and 2023



Overall, only 8.9% of patients reported to be able to ever visit the health center without assistance. This was similar in Diber (7.4%) and Fier (9.7%) and the intervention (9.2%) and control groups (8.7%).

More than two thirds of the patients (72.9%; 2021: 61.2%) experienced barriers to visit the health center in the two months preceding the survey. This was similar in Diber (67.7%) and Fier (72.8%). Thus, in Fier, the proportion of patients experiencing barriers has increased significantly from 59.1% since 2021 (p=0.001). The level of limited access to a health center was similar in the intervention (68.5%) and control groups (64.8%). These rates are mainly explained by the nature of the study population, i.e. largely home-bound or bed-bound patients. In fact, the proportion of patients reported to be entirely bed-bound increased from 16.5% (95% CI 13.2-20.2%) in 2021 to 22.0% (95% CI 18.3-26.1%) in 2023.

Reported barriers are shown in Table 11. As in 2021 (47.1%), 'not being able to walk to the health center' was the main barrier in 2023 (287; 63.8% overall), followed by 'not being able to afford transportation to the health center' (174; 38.7% overall; 2021: 28.6%). In 2023, more than two thirds of patients (36.2%; 95%CI 31.8-40.9%) were both bed-bound and could not afford transport to go to the health facility, which was significantly higher than in 2021 (21.4%; 95%CI 17.7-25.4%).

Table 11: Access barriers to health care, Diber and Fier, 2021 and 2023

	Dibër		Fier		Intervention		Control		Total	
	n	%	n	%	n	%	n	%	n	%
2021										
Can't afford to take the transport	83	46.6	47	17.0	63	28.6	67	28.6	130	28.6
Can't walk to the health facility	92	51.7	122	44.2	101	45.9	113	49.3	214	47.1
Is bed-bound	25	14.0	50	18.1	34	15.5	41	17.5	75	16.5
Other barriers	7	3.9	6	2.2	9	4.1	4	1.7	13	2.9
Can't afford to take the transport & Is bed-bound at the same time	64	36.0	33	12.0	44	20.0	53	22.7	97	21.4
2023										
Can't afford to take the transport	65	37.4	109	37.9	73	39.7	101	38.0	174	38.7
Can't walk to the health facility	99	61.1	188	65.3	119	64.7	168	63.2	287	63.8
Is bed-bound	43	26.5	56	19.4	39	21.2	60	22.6	99	22.0
Other barriers	7	3.9	6	2.2	9	4.1	4	1.7	13	2.9
Can't afford to take the transport & Is bed-bound at the same time	59	36.4	104	36.1	68	37.0	95	35.7	163	36.2

In 2023, none of the patients in reported to be covered by a private health insurance compared to 9 (2.0%) in 2021.

4.6 Health care costs

Reported health care costs in the 2 months preceding the survey are shown in Table 12. As in 2021, for most patients, most costs resulted from buying medication/drugs (82.0%; 2021: 84.6%). In 2023, this was followed by costs for diagnostic tests (33.8%; 2021: 23.6%), cost for transportation to the health center (23.6%; 2021: 26.7%) and costs for consumables (20.2%; 2021: 18.9%).

Inflation was considered as follows: 2021 was taken as the reference value; and inflation rates considered were 8.9% depreciation between 2021 and 2022 (inflation rate for 2023 was not available at the time or the report writing).[3] In addition, in the conversion to USD annual average exchange rates were applied for 2022 and 2023.

The median expenditure for health care overall (excluding hospitalisation costs) slightly increased between 2021 and 2023 from 12,000 LEK to 13,068 LEK. In 2023, highest costs were for medications with 9,093 LEK, compared to 8,000 LEK in 2021. Interestingly, costs for 'transport for health care assistance at home' has decreased from 3,500 LEK in 2021 to 2,178 LEK in 2023.

Twenty-two patients (4.9%) were hospitalised in the 2 months preceding the survey. For those, the median hospitalisation cost was 43,560 LEK [actual range 2,178 – 272,250 LEK] or 434 USD [actual range 22 – 2,714 USD]. This is a considerable increase since 2021 (20,000 LEK [actual

[3] https://www.worlddata.info/europe/albania/inflation-rates.php#:~:text=The%20inflation%20rate%20for%20consumer,the%20price%20increase%20was%202%2C474.13%25

range 500 – 1,200,000 LEK]), however, small sample sizes don't allow for a meaningful comparison.

Few respondents (17, 3.8%; 2021: 5.3%) reported to offer gifts (including money) to the health care providers providing health care assistance at home in the 2 months preceding the survey. This was done as signs of gratitude and respect to the health care provider.

Table 12: Health care costs in the 2 months preceding the survey, Diber and Fier, 2021 and 2023

	Proportion that has paid for the health care need n (%)	Average cost in LEK (median [IQR])[1]	Average cost in USD (median [IQR])[2]
2021			
Medication/drugs	384 (84.6)	8,000 [4,000-16,000]	75 [37-149]
Consumables (e.g. catheter, wound treatment)	86 (18.9)	4,000 [2,000-7,000]	37 [19-65]
Tests	107 (23.6)	5,000 [2,000-9,500]	47 [19-88]
Transport of the health care assistance at home	28 (6.2)	3,500 [1,000-6,000]	33 [9-56]
Transport to the health centre	121 (26.7)	3,000 [2,000-6,000]	28 [19-56]
Outpatient services	33 (7.3)	4,000 [1,000-10,000]	37 [9-93]
Other	37 (8.2)	8,000 [3,500-20,000]	75 [33-186]
Nothing	*39 (8.6)*	*n/a*	*n/a*
No answer	*6 (1.3)*	*n/a*	*n/a*
Overall health care costs (excluding hospitalisation) – self-reported	**n/a**	**12,000 [6,000-30,000]**	**112 [56-279]**
Hospitalisation in 2 months preceding the survey (n=28)	28 (6.2)	20,000 [7,500-52,500]	186 [70-488]
2023			
Medication/drugs	369 (82.0)	9,093 [4,901-16,335]	91 [49-163]
Consumables (e.g. catheter, wound treatment)	91 (20.2)	5,445 [5,445-10,890]	54 [54-108]
Tests	152 (33.8)	5,990 [4,356-10,890]	58 [43-109]
Transport of the health care assistance at home	30 (6.7)	2,178 [0-5,445]	22 [0-54]
Transport to the health centre	106 (23.6)	3,267 [1633-5,445]	33 [16-54]
Outpatient services	30 (6.7)	2,178 [0-4,356]	22 [0-42]
Other	28 (6.2)	13,068 [5,445-21,780]	130 [54-217]
Nothing	*52 (11.6)*	*n/a*	*n/a*
No answer	*0 (0.0)*	*n/a*	*n/a*
Overall health care costs (excluding hospitalisation) – self-reported	**n/a**	**13,068 [6,534-26,681]**	**130 [65-266]**
Hospitalisation in 2 months preceding the survey (n=22)	22 (4.9)	43,560 [11,979-54,450]	434 [119-543]

[1] Inflation rate between 2021 and 2022.9% depreciation between (inflation rate for 2023 was not available at time of report writing)
[2] Exchange rates: 2021, 0.0093 (annual average); 2023, 0.009967 (annual average)

4.7 Care provided by family members

In Fier and Diber, out of the 450 patients, 413 (91.8%) received care support from family members. Thus, comparable to 2021 where the rate was 92.7%. In 2023, the rate was comparable between regions (94.4% in Dibër and 90.3% in Fier). Interestingly, the rate was significantly lower in the intervention group (88.6%; 95% CI 83.1-92.8%) than the control group (94.0%; 95% CI 90.4-96.5%). Whilst in 2021, on average, about 2.3 family members supported the patients' care in a household (range 1-7), this was 1.4 in 2023 (range 1-4). Thus, the burden of health care provided by family members seem to have reduced in terms of number of family

members, however, the care load per caretaker increased (see below). Demographic changes in Albania, particularly the high out-migration of young Albanians might have influenced this finding, resulting in less family members present to care for patients in need.

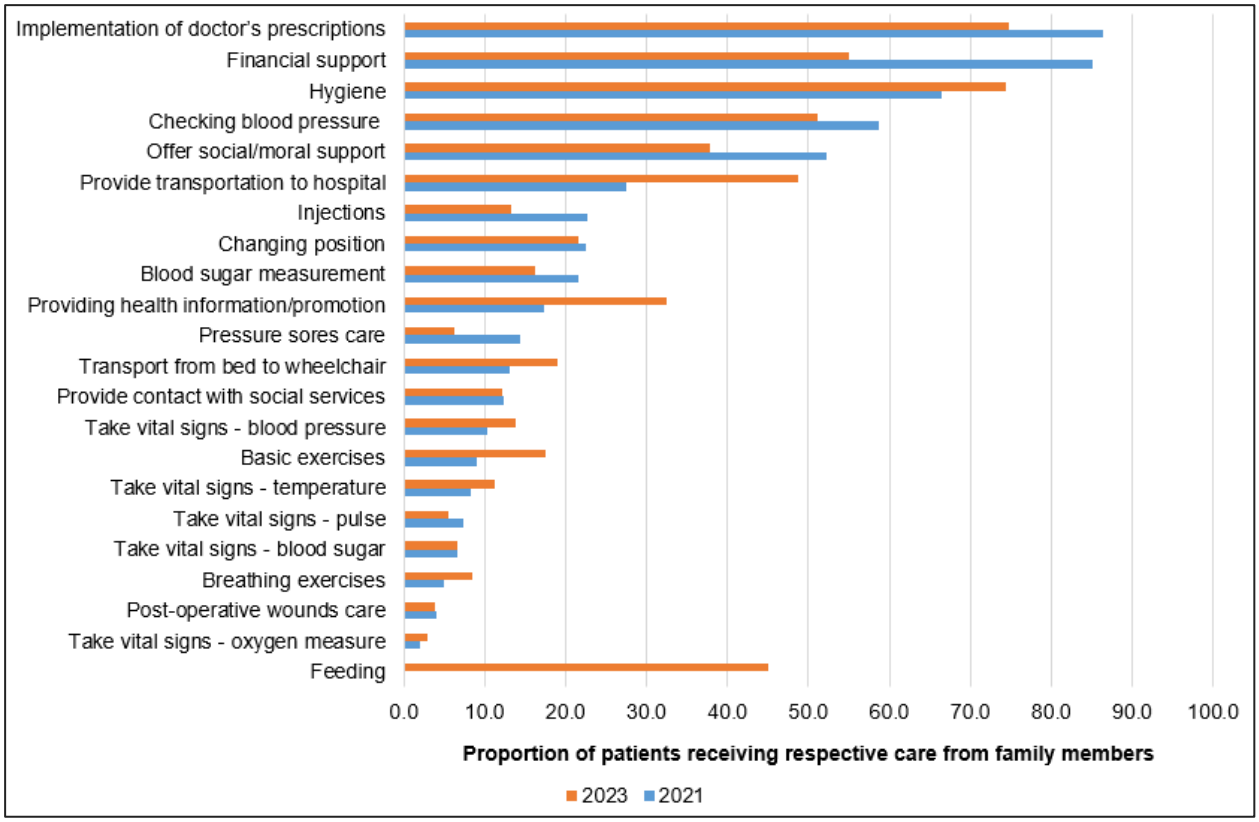
Of those 413 patients with care from family members, in-laws were most frequently involved in care taking (35.6%; Table 13), followed by children (30.2%) and spouses (29.1%). This pattered differed from 2021, were spouses were most frequently involved in care taking (68.7%), followed by siblings (29.4%), children (35.9%), and in-laws (33.9%).

Table 13: Family care takers, Fier and Diber, 2021 and 2023

Care takers	2021		2023	
	n	%	n	%
Spouse	312	68.7	131	29.1
Siblings	179	39.4	22	4.9
Children	163	35.9	136	30.2
In-laws	154	33.9	160	35.6
Parents	79	17.4	70	15.6
Grandchildren	13	2.8	14	3.1
Nieces, nephews	11	2.4	6	1.3
Cousins	1	0.2	7	1.6
Other family member	28	6.2	13	2.9

The different forms of care and support that family members provide in Fier and Diber regions in 2021 and 2023 are shown in Figure 8. In both survey years, more than half of the patients receive support from family members (i) in implementing of doctor's prescriptions, care and treatment; (ii) financial support; (iii) hygiene; and (iv) checking blood pressure. Overall, there was considerable variation between the years. Provision of transportation to the hospital increased by 21.1% and providing health information also increased by 15.0%. In turn, financial support decreased by 30.1%, implementation of doctor's prescription by 11.6% and offering social/moral support by 14.4%.

