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"Understanding the perceptions and experiences of seniors and their caregivers when receiving Home Based Medical Care in Curaçao"

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By

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Declaration:

Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis *"Understanding the perceptions and experiences of seniors and their caregivers when receiving Home Based Medical Care in Curaçao"* is my own work.

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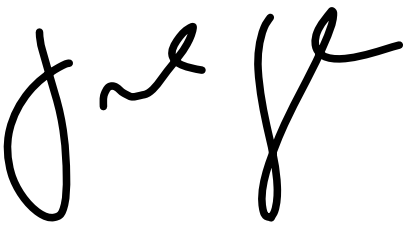

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Abstract

Background

The aging population in Curaçao faces challenges in receiving adequate care and support, both those living at home and those in nursing homes. The emigration of young adults has left many seniors without familial support, increasing feelings of loneliness and dependency on external care services. Due to the absence of a policy framework for preventive care for the elderly, elderly individuals in need of care do not automatically receive the care they are supposed to receive.

Objective

This study aims to address the research gap by exploring the perceptions, experiences, and needs of seniors receiving Home Based Medical Care.

Methodology

Through qualitative methods, including in-depth interviews with ten seniors, a FGD with caregivers, and semi-structured interviews with experts in elderly care, a comprehensive understanding of the challenges faced by the elderly in Curaçao has been attained.

Findings

Limited access to care, an inequitable health system and HRH shortage were identified as barriers to appropriate quality care and health care services in the elderly care. According to the perceptions and experiences of seniors, their voices are not heard.

The study also sheds light on the vital role of caregivers in elderly care, emphasizing the need for additional support and resources to balance caregiving responsibilities with their own well-being. Furthermore, the lack of a comprehensive policy for elderly care and inadequate collaboration among healthcare organizations were identified as challenges in the healthcare system.

Conclusion and Recommendations

Enhancing elderly care in Curaçao requires integrated policies, resources, and consideration of seniors' voices and preferences.

Key words

Seniors, Caregivers, Home Based Medical Care, Access to care, Curaçao

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List of Abbreviations

AEN	Ministry of Agriculture, Environment, and Nature Sector
BES	Bonaire, St Eustatius and Saba
CAS	Curaçao, Aruba, and Sint Maarten
CBS	Centraal Bureau voor de Statistiek
CMC	Curaçao Medical Center
FGD	Focus Group Discussion
GDP	Gross domestic product
GoC	Government of Curaçao
GMN	Ministerie van Gezondheid, Milieu en Natuur, 'The Ministry of Health, Environment, and Nature'
GP	General Practitioner
HBMC	Home Based Medical Care
HRH	Human Resources for Health
IDI	In-depth Interview
KI	Key Informant
NCD's	Noncommunicable diseases
NGO	Non-profit organization
REC	Research Ethics Committee
SOAW	Ministerie van Sociale ontwikkeling, arbeid en welzijn, 'The Ministry of Social Development, Labor, and Welfare'
SVB	Sociale Verzekeringsbank, 'Social Insurance Bank'
WGK	Wit Gele Kruis, 'White Yellow Cross'
WHO	World Health Organization

Definitions of Key Terms

- Caregivers are 18 years and older and provide routinely unpaid nonprofessional care to seniors or family member (19)

- Home Base Medical Care (HBMC) refers to the healthcare services provided by professionals of two organizations in Curaçao, which are delivered at the seniors' own homes. HBMC encompasses a wide range of healthcare services that can be provided at home for the treatment of illnesses or injuries (19)

- The Ministry of Health, Environment, and Nature consists of two sectors: the Health Sector and the Agriculture, Environment, and Nature Sector (AEN).
  The Health Sector comprises the implementation organizations for Medicine and Health Affairs and Veterinary Affairs, while the AEN Sector comprises Environmental & Nature Management and Agricultural and Fisheries Management. Each sector is headed by a sector director, and there is also a policy director at the head of the policy department (30)

- The Ministry of Social Development, Labor, and Welfare takes the lead in working together with all citizens, businesses, and institutions to promote the social development and well-being of the residents of the country Curaçao towards a sustainable, healthy, loving, safe, constructive, livable, stimulating, and emancipated living, learning, working, and residential environment. Family and youth, labor, and social development play a central role in this endeavor (30)

- Seniors are 65 years or older (only for this thesis)

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First and foremost, a heartfelt thank you to my tutor. Your patience and inspiration were invaluable. We shared quite a few laughs, and your wealth of experience has been like gold to me.