Figure 8: Care and support provided by family members, Diber and Fier, 2021 and 2023



Respondents were estimating the number of hours per day that family members take care of the patients' health, all hours from all family members combined. On average, family members invested together 19.7 hours (±7.4 SD) per day for the care and support of the bed / home-bound patient. Thus, this is an increase of 4.1 hours compared to 15.6 hours (±8.1 SD) per day estimated in 2021. This significant increase might be partly due to a deteriorated health status of the patients, requiring more care. In 2023, the time effort was similar in Diber (19.2 hours) and Fier (19.9 hours). In the intervention vs. control groups the effort was 20.7 hours vs. 19 hours.

As for the family member that is taking most care of the patient, 14.8% were reported to have a job or another type of regular occupation or activity outside of the household (2021: 21.9%). Thus, the majority (85.2%) of these main caretakers did not have another regular activity outside of the household. Those having a regular activity, the amount of time these caretakers spend at their regular activity per week was 17.6 hours on average (2021: 20.6 hours) and ranged from 8.3 in Dibër to 20.6 in Fier, potentially indicating that in Fier, more people pursued some sort of regular activity as compared to Dibër. This was similar as in 2021 (7.2 in Dibër vs. 34.1 in Fier). Importantly, this was lower in the intervention group (13.9 hours) than the control group (19.1 hours).

For 125 (27.8%) patients, respondents reported that also friends, neighbours or other acquaintances were also involved in providing care and support for the patient (2021: 22.1%).

4.8 Health care assistance at home

Health care assistance at home is if someone – excluding family members – is visiting a patients' home to care for her/his health needs. HBC, in contrast, refers to the intervention designed by the HAP2 project and approved and taken-up by the MOHSP, and includes – as opposed to health care assistance at home – more services and service provision by nurses. These nurses are specifically trained for advanced nursing procedures, assisted by specific paramedical equipment to ease the chronic patient situation at home.

In interpreting the results of this section, the following considerations have to be taken into account:

- While eligibility criteria dictated that patients should have received HBC at the time of the survey, it's possible that some received it intermittently. The reasons for interruptions or abandonment of HBC could stem from both patient demand and health care system supply factors.
- Recall and response bias from respondents might contribute to obscurity of certain results, e.g. respondents might not always make the distinction between health care assistance at home and HBC (as described above).

4.8.1 Availability of health care assistance at home

About half of the respondents in Fier and Diber (223; 49.6%) were aware, that health care assistance at home exists as a service (2021: 247; 54.4%). Importantly, in 2023, this awareness was significantly higher in the intervention group (70.1%; 95% CI 62.9-76.6%) than the control group (35.4%; 95% CI 29.6-41.4%; p<0.001). In contrast, the awareness about this service was similar in 2021 in the comparison and the control group (57.3% and 51.7%, p=0.234, respectively).

Among those aware, in 2023, most heard about this service from their nurse (89.7%) and their doctor (60.1%). This was markedly higher than in 2021, where 66.0% heard about the service from their nurse and 39.3% from their doctors. Indeed in 2023, hearing from the nurse as well as from the doctor was higher in the intervention group than in the control group (93.8% vs. 84.0%; p=0.018, and 70.5% vs. 45.7%; p<0.001, respectively). These results indicate a marked increase in the intervention group on awareness and communication from these health staff to their patients about this service.

In turn, in 2023 compared to 2021, less respondents heard about it from a family member (1.8% vs 11.3%), a friend (2.7% vs. 7.7%), a health post worker (1.4% vs. 4.5%) or publicity in a health center (2.2% vs. 3.2%). According to the respondents (n=223), it is predominantly nurses that offer this service (95.5%; 2021: 98.4%).

4.8.2 Expected effects of health care assistance at home

Respondents were asked what their expected effects are regarding health care assistance at home. First spontaneously, i.e. without prompting any answers (Table 14). In 2023, as in 2021, expected effects were highest with regard to ‘getting better treatment and care for the disease’, which was stated by more than half of the respondents (62.7%; 2021: 50.0%).

For those options not mentioned spontaneously, respondents were prompted if they would also expect those (note: denominator are those that have not expressed the expectation spontaneously and, thus, varies). The expectation levels for all the prompted options were >65% in 2021. In 2023, expectation levels were in general somewhat lower. For example, the ‘reduction of the transportation needs’ was expected by 74.4% in 2021 but by 49.2% in 2023.

Overall (both spontaneously and prompted combined), expectations were high in both years, with ‘any expectations’ at 98.2% in 2021 and 95.3% in 2023. However, in 2023, the proportion of those having ‘any of the expectations’ was significantly higher in Fier (98.3%; 95% CI 96.0-99.4%) than in Diber (90.1%; 95% CI 84.5-94.2%; p<0.001). No significant difference was found in this regard between the intervention and control groups.

Table 14: Expected effects of health care assistance at home, Diber and Fier, 2021 and 2023

Expected effects	Spontaneous		Prompted		Overall	
	n	%	n	%	n	%
2021						

Better treatment and care for the disease	227	50.0	162	71.4	389	85.7
Pain relief[1]	185	40.8	181	67.3	366	80.6
Reduction of transportation needs	123	27.8	244	74.4	370	81.5
Reduction of the workload for family members in care taking	118	26.0	230	68.5	348	76.7
Increased quality of life	110	24.2	242	70.4	352	77.5
Being better informed about the illness/disease	87	19.2	262	71.4	349	76.9
Any of the above expectations	n/a				446	98.2
2023						
Better treatment and care for the disease	282	62.7	89	53.0	371	82.4
Pain relief[1]	172	28.2	168	60.4	340	75.6
Reduction of transportation needs	125	27.8	160	49.2	285	63.3
Reduction of the workload for family members in care taking	121	26.9	141	42.9	262	58.2
Increased quality of life	136	30.2	206	65.6	342	76.0
Being better informed about the illness/disease	152	33.8	149	50.0	301	66.9
Any of the above expectations	n/a				429	95.3

[1]Incl. medication, moving the patient, exercises

4.8.3 Use of health care assistance at home

4.8.3.1. Past service use

Previously asked for and receiving health care assistance at home

Of the 450 patients in Diber and Fier, 372 (82.4%; 95% CI 78.6-85.8%) reported to have ever asked for health care assistance at home. This was compared to 300/454 (66.1%; 95% CI 51.5-70.4%) patients in 2021 and thus, significantly more patients have ever asked for health care assistance at home in 2023, compared to 2023 ($p<0.001$).

In 2023, significantly more patients reported to ever have asked for health care assistance at home in the intervention group (93.5%; 95% CI 88.9-96.6%) than in the control group (74.8%; 95% CI 69.1-79.9%; $p<0.001$).

Furthermore, 329 (73.1%; 95% CI 68.7-77.2%) have reported to have already received some sort of health care assistance at home in the past in 2023, compared to 293 (64.5%; 95% CI 59.9-68.9%) in 2021. In 2023, significantly more people in Diber have already received some sort of health care assistance at home than in Fier (84.0%; 95% CI 77.4-89.2%, vs. 67.9%; 95% CI 61.3-72.4%; $p<0.001$). The proportion of those already having received some sort of health care assistance at home was also significantly higher in the intervention group (84.8%; 95% CI 78.8-89.6%) than in the control group (65.0%; 95% CI 59.0-70.8%; $p<0.001$).

Means of asking for health care assistance at home

Similarly, the means on how the health care providers were contacted for health care assistance at home differed between the regions. Overall, in Diber and Fier, 114 (30.7%) of respondents reported to having contacted the health center (2021: 31.0%). 90.9% reported to have called the health care provider directly (2021: 81.0%). However, as for the 'contacting the health center' it was not specified whether this was in person or by phone. Thus, these results have to be interpreted with caution. Overall, difference between regions and intervention groups were marginal.

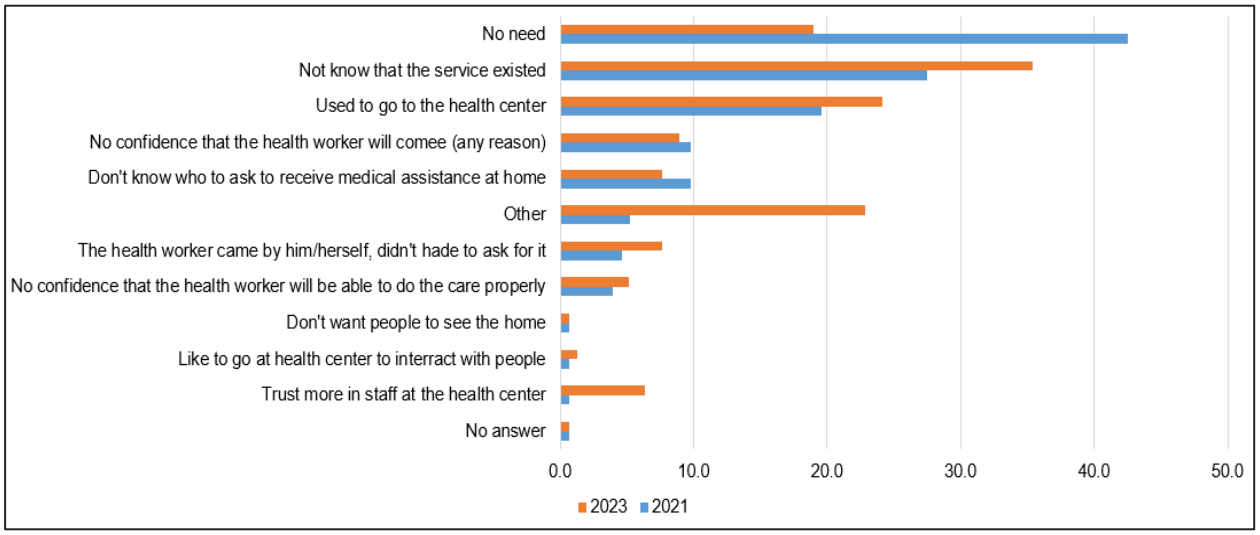
Reasons not seeking health care assistance at home

Reasons for not having sought health care assistance at home in the past as stated by respondents that have never used health care assistance at home (n=121 in 2023; n=153 in 2021) are shown in Figure 9. In 2021, the majority (42.5%) thought that it was not needed. This was markedly lower in 2023, where this proportion reduced by more than half to 19.0%. In 2023, the most frequent reason was not knowing that the service existed (35.4%), followed by 'used to go to the health center' (24.1%).

Interestingly, the proportion of respondents reporting that 'they did not know that this service existed' was markedly higher in the control group (40.3%) than in the intervention group (8.3%), though sample sizes were too small to assess significance.

A better understanding of the factors influencing this health care behaviours for health care assistance at home could be gained with more qualitative research methods, which would complement these findings. For example, the portion that stated that they don't need health care assistance at home might state so because they have family members caring for them, which in turn means that they still need medical assistance at home. Or maybe some didn't need health care assistance at home because they were not sick in the past.