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I want to thank my parents to inspire me and make me reflect on the essence of life. To my brothers, James and Rodney, you both are so important to me. Thank you for your unconditional love and motivational speeches, I really felt supported, safe and confident with you next to me.

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Lastly, I want to express my gratitude in my native language, "Masha masha danki dushis!" Thank you all once again for being an essential part of this journey.

Introduction

Over the past 13 years, I have resided in the Netherlands. I am currently employed by an Non-profit organization (NGO) that targets sexual health improvement in underserved communities. I have more than 15 years of experience in sexual health. In my pursuit of personal and professional growth, I have decided to step out of my comfort zone and explore new areas of knowledge.

The World Health Organization (WHO) has declared 2020-2030 as the "Decade of Healthy Aging," highlighting the urgent need for global efforts in this area (3). This decade calls for collective action to promote well-being in ageing by maintaining functional capacity (2). Healthy aging means enabling individuals to maintain their overall well-being as they get older. Population aging is becoming a global public health challenge. Consequently, I have chosen to delve into this new public health challenge, the domain of senior care. I am dedicated to learning something new that is important to society now. I firmly believe that broadening my horizons will enhance my capabilities as a well-rounded healthcare professional.

It is relevant to note that my motivation for conducting this research stems also from my personal circumstances. Specifically, my parents currently reside on the island of Curaçao. My father, aged 83, has been living in a nursing home for the past few months, while my mother, aged 76, continues to live independently at home without requiring medical assistance. When I am physically present on Curaçao, I actively serve as a caregiver to my parents. Even when I am geographically distant, living in the Netherlands, I remain deeply concerned about their well-being. I grew up in Curaçao, where seniors hold an important and respectful place in society. However, in healthcare, this appears to be the opposite. I experience this paradox with my parents. It is this personal connection and genuine care for my parents' health that have compelled me to undertake this research.

One of my primary objectives in conducting this research is to gain a comprehensive understanding of the healthcare system pertaining to the elderly in Curaçao. By shedding light on the quality of care provided to this demographic group, I hope to generate valuable insights for healthcare professionals and contribute to potential improvements. Recognizing the inherent relationship between "quality of life" and "healthy aging," I am resolute in my desire to facilitate positive changes in elderly care on the island.

In summary, my research aims to enhance the prospects of healthy aging for individuals in Curaçao, drawing from the personal motivation of ensuring my own parents' well-being. My goal is to elevate the quality of life for the elderly and promote better healthcare outcomes, ultimately leading to a higher standard of living for this population.

Chapter one: Background information of Curaçao

Figure 1. Map of the Caribbean.

History, geographical context and demography of Curaçao

The Netherlands Antilles are six islands in the Caribbean Sea. From December 15th, 1954, these islands formed a country within the Kingdom of the Netherlands. In 1986, Aruba continued as a separate country, the so-called *Status Aparte* within the Kingdom. In 2010, Curaçao and St. Maarten followed, while Saba, St. Eustatius and Bonaire (the BES islands) were incorporated as "special municipalities" into the mother country as the Dutch Caribbean. As a result, the Netherlands Antilles no longer exist as a constitutional unit. The islands have since then been referred to as a territory, “the Caribbean part of the Kingdom of the Netherlands”. Curaçao, Aruba, St. Maarten are autonomous countries within the Kingdom and determine their own policy regarding health care. Bonaire, Saba and St Eustatius are Special Municipalities within the Netherlands (Dutch Caribbean). Migration within the Kingdom of the Netherlands is facilitated by the fact that citizens from the BES (Bonaire, Sint Eustatius, and Saba) and CAS (Curaçao, Aruba, and Sint Maarten) islands hold Dutch passports, thereby eliminating the need for a visa requirement (47).

Curaçao is located in the Caribbean sea, near the coast of Venezuela. The island area is 444 square kilometres (12). With an estimated population of 148.925 (54.6% is female and 45.4% is male (12) (see table 1), Curaçao is the largest island of the Kingdom of The Netherlands.