Figure 9: Reasons for not having sought health care assistance at home in the past, Diber and Fier, 2021 and 2023



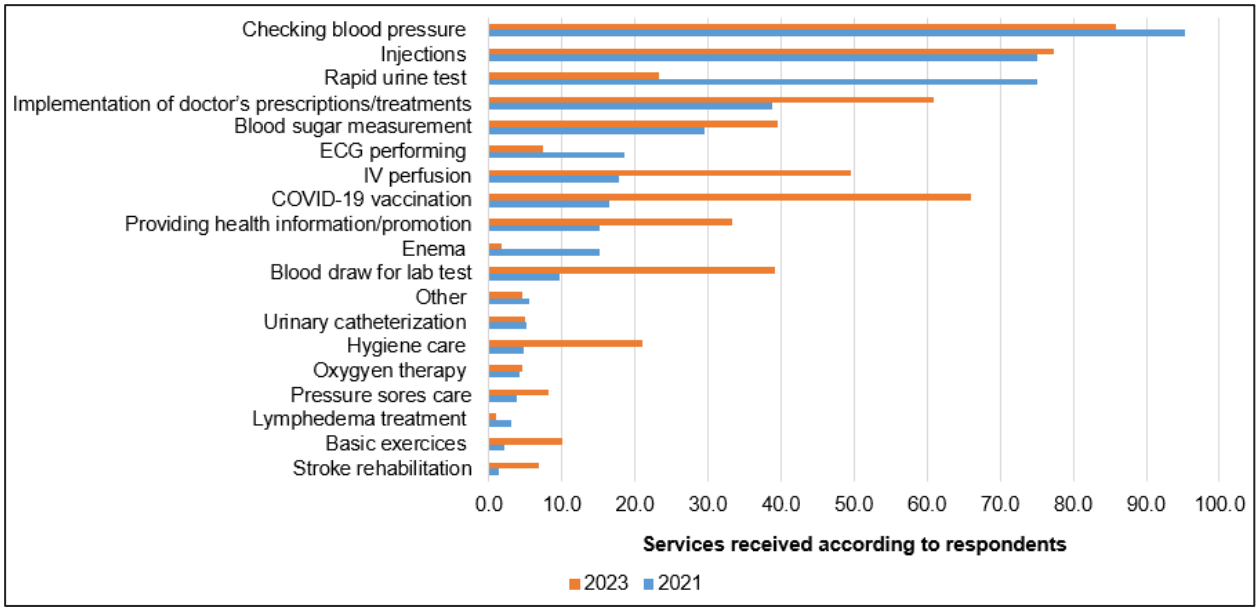
4.8.3.2. Current service use

In 2023 in Diber and Fier regions, at the time of the survey, 220 (48.9%; 95% CI 59.7-68.7%) patients reported to receive health care assistance at home. This was significantly less than in 2021 where 292 (64.3%; 95% CI 59.7-68.7%) patients reported to receive health care assistance at home. Whilst in 2021, there was no significant difference in the current service use between the intervention group and the control group, in 2023, current service use was significantly higher ($p<0.001$) in the intervention group (64.7%; 95% CI 57.3-71.6%) than in the control group (38.0%; 95% CI 32.1-44.1%). Moreover, there was also a higher service use in Diber (60.5%; 95% CI 52.5-68.1%) than in Fier (42.4%; 95% CI 36.6-48.3%; $p<0.001$).

Services of health care assistance at home received

The types of services received among those that were receiving health care assistance at home during the survey are displayed in Figure 10. In both years, measuring of blood pressure and injections were the services received most often.

Figure 10: Current services received, Diber and Fier, 2021 and 2023



Services of health care assistance at home needed

Among the 220 patients that received health care assistance at home during the time of the survey, 206 (93.6%) felt that they received enough support (2021: 91.8%). However, given the expectations mentioned in Table 14 in section 4.8.2, the need for additional support and services exist. Services that respondents would need but were not offered included:

- HBC in general (e.g. hygiene, showers, etc.)
- Different, specific services (e.g. psychological support, babysitter)
- Services around the clock (24/7)
- Support for equipment, especially wheelchairs
- Services that could not be offered through HBC, such as operations, chemotherapy, or echography

In addition to medical assistance, respondents stated that they would need 'financial support' and support for transportation. Some transportation needs, however, would be rendered unnecessary through the offering of HBC.

Frequency of health care assistance at home

The received and needed frequencies of health care assistance at home are shown in Table 15. In 2023 in Diber and Fier, the need for care was generally higher than what was currently received. For those needing medical assistance more frequently, the gap between what is currently received and actually needed is bigger than for those needing medical assistance less frequently.

Table 15: Frequency of health care assistance at home (received and needed), Diber and Fier, 2021 and 2023

	Receiving currently		Actual need	
	n	%	n	%
2021				
Every day	11	3.8	24	8.2
More than once a week	37	12.7	40	13.7
Once a week	52	17.8	72	24.7
Twice a month	39	13.4	38	13.0
Once a month	87	29.8	76	26.0
Once every 3 months	39	13.4	29	9.9
Once every 6 months	16	5.5	5	1.7
Never	6	2.1	4	1.4
Don't know	5	1.7	4	1.4
2023				

Every day	7	3.2	9	4.1
More than once a week	30	13.6	31	14.1
Once a week	52	23.6	57	25.9
Twice a month	62	28.2	52	23.6
Once a month	42	19.1	0	0.0
Once every 3 months	6	2.7	41	18.6
Once every 6 months	1	0.5	4	1.8
Never	2	0.9	25	11.4
Don't know	18	8.2	1	0.5

Difficulties in obtaining health care assistance at home

In total, in Diber and Fier in 2023, only 5/220 (2.3%) of respondents reported that they have already encountered difficulties in receiving health care assistance at home. This was lower than in 2021, where 47/292 (16.1%) of respondent reported that they have already encountered difficulties in receiving health care assistance at home. Among those, one respondent reported each that 'no health care worker was available' and another one respondent that he/she 'not able to reach the health care worker'. Two reported that they were 'not able to afford the health care assistance at home' and also two that they did 'not understand health care assistance at home'.

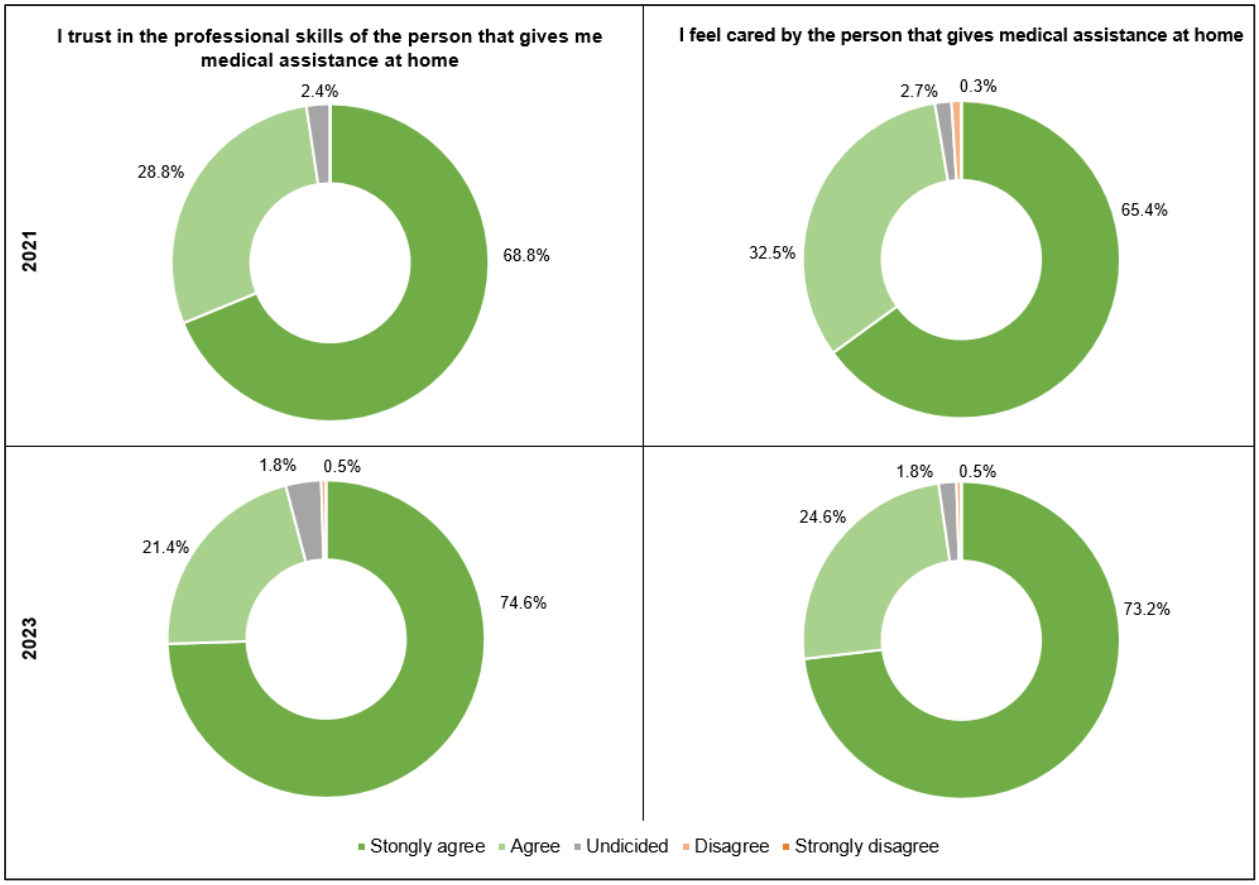
Person providing health care assistance at home

In Diber and Fier, the persons providing health care assistance at home were predominantly nurses (213; 96.8%) and family doctors (119; 54.1%). Thus, this was similar to 2021 with 95.6% and 54.1%, respectively. In 2023, the proportion of nurses providing the service was similar in the intervention and control groups (97.5% and 96.0%, respectively) but for doctors, the proportion was insignificantly higher in the intervention (57.1%) as compared to the control group (50.5%). No meaningful differences were found between the two regions.

Satisfaction with the health care assistance at home

As shown in Figure 11, in Diber and Fier, the majority of respondents had confidence in the professional skills of the person that provides health care assistance at home as 74.6% in 2023 strongly agree (2021: 68.8%) and 21.4% (2021:28.8%) agree that they have trust in the professional skills of the person that provides health care assistance at home. Similarly, the majority of people feel cared for by the person that provides health care assistance at home, as already in 2021.

Figure 11: Satisfaction with current health care assistance at home provided, Diber and Fier, 2021 and 2023



Prescriptions provided by the health care provider of health care assistance at home

In 2023 in Diber and Fier, overall, 98 out of 220 (44.6%) patients that were receiving health care assistance at home during the time of the survey were prescribed any medication in the past month. This was similar as in 2021 where 48.3% (141/292) received this support. No significant differences were found between intervention and control groups or regions. Of note, HBC nurses are not qualified to issue prescriptions.

Cost of health care assistance at home

In 2023 in Diber and Fier, three (1.4%) respondents reported that they currently pay for health care assistance at home. Thus this was similar to 2021, where nine (3.1%) respondents reported that they currently pay for health care assistance at home. In 2023, these three respondents reported that they pay between 200 and 1,000 LEK per month (2021: between 100 and 20,000 LEK).

4.8.4 Non-use of health care assistance at home

At the time of the survey, 230 (51.1%) patients in Fier and Diber did not receive health care assistance at home (35.3% in the intervention and 62.0%% in the control group; p<0.001; see also 4.8.3.2). This was lower in 2021 (162; 35.7%; p<0.001; see also 4.8.3.2). Among the 230, 100 (82.6%) reported that they would like to receive medical assistance now or in the future (2021: 66.5%).

As pointed out earlier, the following considerations have to be taken into account:

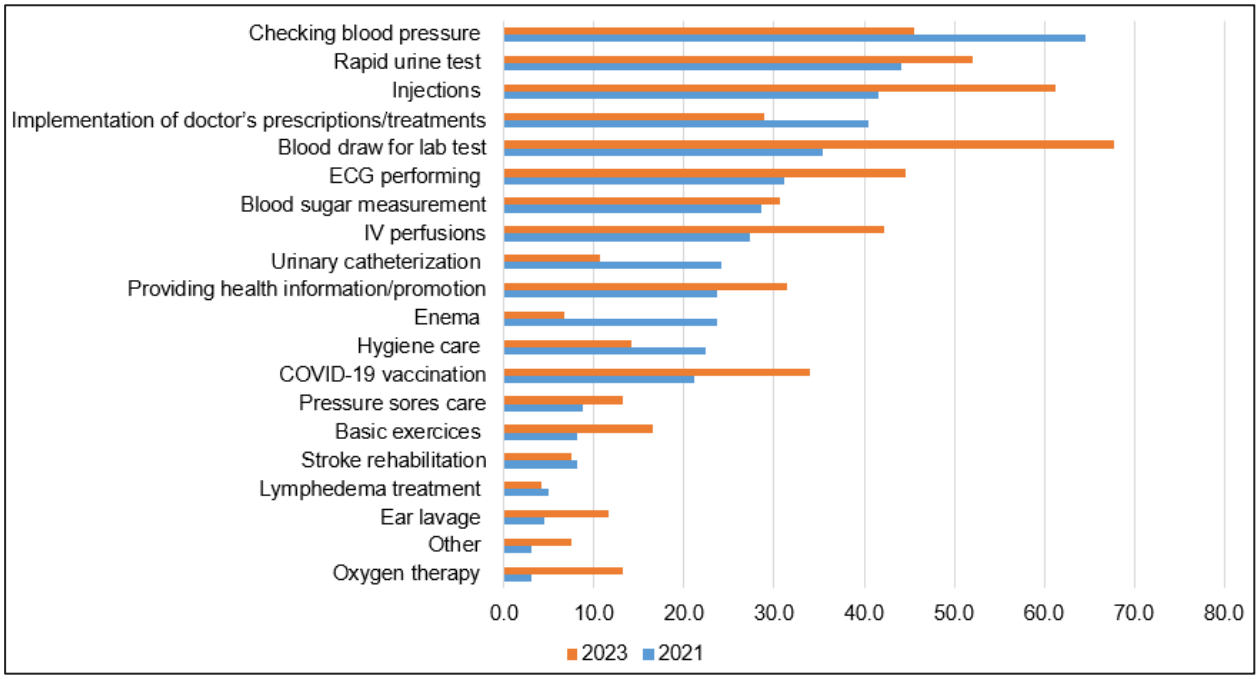
- While eligibility criteria dictated that patients should have received HBC at the time of the survey, it's possible that some received it intermittently. The reasons for interruptions or abandonment of HBC could stem from both patient demand and health care system supply factors.

- Recall and response bias from respondents might contribute to obscurity of certain results, e.g. respondents might not always make the distinction between health care assistance at home and HBC (as described above).

Services of health care assistance at home needed

Among those that would like to receive health care assistance at home in Diber and Fier (n=100 in 2023), those most desired were: blood drawing for blood tests (67.8%), injections (61.2%) and rapid urine tests (52.1%; Figure 12). This compared to blood pressure measurements (64.6%), rapid urine tests (44.1%) and injections (41.6%) in 2021 as top desired services.

Figure 12: Services needed, Diber and Fier, 2021 and 2023



Frequency of health care assistance at home needed

The received and needed frequencies of health care assistance at home are shown in Table 16. In 2023 in Diber and Fier, the need for care was generally higher than what was currently received. For those needing medical assistance more frequently, the gap between what is currently received and actually needed is bigger than for those needing medical assistance less frequently.

Table 16: Frequency of health care assistance at home needed Diber and Fier, 2021 and 2023

	Needed by those not receiving currently		Needed by those receiving currently	
	N	%	n	%
2021				
Every day	22	20.6	24	8.2
More than once a week	6	5.6	40	13.7
Once a week	24	22.4	72	24.7
Twice a month	15	14.0	38	13.0
Once a month	25	23.4	76	26.0
Once every 3 months	4	3.7	29	9.9
Once every 6 months	3	2.8	5	1.7
Never	3	2.8	4	1.4
Don't know	5	4.8	4	1.4
2023				
Every day	12	12.0	9	4.1
More than once a week	7	7.0	31	14.1
Once a week	24	24.0	57	25.9

Twice a month	32	32.0	52	23.6
Once a month	12	12.0	0	0.0
Once every 3 months	2	2.0	41	18.6
Once every 6 months	1	1.0	4	1.8
Never	5	5.0	25	11.4
Don't know	5	5.0	1	0.516

4.9 Quality of life

4.9.1 VR-12

The mean values ±SD for the PHC, MHC and GHC at the moment of this baseline study are shown in Table 17. Individuals below 18 years of age were excluded from the QoL analysis as no QoL reference values exist for this age group.

The following findings are noteworthy:

- For both years (2021 and 2023) and all regions, overall scores and scores for specific subgroups were all categorized as 'low', meaning that these are scores that are obtained by 20% or less of the respective normative population (see also Table 5 in the Methods section). These individuals experience physical and mental health symptoms that impede life functioning, which is explained by the general health status of the patients (bed-ridden or home-bound) and at the same time, the inclusion criteria in the study.
- Overall, no significant changes or differences were found between the years or different stratification groups.
- There seems to be no gender-specific differences.
- Diber showed higher QoL scores than Fier in 2023, which was the opposite in 2021.
- The intervention group showed higher QoL scores in 2023, which was the opposite in 2021.
- The wealthiest quantile has highest QoL scores throughout.
- No real change in QoL was detected since the implementation of HBC, which is to be expected in this specific study population (bed-ridden or home-bound).

Of note, at the individual level, clinical judgement should always be exercised in interpreting a persons' QoL scores [8].

Table 17: Quality of life scores, Diber and Fier, 2021 and 2023

	2021			2023		
	PHC	MHC	GHC	PHC	MHC	GHC
Sex						
Female	30.0 ±9.4	28.4 ±9.6	26.7 ±9.5	31.6 ±8.7	24.2 ±9.6	25.7 ±8.7
Male	29.4 ±10.4	29.3 ±9.3	26.4 ±9.6	29.8 ±9.1	25.8 ±9.4	25.7 ±9.9
Region						
Dibër	27.3 ±10.0	27.4 ±7.4	24.8 ±7.9	31.2 ±8.0	26.5 ±8.6	27.4 ±8.1
Fier	30.6 ±9.8	29.8 ±10.7	27.8 ±10.4	30.9 ±9.3	23.8 ±9.2	24.9 ±9.4
Intervention group						
Intervention	28.9 ±10.0	28.4 ±8.7	26.2 ±8.9	31.4 ±9.1	25.3 ±9.7	26.2 ±9.9
Control	29.6 ±10.0	29.2 ±10.3	26.9 ±10.2	30.7 ±8.7	24.4 ±8.6	25.3 ±8.5
Wealth quantile						
Poorest	28.1 ±9.4	26.5 ±6.9	24.5 ±7.4	30.7 ±7.9	24.5 ±8.5	25.1 ±7.9
Second	27.5 ±10.2	27.5 ±9.1	24.8 ±8.9	30.5 ±9.9	24.2 ±9.9	25.3 ±10.7
Third	29.9 ±9.8	29.9 ±10.3	27.6 ±10.2	30.7 ±8.7	25.5 ±8.5	26.2 ±8.6
Wealthiest	32.0 ±10.4	31.6 ±10.7	29.9 ±10.7	33.4 ±9.2	25.7 ±9.9	27.2 ±9.3
Overall	**29.3 ±10.0**	**28.8 ±9.5**	**26.5 ±9.5**	**31.0 ±8.9**	**24.8 ±9.1**	**25.7 ±9.1**

4.9.2 Other quality of life indicators

In Diber and Fier, more patients strongly agreed or agreed that they felt good/comfortable in their home at the time of the survey in 2023 (89.1%) compared to 2021 (77.3%) (Table 18). There was no difference in 2023 between intervention (89.7%) and control (88.7%).

In both years, about half of the patients (50.0% and 51.8%, respectively, in 2021 and 2023) strongly agree that they would like to have more companionship and another 25.1% and 26.7%, respectively, agreed. To the statement 'I have freedom to take my own decisions', more patients strongly agreed in 2023 (24.7%) than in 2021 (18.7%).

Table 18: Agreement with statements on emotional well-being, Diber and Fier, 2021 and 2023

	I feel good/comfortable in my home (%)	I would like to have more companionship or contact with other people (%)	I have freedom to make my own decisions (%)
2021			
Strongly agree	48.7	50.0	18.7
Agree	28.6	25.1	24.2
Undecided	10.1	11.0	21.8
Disagree	6.4	5.5	9.9
Strongly disagree	4.4	6.8	23.8
No answer	1.8	1.5	1.5
2023			
Strongly agree	66.0	51.8	24.7
Agree	23.1	26.7	25.3
Undecided	7.3	10.2	11.6
Disagree	1.8	5.3	12.9
Strongly disagree	1.3	5.8	23.3
No answer	0.4	0.2	2.2

Overall, the patient's self-reported physical and mental health deteriorated in the year preceding the survey, which is certainly partly explained by the natural progression of disease and/or disability (Table 19). Changes between 2021 and 2023 were minimal.

Table 19: Evolvement of physical and mental health in the past year, Diber and Fier, 2021 and 2023

	Compared to one year ago, how would you rate your physical health in general now? (%)	Compared to one year ago, how would you rate your emotional problems (such as feeling anxious, depressed or irritable) now? (%)
2021		
Much better	0.7	0.4
Slightly better	7.3	4.0
About the same	23.1	33.5
Slightly worse	41.0	39.9
Much worse	27.3	21.6
No answer	0.7	0.7
2023		
Much better	0.2	0.2
Slightly better	4.4	4.0
About the same	26.0	32.4
Slightly worse	50.7	46.2
Much worse	18.7	16.9
No answer	0.0	0.2

4.10 Limitations of the survey

The present survey had several limitations:

- While the eligibility criteria was a Karnofsky Performance Scale score <40, in practice, the health care providers might have included also patients that had a score above 40 because they were chronically ill, palliative patients, elderly, and/or having previously received health care assistance at home. As per Annex 9.1, while the 'Values' and associated 'Level of functional capacities' applied are as in the original Karnofsky Performance Scale, the 'Definition' corresponding to the value was complemented with HBC-specific interpretation. This potentially systematic bias might have influenced some of the findings, for example the disease patterns shown in section 4.4.
- In addition, while eligibility criteria dictated that patients should have received HBC at the time of the survey, it's possible that some received it intermittently. The reasons for interruptions or abandonment of HBC could stem from both patient demand and health care system supply factors.
- There is potential non-response bias caused by refusals and non-contact/unavailability of eligible patients, whose answers might differ from the participants.
- Surveys relying on respondents' self-report always introduce some extent of response and recall bias. Results should all be cautiously interpreted with this limitation in mind. For example, the strong increase in self-reported circulatory system issues from 15.0% in 2021 to 86.2% in 2023 is potentially partly explained by reporting biases, e.g. underreporting in 2021, or increased awareness in 2023.
- For many patients (see Figure 2), a proxy was replying or supporting the responses to the questions. Thus, for some answers on self-perception, these might only reflect approximate answers but not the actual condition/perception of the patient.
- To our knowledge, the VR-12 was never validated in the Albanian context. Therefore, the T scores standardized for the U.S. population were used. The standards as prevailing in Albania may, for example for cultural reasons, differ [8]. This might limit comparison with findings from other VR-12 studies.

5. CONCLUSIONS AND NEXT STEPS

In conclusion:

- Intrinsic to the study eligibility and inclusion criteria, the surveyed population had high burden of chronic diseases. Self-reported prevalence of these increased overall between 2021 and 2023. The proportion of patients entirely bed-bound increased slightly from 16.5% in 2021 to 22.0% in 2023.
- The burden of health care provision by family members remains high and even increased since 2021, potentially also due to the increased burden of disease.
- Generally, awareness, demand and previous use of health care assistance at home, or HBC, has increased between 2021 and 2023 and importantly, were consistently higher in the intervention group than in the control group. These findings suggest an impact of HAP's HBC intervention.
- Whilst QoL scores were consistently 'low' (all years, regions, intervention groups or wealth quartile), in 2023, the intervention group showed slightly higher QoL scores in contrast to the pattern in 2021. However, no significant change in QoL since the implementation of HBC was to be expected in this physically distressed study population. For a more nuanced understanding of the QoL of home-bound and bed-bound patients, a qualitative research study would be indicated.

PART II

Assessment of Quality of Life and Home Based Care (HBC) needs in **Durres and Shkoder** regions

EXECUTIVE SUMMARY

In 2022, based on the HAP2 pilot, the Ministry of Health and Social Protection decided to extent the HBC services beyond Fier and Diber into 6 additional regions, namely Durres, Korce, Shkoder, Elbasan, Tirana and Berat. Thus, for the current 2023 survey, it was decided to also collect data in these newly added regions. These data would serve as a baseline in the respective regions for future comparison. Therefore, Durres and Shkoder regions were selected, specifically the health centers in Manez, Ishem, Durres No. 1 and Shijak in Durres, and Bushat, Vau Dejes, and Ana Malit in Shkoder, respectively.

Of an estimated 284 eligible patients in Durres and Shkoder, 229 were included in the study (80.6% recruitment rate). Overall, 69 patients were from Durres, 160 from Shkoder. For 25.4% of interviews it was the patient responding her-/himself to the interviewer, for 49.6% of interviews it was the proxy who responded and for 25.0% of interviews it was both together. The main findings in 2023 in Durres and Shkoder are shown in Table 20.