Curaçao is ranked as a high income country by the World Bank. The GDP per capita stands at 17,717 USD, showing a growth rate of 4.2%. The unemployment rate is 13.1%, and the population growth rate is -1.7%. In 2022, the net migration rate for Curacao was 3.117 per 1000 population, marking a 0.48% decline from 2021 (13). The fertility rate is 1.4 (total births per woman), and the infant mortality rate is 5.7 per 1000 live births. Life expectancy at birth is 74.7 years for males and 81.5 years for females (12).

Table 1. Total population in Curaçao

Population 2021	**1st January 2021**	**1st January 2022**	**1st January 2023**
Total population	153.671	151.066	148.925
Female	83.757	82.410	81.312
Male	69.914	68.656	67.613

Table 2. Age percentage in total population

Percentage of total Population	Age
16%	0-14 years
64%	15-64 years
20%	65+ years

In table 2, the total population is divided by age (22).

Ethnicity, Religion and Population distribution

Curaçao has more than 50 different nationalities. The four largest nationalities are Curaçaoan (75%) Dutch (6%), Dominican (3.6%) and Colombian (3%). Other nationalities represented in Curaçao are from the BES islands, Haiti, Surinam, Venezuela and Aruba (14).

Papiamento is the official language (80%). Papiamento is a creole language that is a mixture of Portuguese, Spanish, Dutch, English, African languages and the language of the Arawak. Dutch is the second official language (8.8%), English is the third official (3.1%) and Spanish is commonly used (3.6%) (14).

Table 3. Overview Religion in Curaçao

Religion		
Roman Catholic 72.8%	Protestant 3.2%	Jehovah's Witness 2%
Pentecostal 6.6%	Adventist 3%	Evangelical 1.9%

People from Curaçao practice several religion in table 3 an overview is presented (14).

Population Distribution

Curaçao is divided into two parts Bandabou (western side) and Bandariba (eastern side). The largest population and concentration on the island are in Bandariba. Willemstad (part Bandariba) is the capital city of Curaçao (figure 2). Employment opportunities are mainly concentrated in Willemstad, which attracts people. The eastern side has the highest population and the lowest unemployment rate. The western side of the island has the highest unemployment rate of the island (12).

Figure 2. Curaçao divided into parts.

Health system in Curaçao

The health system of Curaçao consist of primary and secondary healthcare. Primary healthcare starts with a consultation with the general practitioner (GP). Approximately 80% of adults in Curaçao consult a GP each year. The GP refers 90% of adults to a pharmacy or a medical laboratory in the context of the treatment, or to another healthcare provider. 15% of the adults consult with a physiotherapist, 54% with a dentist and/or orthodontist annually. At the secondary healthcare: 35% of adults have a consultation with a medical specialist. 41% of adults in Curacao make use of medical specialists abroad. Secondary healthcare services are provided at Curaçao Medical Center, and some specialist consultants operate private practices. These data were collected by the Volksgezondheid Instituut Curaçao, 'Public Health Institute' in 2017 (15).

There are three hospitals in Curacao. The Curaçao Medical Center is the largest hospital. It has a comprehensive emergency room and the only intensive care unit on the island. The Taams Clinic and the Antillean Adventist Hospital also offer a wide range of medical services and specialists (15).

Some facts concerning the health system

99% of adults in Curaçao have a health insurance. Most adults are insured through:
- Social Insurance Bank (SVB): 86%
- Private Insurers: 8%
- Company Insurance: 6% (15)

Caregivers (are providing unpaid nonprofessional care to seniors or family member)
- 20% of the working adults are caregivers.
- Most caregivers are between the age of 45-64 years.
- 18% is male and 20% is female caregivers.
- 26% of the caregivers have their parents at home.
- 64% of the caregivers are involved in caring for one or more family members.
- 17% of caregivers spend 20 hours or more per week providing care (15).

Number of Medical Specialists in Curaçao:
- Internists: 15
- Gynecologists: 10
- Surgeons: 9
- Pediatricians: 9
- Other Medical Specialists[1]: unknown

Number of Healthcare Professionals in Curaçao:
- Nurse[2]: unknown
- General Practitioners: 85
- Physiotherapists: 56, Dentists: 39
- Psychologists: 36, Pharmacists: 33
- Opticians: 17, Dieticians: 12 (16)

[1] Other medical specialists such as cardiologists, psychiatrists, neurologists and other are available but the numbers are unknown.
[2] Unfortunately number of nurses unknown.

Major health problems adults

In Curaçao, a portion of the adult population, around 37%, experience having one or more noncommunicable diseases (NCDs). Once individuals reach the age of 65, this percentage increases to 50% among Curaçao residents. Additionally, 13% of adults have two or more NCDs, and this figure grows to 20% among individuals aged 65 and above. 36% of the total population is overweight and 29% is obese (15). Excess weight or obesity can be a risk factor for the development of type 2 diabetes, cardiovascular diseases, and specific types of cancer (20).

The leading causes of mortality in Curaçao can be attributed to cardiovascular diseases, accounting for 37% of deaths, followed by cancer at 26%. External causes, such as accidents or injuries, contribute to 8% of mortality, while respiratory diseases account for 6% (15).

Table 4. Causes of death in age

64 years and younger	65 years and older
1. coronary heart disease	1. coronary heart disease
2. homicide	2. stroke
3. lung cancer (21)	3. cardiac arrest (21)

Senior care

Following Curaçao's attainment of Status Aparte in 2010, elderly care has been placed under the jurisdiction of different ministries. It is now divided between two ministries: the Ministry of Health, Environment and Nature (GMN), and the Ministry of Social Development, Labor and Welfare (SOAW) (30). Each of these ministries have distinct areas of focus concerning elderly care. An example of this is the legal allocation of the budget for nursing home subsidies to the Ministry of SOAW, while the Ministry of GMN took on the responsibilities related to permit issuance. Possessing a license does not guarantee eligibility for subsidies. At present, there are approximately 40 nursing homes, but only 7 of them are officially registered as licensed facilities (44).

The government of Curaçao (GoC) lacks a vision for effectively organizing and improving elderly care and well-being, leading to a lack of well-developed policies with concrete objectives. There is an absence of urgency and commitment from the two ministries to formulate and implement specific policy goals, resulting in a limited impact on the quality of elderly care and well-being (44).

Additionally, there is an independent inspection authority responsible for overseeing aspects of elderly care. The inspection authority relies on various parts of legislation to carry out its duties. The newspaper reports that the inspection is facing challenges due to a lack of personnel and is also operating within an outdated legal framework. The regulation on the control of infectious diseases has been in effect since 1921[3]. Packaged medicines are subject to control under a law enacted in 1961 (29).

The Social Insurance Bank has various areas of focus within elderly care:

- Provides a pension for all residents of Curaçao when they reach the age of 65, known as AOV (old-age pension).
- Provides basic health insurance, offering standardized insurance coverage for individuals falling under its scope.

[3] This Information is also known within other Health care sectors.

- Indicates the start of HBMC and provides additional materials for health care aids or needs for home use (such as wheelchairs, special beds, etc.) (31).

There are two key organizations involved in promoting the well-being of the elderly population. The Raad van Ouderenbeleid, 'Council of Elderly policy' focuses mainly on policy making. In addition, this organization aims to assess the needs, address the financial aspects of senior care, develop senior care legislation, determine care requirements, and educate about preventive measures for the elderly. The findings and recommendations of this council are communicated to the ministries (17).

The Birgen di Rosario Foundation is an organization that has a care service agreement with the government. This foundation concentrates on patient care. This agreement ensures that the foundation receives partial subsidies for the inpatient, outpatient, and semi-mural care services they provide. The rest of the funds are private funds (the patients) and the Social Insurance Bank (23). Additionally, the government monitors the quality of care offered by the foundation (17).

Overall, senior care in Curaçao operates with a triple-layered system: the executive body (Birgen di Rosario Foundation), the supervisory and advisory role (Council of Elderly policy), and the government, which provides subsidies and incorporates the findings into senior care policies (17). A policy framework for the elderly care in Curaçao is not developed (5).

There are two organizations in charge of Home Base Medical Care: Wit Gele Kruis, 'White Yellow Cross' Foundation (WGK) and the Home Based Medical Care Banda Bou. These organizations have over 4,200 seniors in care, which is to 20% of the total senior population. The WGK is responsible for approximately 95% of all care provided at home (5).