Table 20: Summary findings, Durres and Shkoder, 2023

Section	Main findings
Patient and household characteristics	**2023 Durres and Shkoder** • Mean age was 65.3 years (70.0 in Durres and 63.4 in Shkoder). • Half (50.0%) were married and about a quarter (23.7%) widowed. • 21.1% did not have any education or only Kindergarten. About a quarter (25.9%) attained primary school level and another third (33.3%) attained secondary school level. 17.5% went to high school, and 1.8% to college or university, including technical university. • Wealth distribution differed markedly between Durres (47.7% in the poorest quartile) and Shkoder (45.2% in the richest quartile).

Health issues	**2023 in Durres and Shkoder**
	• A total of 389 health issues were reported by the 229 patients, most prevalent of all reported issues were:
	  ○ Diseases of the nervous system: 48.2%
	  ○ Diseases of the musculoskeletal system and connective tissue: 26.8%
	  ○ Endocrine, nutritional and metabolic diseases: 21.9%
	  ○ Diseases of the circulatory system: 20.2%

Access to health care	**2023 Durres and Shkoder** • In Durres and Shkoder, 80.9% and 76.1% reported to have experienced barriers to visit the health center in the two months preceding the survey. • The proportion of patients who are bed-bound and can't afford to take the transport was 47.1% in Durres and 10.6% in Shkoder.
Costs of health care	**2023 Durres and Shkoder** • Average median costs were 16,335 LEK. • Medication/drugs were the main cost driver (10,890 LEK on average), closely followed by consumables (9,801 LEK).
Care and support provided by family members	**2023 Durres and Shkoder** • In Durres and Shkoder, 90.4% of patients received care support from family members. • On average, about 1.4 family members supported the patients' care in a household in Durres and 1.6 family members in Shkoder. • Spouses were most frequently involved in care taking (32.9%).
Health care assistance at home	**2023 Durres and Shkoder** • 68.0% were aware that health care assistance at home exists as a service, which was significantly higher in Shkoder (74.4%) than in Durres (52.9%; p=0.002). • Most heard about the service from their nurse (81.9%) and/or their doctor (65.2%). • 46.5% of patients did receive health care assistance at home at the time of the survey.
Quality of life	**2023 Durres and Shkoder** • Overall scores and scores for specific subgroups (sex, region, intervention and wealth quartile) were all categorized as 'low'. • Males seem to have slightly higher QoL scores.

Section	Main findings
	• All QoL scores were slightly higher in Shkoder than in Durres. • The wealthiest quantile has highest QoL scores.

6. METHODS

The data collection in Durres and Shkoder regions applied the exact same methods and tools as described in the method section 3.

In 2022, based on the HAP2 pilot, the Ministry of Health and Social Protection decided to extent the HBC services beyond Fier and Diber into 6 additional regions, namely Durres, Korce, Shkoder, Elbasan, Tirana and Berat. Thus, HBC is presently being implemented in 49 additional health centers (22 HC started during 2022, and 27 during 2023).

Thus, for the current 2023 survey, it was decided to also collect data in these newly added regions. These data would serve as a baseline in the respective regions for future comparison. Therefore, Durres and Shkoder regions were selected, specifically the health centers in Manez, Ishem, Durres No. 1 and Shijak in Durres, and Bushat, Vau Dejes, and Ana Malit in Shkoder, respectively (Figure 13). Table 21 and Table 22 show the eligible population and sample sizes by health center for Durres and Shkoder.

Figure 13: Study areas, Durres and Shkoder, 2023

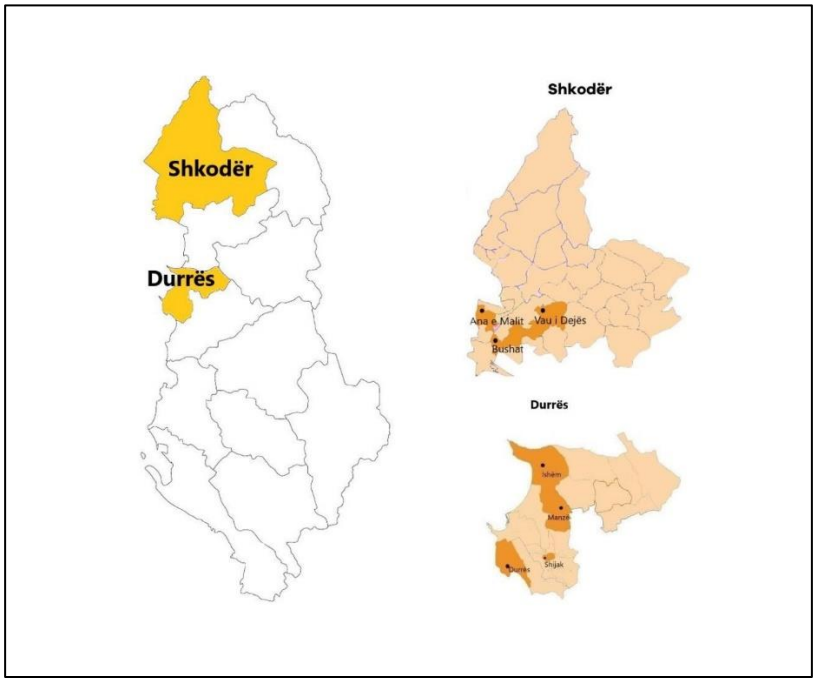


Table 21: Catchment population and estimated eligible population by health center, Durres and Shkoder, 2023

Region	Municipality	Health center	HC Catchment population	Administrative category	Eligible population
Durres	Durres	Nr. 1	24’632	Urban	34
	Shijak	Shijak	13’080	Urban	14
	Durres	Manez	12’280	Rural	31
	Durres	Ishem	8’214	Rural	13
Subtotal					***92***
Shkoder	Shkoder	Bushat	20’220	Rural	102
	Vau Dejes	Vau Dejes	12’748	Rural	73
	Shkoder	Ana Malit	5’700	Rural	23

Subtotal					***198***
Total					**518**

Table 22. Estimated sample size of intervention and control groups by region and health center, Durres and Shkoder, 2023

Region	Intervention health center	No of patients	Control health center	No of patients	Total
Durres	Nr. 1	34	n/a	n/a	***92***
	Shijak	14	n/a	n/a	
	Manez	31	n/a	n/a	
	Ishem	13	n/a	n/a	
Subtotal 3		***92***		***n/a***	
Shkoder	Bushat	102	n/a	n/a	***198***
	Vau Dejes	73	n/a	n/a	
	Ana Malit	23	n/a	n/a	
Subtotal 4		***198***		***n/a***	
Total		**518**		**280**	**798**

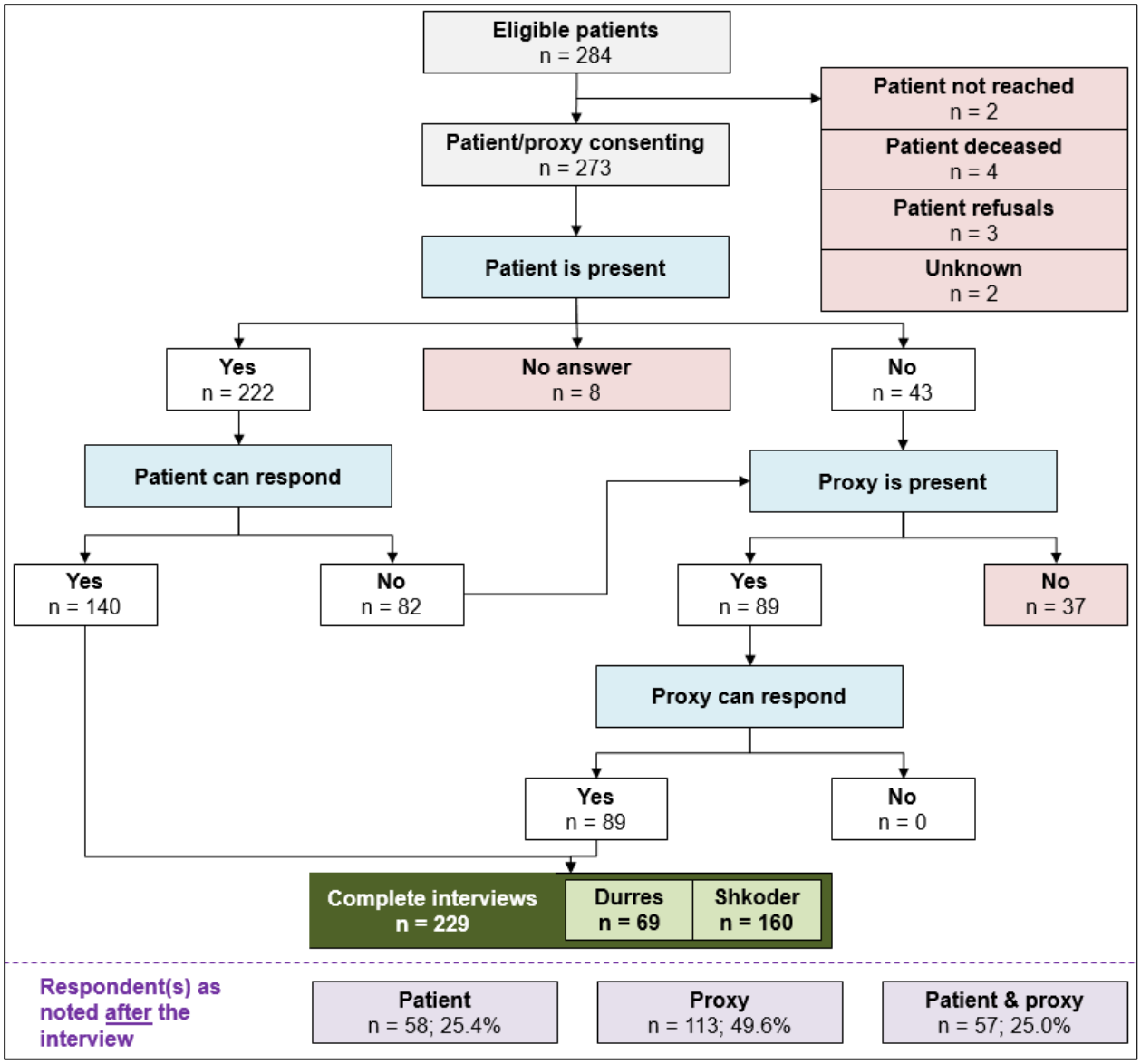
7. RESULTS

7.1 Study population

Figure 14 shows the flowchart of the study respondents (patients and proxy). Overall, 284 persons were registered as eligible for the study and approached by the data collection team. Thereof, 12 patients could not be reached, 4 have deceased, and 3 have refused to participate in the study already at contact stage, resulting in a 4.2% refusal rate.

Finally, 229 persons were consenting to participate in the study and completed interviews, thereof 69 (30.1%) were from Durres and 160 (69.9%) from Shkoder, respectively.

Figure 14: Respondent flowchart, Durres and Shkoder, 2023



At the start of the interview, 140 of patients reported to be able to respond themselves to the questionnaire and for 89 of interviews the proxy was the designated respondent. At the end of the interview, the interviewer was noting down (again) who finally was the person that was responding. For 58 of interviews, it was the patient her-/himself alone (25.4%), for 113 (49.6%) of interviews it was the proxy and for 57 (25.0%) of interviews it was both together. Thus, often, it was required that household members 'supported' the patient in answering the questions.

For the 88 patients where a proxy was responding to the questionnaire, the proxy respondents were in most cases a son- or daughter-in-law (25.4%), followed by a parent (20.1%) and the patient's children (18.5%) (Table 23). The same four proxy respondent categories were most frequent in 2021 but with marginal differences in the proportions.

Table 23: Proxy respondents, Durres and Shkoder, 2023

	2023	
Proxy relationship to the patient	n	%
Parent	22	25.0
Spouse / partner	19	21.6
Son / daughter	13	14.8
Head of household	8	9.1

Other	8	9.1
Son- / daughter-in-law	7	8.0
Other relative	6	6.8
Sister / brother	3	3.4
Niece / nephew	1	1.1
Parent-in-law	1	1.1
Total	**88**	**100.0**

Overall, the total number of interviews per region and health center are shown in Table 24.

Table 24: Number of respondents by health center, Durres and Shkoder, 2023

		Intervention			Control		Total	
		2021	2023		2021	2023	2021	2023
Total		**220**	**184**		**234**	**266**	**454**	**450**
Durres	Nr. 1	n/a	21	n/a	n/a	n/a	n/a	**69**
	Shijak	n/a	9	n/a	n/a	n/a		
	Manez	n/a	26	n/a	n/a	n/a		
	Ishem	n/a	13	n/a	n/a	n/a		
Subtotal			***69***		***n/a***	***n/a***		
Shkoder	Bushat	n/a	84	n/a	n/a	n/a	n/a	**160**
	Vau Dejes	n/a	50	n/a	n/a	n/a		
	Ana Malit	n/a	26	n/a	n/a	n/a		
			160		***n/a***	***n/a***	***160***	
Total		**n/a**	**160**		**n/a**	**n/a**	**n/a**	**229**

7.2 Patient characteristics

In Durres and Shkoder, the proportion of female patients was 54.4% for both (Table 25). The mean age was 70.0 years and 63.4 years, respectively. In both regions, 50.0% of patients were married and 30.9% and 20.6%, respectively, were widowed. 22.1% and 18.1% had no education.

Table 25: Patient characteristics (%), Durres and Shkoder, 2023

	Durres	Shkoder	Total
Sex			
Female	54.4	54.4	54.4
Male	45.6	45.6	45.6
Age in years			
<18 years	1.5	5.7	4.4
18-24 years	1.5	3.1	2.7
25-44 years	11.9	13.2	12.8
45-65 years	13.4	22.0	19.5
> 65 years	71.6	56.0	60.6
Mean age in years	70.0	63.4	65.3
Marital status			
Married	50.0	50.0	50.0
Divorced	0.0	0.6	0.4
Separated	0.0	2.5	1.8
Widow/er	30.9	20.6	23.7
Single	19.1	26.3	24.1
Educational attainment			

None	22.1	18.1	19.3
Pre-school, Kindergarten	1.5	1.9	1.8
Primary (grade 1-5)	25.0	26.3	25.9
Secondary (grade 6-9)	26.5	36.3	33.3
High school	23.5	15.0	17.5
College, Technical University	0.0	1.3	0.9
University	1.5	0.6	0.9

7.3 Household characteristics

7.3.1 Household composition

In Durres and Shkoder, 35.2% lived in a 2-person household in 2023, whereof only 53.8% lived with their spouse. According to the Albania DHS, the proportion of 2-person households was 26.4% in rural and 29.1% in urban households [6].

7.3.2 Housing conditions

In Durres, houses were typically with ceramic tiles floors (89.7%), brick walls (73.5%) and roofs out of reinforced concrete (0.6%). In contrast in Shkoder where the main wall materials were covered adobe (56.9%) and the main roof materials ceramic tiles (73.8%).

7.3.3 Household income

Households stated their main sources of income, whereby all existing sources were mentioned. In Durres, 95.6% of patients reported income from the pension funds. In Shkoder, however, this proportion was lower at 75.0%. In turn, more patients in Shkoder (33.1%) reported to receive social aid than in Durres (23.5%).

7.3.4 Wealth quartiles

As described in the methods, 2021 households are considered the baseline, against which the 2023 wealth scores were measured. In Durres, almost half of the patients (47.7%) were found in the poorest quartile (Table 26). In contrast, only 7.7% were found in the second and only 13.9% were found in the wealthiest quartiles, respectively. In Shkoder, the highest proportion of patients were in the wealthiest quartile (45.2%). Importantly, the study sites and thus populations in Durres and Shkoder are very heterogeneous.

Table 26: Wealth quartiles, Durres and Shkoder, 2023

	Durres		Shkoder		Total	
	n	%	n	%	n	%
Poorest	31	47.7	34	21.7	65	29.3
Second	5	7.7	31	19.8	36	16.2
Third	20	30.8	21	13.4	41	18.5
Wealthiest	9	13.9	71	45.2	80	36.0

7.4 Patient's health problems

Table 27 and Figure 15 show the health issues reported by patients, in terms of frequency and proportion of all problems reported. Of note, these are self-reported health issues by the patient or the proxy, where the accuracy of the diagnosis and/or the medical terminology was not verified

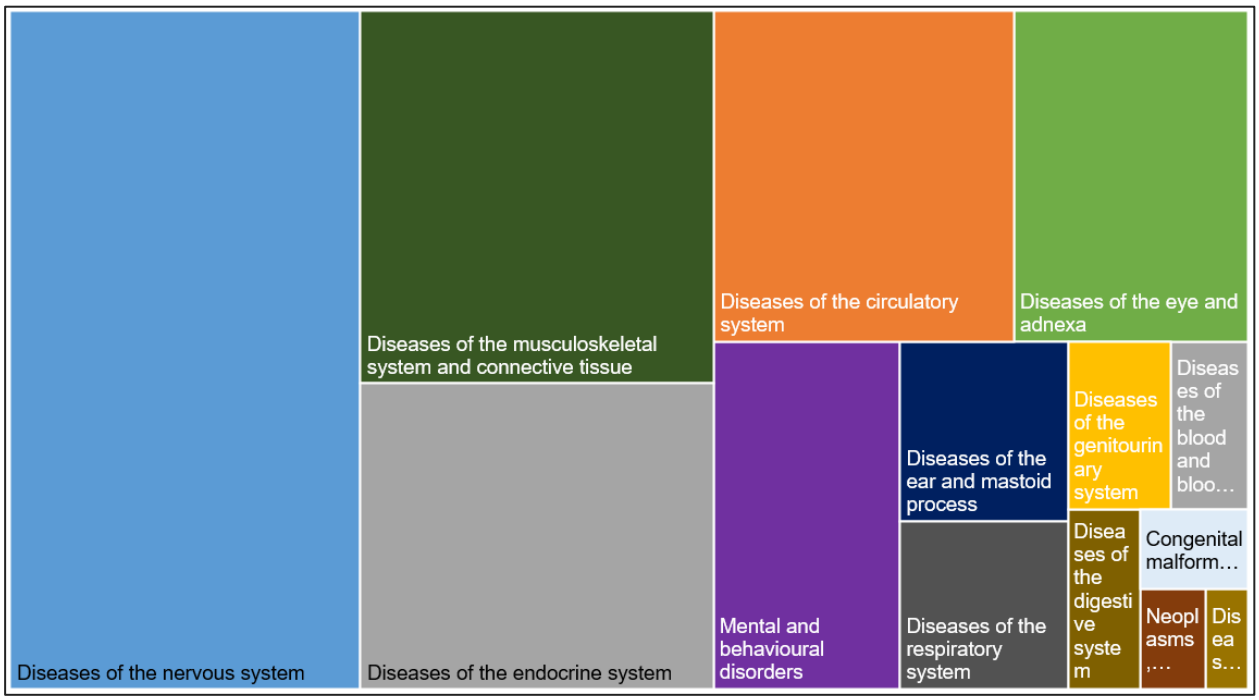
and where issues were summarized into ICD-10 classification. However, some respondents' answers were medically unclear and did not allow precise classification.

In Durres and Shkoder, diseases of the nervous system were most frequently reported by nearly half of the patients (48.2%), amounting to 28.3% of all health issues reported. Second most frequent were musculoskeletal and connective tissue disorders (26.8%), followed by endocrine, nutritional and metabolic diseases (21.9%) and diseases of the circulatory system (20.2%).

Table 27: Health problems reported, Durres and Shkoder, 2023

ICD-10 code	Health issue	n	% of patients	% of total health issues
C00–D48	Neoplasms	3	1.3	0.8
D50–D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	6	2.6	1.5
E00–E90	Endocrine, nutritional and metabolic diseases	50	21.9	12.9
F00–F99	Mental and behavioural disorders	30	13.2	7.7
G00–G99	Diseases of the nervous system	110	48.2	28.3
H00–H59	Diseases of the eye and adnexa	36	15.8	9.3
H60–H95	Diseases of the ear and mastoid process	14	6.1	3.6
I00–I99	Diseases of the circulatory system	46	20.2	11.8
J00–J99	Diseases of the respiratory system	13	5.7	3.3
K00–K93	Diseases of the digestive system	6	2.6	1.5
L00–L99	Diseases of the skin and subcutaneous tissue	2	0.9	0.5
M00–M99	Diseases of the musculoskeletal system and connective tissue	61	26.8	15.7
N00–N99	Diseases of the genitourinary system	8	3.5	2.1
Q00–Q99	Congenital malformations, deformations, and chromosomal abnormalities	4	1.8	1.0
	Infectious and parasitic diseases	0	0.0	0.0
	Total health issues reported	**389**	**n/a**	**100.0**

Figure 15: Health issues reported, Durres and Shkoder, 2023



1.5% and 8.1% of patients had an operations in the 12 months preceding the survey, respectively.

7.5 Access to health care

In Durres and Shkoder, 80.9% and 76.1% reported to have experienced barriers to visit the health center in the two months preceding the survey – for any kind of health issues.

In Durres, affordability of transport was a big barrier in 2023, stated by 54.4%. In contrast, in Shkoder, affordability of transport was a barrier for only 13.1% of patients. The proportion of patients who could not access a health facility because they were bed-bound was similar in Durres (26.5%) and in Shkoder (24.4%). Only one person in Shkoder reported to have a private health insurance.

Table 28: Access barriers to health care, Durres and Shkoder, 2023

	Durres		Shkoder		Total	
	n	%	n	%	n	%
Can't afford to take the transport	37	54.4	21	13.1	58	25.4
Can't walk to the health facility	48	70.6	102	63.8	150	65.8
Is bed-bound	18	26.5	39	24.4	57	25.0
Can't afford to take the transport & Is bed-bound at the same time	32	47.1	17	10.6	49	21.5

7.6 Health care costs

Reported health care costs in the 2 months preceding the survey are shown in Table 29.

In Durres and Shkoder, average overall costs were 16,335 LEK in the 2 months preceding the survey. Similar the costs during hospitalisations in the 2 months preceding the survey, where the average for Durres and Shkoder was 65,340 LEK [actual range 16,355 – 1,415,700 LEK] or 651 USD [actual range 162 – 14,110 USD]. Slightly more respondents (27, 11.8%) reported to offer gifts (including money) to the health care providers providing health care assistance at home in the 2 months preceding the survey.

Table 29: Health care costs in the 2 months preceding the survey, Durres and Shkoder, 2023

	Proportion that has paid for the health care need n (%)	Average cost in LEK (median [IQR])[1]	Average cost in USD (median [IQR])[2]
Medication/drugs	192 (84.2)	10,890 [3,267-19,602]	109 [33-195]
Consumables (e.g. catheter, wound treatment)	89 (39.0)	9,801 [4,901-15,246]	98 [49-152]
Tests	46 (20.2)	5,445 [3,267-10,890]	54 [33-108]
Transport of the health care assistance at home	33 (14.5)	5,445 [1,089-6,534]	54 [11-65]
Transport to the health centre	45 (19.7)	2,178 [1,089-5,445]	22 [11-54]
Outpatient services	25 (11.0)	5,445 [1,089-5,445]	54 [11-54]
Other	9 (4.0)	9,801 [4,356-10,890]	98 [43-108]
Nothing	*20 (8.8)*	*n/a*	*n/a*
No answer	*0 (0.0)*	*n/a*	*n/a*
Overall health care costs (excluding hospitalisation) – self-reported	**n/a**	**16,335 [3,267-40,383]**	**163 [33-407]**
Hospitalisation in 2 months preceding the survey (n=12)	12 (5.3)	65,340 [27,225-108,900]	651 [271-1,085]

[1] Inflation rate between 2021 and 2022.9% depreciation between (inflation rate for 2023 was not available at time of report writing)

[2] Exchange rates: 2021, 0.0093 (annual average); 2023, 0.009967 (annual average)

7.7 Care provided by family members

In Durres and Shkoder, 86.8% and 91.9% of patients received care support from family members, respectively (90.4% overall). On average, about 1.4 family members supported the patients' care in a household in Durres (range 1-4) and 1.6 family members in Shkoder (range 1-4). In these, regions, spouses were most frequently involved in care taking (32.9%; Table 30), closely followed by children (31.1%) and in-laws (27.2%).