Rehab centre

The Rehabilitation Centre Curaçao Foundation provides specialized treatment and guidance to adults who have physical limitations due to illness, accidents, or congenital conditions. The Rehab centre focuses on achieving optimal recovery and provides support in social and community aspects, with the aim of reintegrating the clients into society (45).

Chapter two: Problem statement, Justification, Objective and Methodology

Problem statement

Humans become older. Between 2015 and 2050, the world's population of 60 years and older will nearly double from 12% to 22%. The pace of population ageing is much faster than in the past. The life expectancy will increase by 8 years worldwide in 2050 from 68.6 years in 2015 to 76.2 years. By 2030, 1 in 6 persons in the world's population will be 60 years or older (1).

The decline in fertility rates and increase in life expectancy is causing the population to age worldwide. As a result, the historic first time that there will be more older people than younger people is rapidly approaching (1).

Overal health has improved due to the prevention of chronic and communicable diseases: improved access to primary care for the elderly, and the WHO's focus on creating age-friendly communities (1).

The GoC foresees that they will face challenges due to the ageing population. There are approximately 149,000 people living in Curaçao, 24,000 (15%) of which are aged 65+ (4). In 2030 Central Bureau of Statistics (CBS) predicts that the number of seniors in Curaçao will be 25% of the total population (4). This huge increase will have impact on the demand of care. Family structure and local culture often creates pressure for family members with the care of seniors (5,6). Emigration of young and highly educated people the so-called brain drain (15-35 years) is yearly almost 4% of the total population (5). The brain drain negatively affects the accumulation of retirement funds and other senior care facilities. Proportionally, fewer working people are paying contributions in order to pay for these facilities (9).

Seniors living at home

In Curaçao 10% of seniors living at home needs help that they are not able to receive, such as help with household activities, transport, physical care and nursing. Physical and nursing care are mentioned by seniors. Of the 80+ years seniors in Curaçao, around 40% have professional help (5). WGK and the HBMC Banda Bou mentioned in a needs assessment that they are facing difficulties in providing care due to shortages of staff (5).

Emigration of young adults from Curaçao to the Netherlands in recent years has left seniors alone. When the seniors need help, they are unable to rely on the help of their children. Care provided by family members threatens to fade due to emigration. Traditionally older people could continue to live in their own living environment with the support of their children. This is often no longer possible. The study conducted in Curaçao by the Permanent Commission on Population Issues shows that seniors whose children emigrated are much more likely to report feeling lonely (7).

Seniors in nursing homes

With regard to users of care in nursing homes, it applies that they not only have more serious but also more different limitations. In all cases, residents suffer from one or more somatic disorders. 30% has psychogeriatric problems and 20% has physical limitations. In total, around 3% of seniors between 65-79 years and 14% of 80+ seniors are housed in nursing homes. There are 16 organizations providing nursing home care in Curaçao (5,8).

The lack of a legal and policy framework for preventive care for the elderly results in a situation where elderly individuals in need of care may not receive the appropriate level of support. Consequently, some seniors who could have continued living at home may end up entering nursing homes prematurely. Both Nursing & Care and Elderly Care sectors are grappling with an imbalance between the demand for care facilities and the available supply to meet this demand. This challenge is compounded by an indication and placement system that lacks coherence and fails to regularly re-evaluate the needs of the elderly after admission (5).

Justification of the study

In Curaçao, over the years, research has been performed on the needs on care and network of the seniors living independently (without HBMC) at home. Furthermore, the Federation of Care Institutions in the Netherlands Antilles has conducted research on the quality of care offered to elderly residents in nursing homes (5). What appears to be a research gap is seniors at home receiving HBMC. Therefore, a qualitative

study will be carried out to explore the perception, experiences and needs among seniors and their family on Home Based Medical Care for seniors in Curaçao.

General Objectives

Understanding the perceptions and experiences of seniors and their caregivers when receiving Home Based Medical Care in Curaçao.

Specific objectives of the research:

- Identify what the needs are to support seniors in healthy aging at home
- Understand perceptions on Home Based Medical Care among seniors and their caregivers at home
- Describe the experiences among seniors and their caregivers about Home Based Medical Care

Chapter 3: Methodology

Study Type

Qualitative research was conducted through in-dept (IDI) interviews with seniors, a focus group discussion (FGD) with caregivers and interviews with experts in the field of senior care. The data were collected in the eastern and western parts of Curaçao between May and July 2023.