Table 30: Family care takers, Durres and Shkoder, 2023

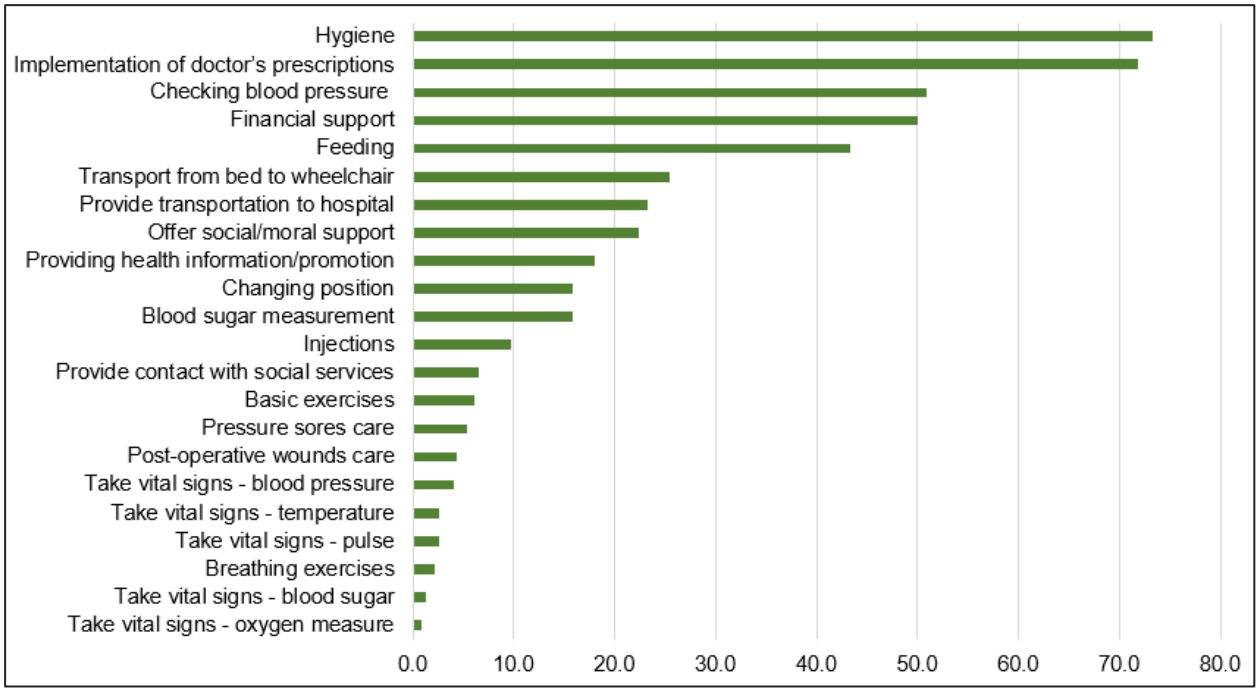
Care takers	n	%
Spouse	75	32.9
Siblings	16	7.0
Children	71	31.1
In-laws	62	27.2
Parents	41	18.0
Grandchildren	6	2.6
Nieces, nephews	4	1.8
Cousins	3	1.3
Other family member	17	7.5

The different forms of care and support that family members provide in Durres and Shkoder regions in 2023 are shown in Figure 16. Hygiene was the most frequent provided support (73.3%), followed by implementing of doctor's prescriptions, care and treatment (71.9%), checking for blood pressure (50.9%) and financial support (50.0%).

The number of hours per day that family members take care of the patients' health (all hours from all family members combined) was, on average, 19.7 hours (±7.4 SD) in Durres and 15.4 hours (±9.0 SD) in Shkoder (16.7 hours overall).

As for the family member that is taking most care of the patient, 15.1% were reported to have a job or another type of regular occupation or activity outside of the household (8.5% in Durres and 17.7% in Shkoder). In turn, 84.5% did not have another regular activity outside of the household. The amount of time these caretakers spend at their regular activity per week was 13.2 hours overall but ranged from 7.6 in Durres to 14.3 in Shkoder. In addition, 11.9% (n=27) reported that also friends, neighbours or other acquaintances were also involved in providing care and support for the patient.

Figure 16: Care and support provided by family members, Durres and Shkoder, 2023



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7.8 Health care assistance at home

Health care assistance at home is if someone – excluding family members – is visiting a patients' home to care for her/his health needs. HBC, in contrast, refers to the intervention designed by the HAP2 project and approved and taken-up by the MOHSP, and includes – as opposed to health care assistance at home – more services and service provision by nurses. These nurses are specifically trained for advanced nursing procedures, assisted by specific paramedical equipment to ease the chronic patient situation at home.

7.8.1 Availability of health care assistance at home

In Durres and Shkoder, 68.0% (n=155) were aware, that health care assistance at home exists as a service. However, this was significantly higher in Shkoder (74.4%) than in Durres (52.9%; p=0.002). Most heard about the service from their nurse (81.9%) and/or their doctor (65.2%). Some also heard about the service from a family member (7.1%), a friend (5.8%) or a neighbour (1.9%). Among those aware (n=155), 83.9% believe that these medical assistance services at home are provided by nurses.

7.8.2 Expected effects of health care assistance at home

Respondents were asked what their expected effects are regarding health care assistance at home. First spontaneously, i.e. without prompting any answers (Table 31). In Durres and Shkoder, overall expectations were at a similar level in 2023 as in Durres and Fier (97.8% for any expectations). Also similarly, the highest expectations were for 'better treatment and care for the disease' (stated by 87.3% either spontaneously or when prompted).

Table 31: Expected effects of health care assistance at home, Durres and Shkoder, 2023

Expected effects	Spontaneous		Prompted		Overall	
	n	%	n	%	n	%
Better treatment and care for the disease	146	64.0	53	64.6	199	87.3
Pain relief [1]	121	53.1	48	44.9	169	74.1
Reduction of transportation needs	108	47.4	79	65.8	187	82.0
Reduction of the workload for family members in care taking	97	42.5	89	67.9	186	81.6
Increased quality of life	128	56.1	67	67.0	195	85.5
Being better informed about the illness/disease	85	37.3	69	48.3	154	67.5
Any of the above expectations	n/a				223	97.8

[1]Incl. medication, moving the patient, exercises

7.8.3 Use of health care assistance at home

7.8.3.1. Past service use

Previously asked for and receiving health care assistance at home

In Durres and Shkoder in 2023, 69.1% and 85.0% have ever asked for health care assistance at home. Furthermore, 63.2% and 80.0% have ever received health care assistance at home, respectively.

Means of asking for health care assistance at home

In Durres and Shkoder, 30.7% reported to having contacted the health center and an additional 67.2% reported to have called the health care provider directly to ask for health care assistance at home. For the latter, the proportion was higher in Durres (89.4%) than in Shkoder (59.6%). Furthermore, as for the 'contacting the health center' it was not specified whether this was in person or by phone. Thus, these results have to be interpreted with caution.

Reasons not seeking health care assistance at home

Reasons for not having sought health care assistance at home in the past were stated by respondents that have never used health care assistance at home. The most stated reason for not having sought health care assistance at home in the past was 'used to go to the health care center' (28.9%), followed by 'not knowing that the service existed' (24.4%) and 'not needed' (20.0%).

A better understanding of the factors influencing this health care behaviours for health care assistance at home could be gained with more qualitative research methods, which would complement these findings. For example, the portion that stated that they don't need health care assistance at home might state so because they have family members caring for them, which in turn means that they still need medical assistance at home. Or maybe some didn't need health care assistance at home because they were not sick in the past.

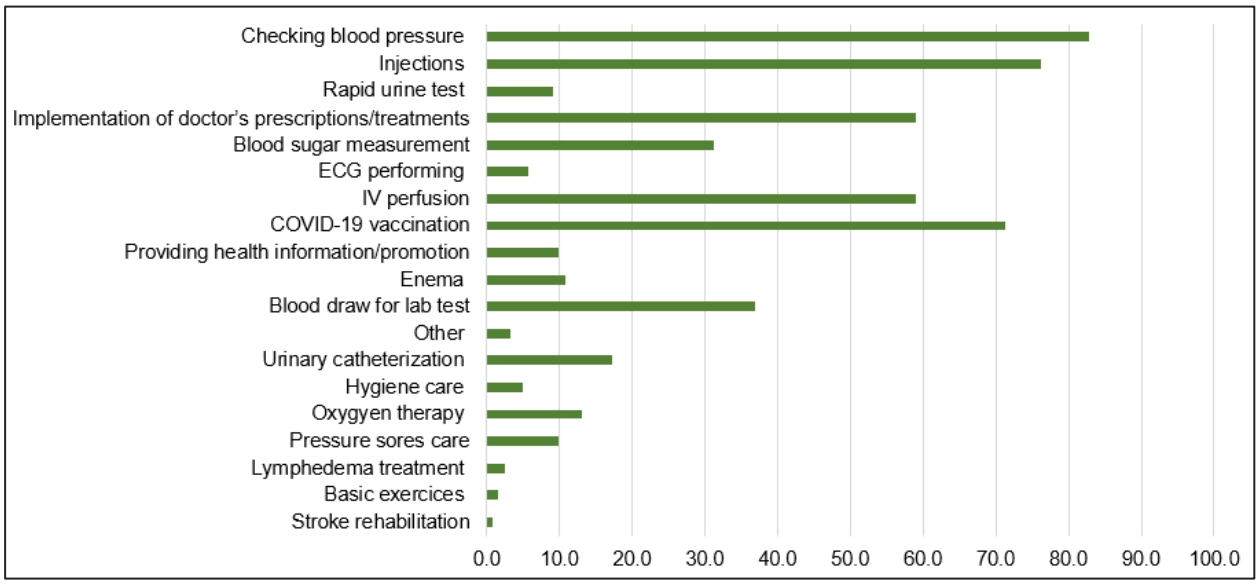
7.8.3.2. Current service use

In Durres and Shkoder, 47.1% and 56.3% patients, respectively, reported to receive health care assistance at home at the time of the survey (53.3% overall).

Services of health care assistance at home received

The types of services received among those that were receiving health care assistance at home during the survey are displayed in Figure 17. Measuring of blood pressure and injections were the services most used at the time of the survey.

Figure 17: Current services received, Durres and Shkoder, 2023



Services of health care assistance at home needed

Among the 122 patients that received health care assistance at home during the time of the survey, 106 (86.9%) felt that they received enough support.

Frequency of health care assistance at home

The received and needed frequencies of health care assistance at home are shown in Table 32. The need for care was generally higher than what was currently received for those needing daily care or several times a week.

Table 32: Frequency of health care assistance at home (received and needed), Durres and Shkoder, 2023

	Receiving currently		Actual need	
	n	%	n	%
Every day	3	2.5	16	13.1
More than once a week	12	9.8	37	30.3
Once a week	38	31.2	31	25.4
Twice a month	24	19.7	10	8.2
Once a month	27	22.2	19	15.6
Once every 3 months	8	6.6	3	2.5
Once every 6 months	4	3.3	1	0.8
Never	1	0.8	4	3.3
Don't know	5	4.1	1	0.8

Difficulties in obtaining health care assistance at home

14/122 (11.5%) of respondent reported that they have already encountered difficulties in receiving health care assistance at home. For four, they were 'not able to afford medical assistance at home', for four 'no health care worker was available', for three, the services were not able 24/7 and specifically at night, and for one each, they did 'not understand health care assistance at home' and was 'not able to reach the health care worker', respectively.

Person providing health care assistance at home

In Durres and Shkoder, nurses were predominantly providing health care assistance at home (99.2%) as well as doctors, but again to a lesser extent (55.7%).

Satisfaction with the health care assistance at home

In Durres and Shkoder, the proportion of those strongly agreeing that they have trust in the professional skills of the person that provides health care assistance at home was 81.2% with an additional 13.9% agreeing. Slightly less but still the majority of people in Durres and Shkoder feel cared for by the person that provides health care assistance at home (70.5% strongly agree and 22.1% agree, respectively).

Prescriptions provided by the health care provider of health care assistance at home

61.5% of patients that were receiving health care assistance at home during the time of the survey were prescribed any medication in the past month (75/122). No significant differences were found between regions.

Cost of health care assistance at home

In Durres and Shkoder, three respondents (2.5%) reported that they currently pay for health care assistance at home, with monthly amounts ranging between 2,000 and 80,000 LEK.

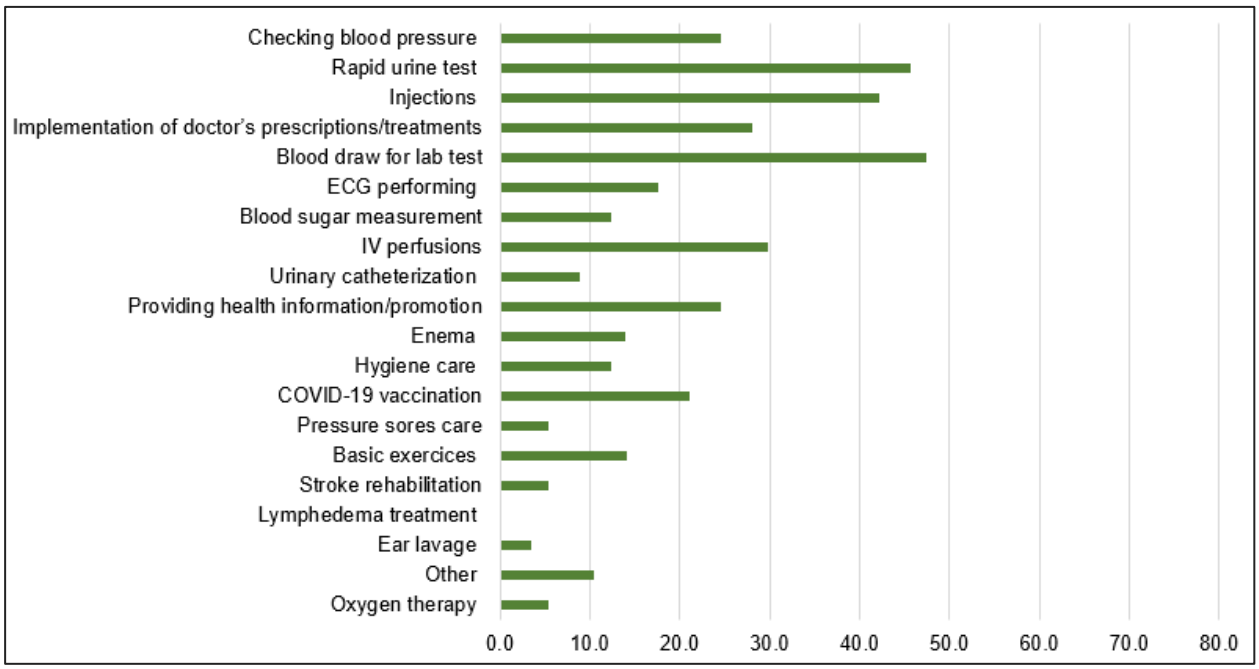
7.8.4 Non-use of health care assistance at home

At the time of the survey, 122 (53.5%) patients did not receive health care assistance at home at the time of the survey.

Services of health care assistance at home needed

Among those that would like to receive health care assistance at home in Durres and Shkoder (n=122), those most desired were: blood drawing for blood tests (47.4%), rapid urine tests (45.6%) and injections (42.1%; Figure 18).

Figure 18: Services needed, Durres and Shkoder, 2023



Frequency of health care assistance at home needed

The received and needed frequencies of health care assistance at home are shown in Table 33. The need for care was generally higher than what was currently received for those needing medical assistance more frequently, i.e. daily or several times a week.

Table 33: Frequency of health care assistance at home needed, Durres and Shkoder, 2023

	Needed by those not receiving currently		Needed by those receiving currently	
	N	%	n	%
Every day	14	28.6	16	13.1
More than once a week	10	20.4	37	30.3
Once a week	6	12.2	31	25.4
Twice a month	5	10.2	10	8.2
Once a month	5	10.2	19	15.6
Once every 3 months	1	2.0	3	2.5
Once every 6 months	2	4.1	1	0.8
Never	5	10.2	4	3.3
Don't know	1	2.0	1	0.8

7.9 Quality of life

7.9.1 VR-12

The mean values ±SD for the PHC, MHC and GHC at the moment of this baseline study are shown in Table 34. Individuals below 18 years of age were excluded from the QoL analysis as no QoL reference values exist for this age group. Of note, at the individual level, clinical judgement should always be exercised in interpreting a persons' QoL scores [8].

The following findings stand out:

- Males seem to have slightly higher QoL scores.
- All QoL scores were higher in Shkoder than in Durres.
- The wealthiest quantile has highest QoL scores.

Table 34: Quality of life scores, Durres and Shkoder, 2023

	2023		
	PHC	MHC	GHC
Sex			
Female	30.6 ±9.2	26.1 ±9.7	27.3 ±9.8
Male	32.9 ±9.4	28.4 ±9.8	29.6 ±8.9
Region			
Durres	27.8 ±7.4	23.6 ±8.1	23.3 ±7.2
Shkoder	33.3 ±9.6	28.8 ±10.1	30.5 ±9.4
Wealth quantile			
Poorest	31.1 ±9.7	25.4 ±8.9	26.9 ±9.2
Second	31.0 ±8.7	25.9 ±10.1	27.1 ±8.5
Third	31.1 ±9.0	28.5 ±11.1	28.7 ±11.1
Wealthiest	33.5 ±9.7	28.5 ±9.3	30.7 ±8.7
Overall	**31.8 ±9.3**	**27.2 ±9.7**	**28.5 ±9.4**

7.9.2 Other quality of life indicators

In Durres and Shkoder, interestingly, there were high proportions of patients 'strongly agreeing' to 'I feel good/comfortable in my home' (76.3%) and 'I would like to have more companionship or contact with other people' (57.0%).

Table 35: Agreement with statements on emotional well-being, Durres and Shkoder, 2023

	I feel good/comfortable in my home (%)	I would like to have more companionship or contact with other people (%)	I have freedom to make my own decisions (%)
Strongly agree	76.3	57.0	28.9
Agree	14.0	17.1	22.4
Undecided	3.1	7.0	12.7
Disagree	5.7	7.5	13.6
Strongly disagree	0.4	10.1	21.1
No answer	0.4	1.3	1.3

Overall, the patient's self-reported physical and mental health deteriorated in the year preceding the survey, which is certainly partly explained by the natural progression of disease and/or disability (Table 36).

Table 36: Evolvement of physical and mental health in the past year, Durres and Shkoder, 2023

	Compared to one year ago, how would you rate your physical health in general now? (%)	Compared to one year ago, how would you rate your emotional problems (such as feeling anxious, depressed or irritable) now? (%)
Much better	5.7	5.7
Slightly better	12.7	12.3
About the same	28.1	29.0
Slightly worse	25.0	25.0
Much worse	28.1	27.6
No answer	0.4	0.4

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9. ANNEXES

9.1 Annex 1: Karnofsky Performance Scale

Table 37 shows the original Karnofsky Performance Scale and Table 38 shows the Karnofsky Performance Scale with locally adapted definitions. Of note, while the 'Definition' are adapted to the context of HBC, the 'Values' and the corresponding 'Level of functional capacity' remain unchanged.

Table 37: Karnofsky Performance Scale – Original

Value	Level of functional capacity	Definition
100	Normal, no complaints, no evidence of disease	Able to carry on normal activity and to work; no special care needed
90	Able to carry on normal activity, minor signs or symptoms of disease	
80	Normal activity with effort, some signs or symptoms of disease	
70	Cares for self, unable to carry on normal activity or to do active work	Unable to work; able to live at home and care for most personal needs; various degrees of assistance needed
60	Requires occasional assistance but is able to care for most needs	
50	Requires considerable assistance and frequent medical care	
40	Disabled, requires special care and assistance	Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly
30	Severely disabled, hospitalization is indicated although death is not imminent	
20	Hospitalization is necessary, very sick, active supportive treatment necessary	
10	Moribund, fatal processes progressing rapidly	
0	Dead	

Table 38: Karnofsky Performance Scale – Local adaption

Value	Level of functional capacity	Definition
100	Normal, no complaints, no evidence of disease	Fully active, Able to perform all activities as before the diagnosis of the disease, without restrictions.
90	Able to carry on normal activity, minor signs or symptoms of disease	
80	Normal activity with effort, some signs or symptoms of disease	Able to go to the health center, Limited to strenuous physical activity, but able to do light or sedentary work such as light housework or office work.
70	Cares for self, unable to carry on normal activity or to do active work	
60	Requires occasional assistance but is able to care for most needs	Able to go to the health center Able to live at home and care for most personal needs any work activity.
50	Requires considerable assistance and frequent medical care	
40	Disabled, requires special care and assistance	Able for limited self-care, home bound, can stay on the chair more than 50% of hours.
30	Severely disabled, hospitalization is indicated although death is not imminent	
20	Hospitalization is necessary, very sick, active supportive treatment necessary	Unable to care for self, bed bound, requires health care assistance at home.
10	Moribund, fatal processes progressing rapidly	
0	Dead	Dead

9.2 Annex 2: VR-12 questionnaire

Table 39: VR-12 questionnaire

No.	Question	Answer categories
1	In general, would you say your health is:	01 Excellent 02 Very good 03 Good 04 Fair 05 Poor
	The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	
2	Moderate activities, such as moving a table, pushing a vacuum cleaner, simple plays with boll?	01 Yes, limited a lot 02 Yes, limited a little 03 No, not limited at all
3	Climbing several flights of stairs?	01 Yes, limited a lot 02 Yes, limited a little 03 No, not limited at all
	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	
4	Accomplished less than you would like	01 Yes 02 No
5	Were limited in the kind of work or other activities	01 Yes 02 No
	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as result of any emotional problems (such as feeling depressed or anxious)?	
6	Accomplished less than you would like	01 Yes 02 No
7	Did work or other activities less carefully as usual	01 Yes 02 No
8	During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?	01 Not at all 02 A little bit 03 Moderately 04 Quite a bit 05 Extremely
	These questions are about how you have been feeling during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much time during the past 4 weeks…	
9	Have you felt calm and peaceful?	01 All of the time 02 Most of the time 03 A good bit of the time 04 Some of the time 05 A little of the time 06 None of the time
10	Did you have a lot of energy?	01 All of the time 02 Most of the time 03 A good bit of the time 04 Some of the time 05 A little of the time 06 None of the time
11	Have you felt downhearted and blue?	01 All of the time 02 Most of the time 03 A good bit of the time 04 Some of the time 05 A little of the time 06 None of the time
12	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	01 All of the time 02 Most of the time 03 Some of the time 04 A little of the time 05 None of the time

9.3 Annex 3: Additional table

Table 40: Housing conditions, 2023

	Dibër		Fier		Durres		Shkoder		Total	
	n	%	n	%	n	%	n	%	n	%
Material of the floor										
Earth, sand	1	0.6	0	0.0	0	0.0	0	0.0	1	0.2
Wood, planks	3	1.9	1	0.4	2	2.9	0	0.0	6	0.9
Parquet or polished floor	3	1.9	2	0.7	3	4.4	1	0.6	9	1.3
Vinyl or asphalt stripes	2	1.2	0	0.0	0	0.0	4	2.5	6	0.9
Ceramic tiles	188	72.8	220	76.4	61	89.7	125	78.1	524	77.3
Cement	35	21.6	65	22.6	2	2.9	28	17.5	130	19.2
Material of the walls										
Stone with mud	5	3.1	1	0.4	0	0.0	1	0.6	7	1.0
Uncovered adobe	3	1.9	3	1.0	2	2.9	5	3.1	13	1.9
Cement	3	1.9	5	1.7	2	2.9	4	2.5	14	2.1
Stone with lime/cement	21	13.0	12	4.2	0	0.0	5	3.1	38	5.6
Bricks	36	22.2	126	43.8	50	73.5	52	32.5	264	38.9
Cement blocks	0	0.0	3	1.0	1	1.5	1	0.6	5	0.7
Covered adobe	93	57.4	137	47.6	13	19.1	91	56.9	334	49.3
Other	1	0.6	1	0.4	0	0.0	1	0.6	3	0.4
Material of the roof										
Rustic mat	4	2.5	0	0.0	0	0.0	0	0.0	4	0.6
Wood planks	1	0.6	2	0.7	1	1.5	4	2.5	8	1.2
Ceramic tiles	147	90.7	162	56.3	2	2.9	118	73.8	429	63.3
Cement	1	0.6	4	1.4	14	20.6	7	4.4	26	3.8
Reinforced concrete	6	3.7	120	41.7	48	70.6	24	15.0	198	29.2
Other	3	1.9	0	0.0	3	4.4	7	4.4	13	1.9