Study Population

Seniors receiving HBMC were recruited through the organizations WGK and the Home Base Medical Care Bandabou. The selection of the participants was done at random by a list provided by the WGK and the Home Base Medical Care Bandabou. The seniors (not in care) and caregivers for FGD were recruited through a call for participation. This call was sent to family and friends. By using the snowball sampling approach other participants were recruited (18). While the experts were recruited through the organizations and through snowball sampling.

Inclusion criteria

In order to be included in this qualitative study, participants had to meet specific criteria. These criteria included being female or male seniors aged 65 or older receiving or not receiving HBMC. Another inclusion criterion was the location of the participants (the east or west of the island). Additionally, participants needed to be mentally fit without dementia.

For the focus group discussion, participants were selected from caregivers who were 18 years or older and provided regular unpaid care to seniors or their family members. These caregivers were considered nonprofessionals in terms of providing care. The caregivers were not related to the 10 seniors interviewed. Furthermore, experts in the field, including professionals in senior care, healthcare providers, and a psychologist with relevant expertise, were interviewed as part of the study.

Table 5. Overview study population

Method	Sort of Participants	Target
Interviews (IDIs)	Seniors receiving HBMC Selected by age, female or male, Social Economical Status, location island (east or west), Mentally fit (not having any form of dementia or Alzheimer) Seniors not receiving HBMC or other care (living at home)	6 interviews 4 interviews
FGD	Caregivers caregivers are 18 years and older and provides routinely unpaid care to seniors or family member	1 FGDs with 6 participants
KI	Gerontologist Psychologist Manager Chair of The Raad van Ouderenbeleid (Council of Elderly policy	4 experts

The conceptual framework of the elderly health needs

Based on reviews of studies and previous experiences, it becomes evident that most needs assessments for the elderly primarily focus on assessing physical health, while mental and social health dimensions receive comparatively less attention despite their significance (11).

Healthy aging is influenced by various conditions and factors, as identified through research and needs assessments conducted by the WHO to promote healthy and active aging. Sima Ghasemi's conceptual framework (refer to figure 3) further outlines the principal conditions and factors associated with the health needs of the elderly (11).

Investigation of need assessment in elderly should be more focused on mental needs, as it is influenced by social, emotional interactions, functional and cognitive abilities and social support. This framework provided guidance for the literature study of this research. For literature, searches have been conducted in both Dutch and English.

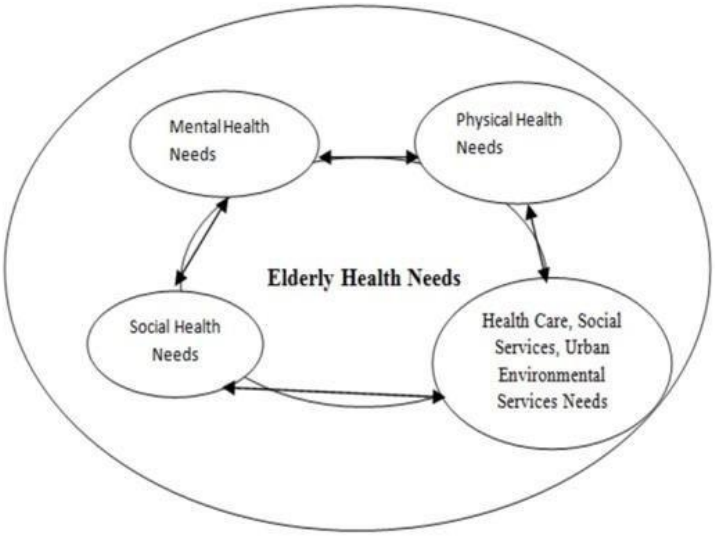

Figure 3 The conceptual framework of the elderly needs, Sima Ghasemi ea.

- Mental health needs are treatment and care for mental disorders (depression and dementia).
- Social health needs are access to transportation, access to food and housing and paying for prescriptions or medical bills and literacy.
- Physical health needs are possibilities to do exercise regularly, to have a balanced diet and to proper sleep.
- Health Care, social services and environmental services needs are access to quality health services, good water quality, support from family or community.

Data collection methods

In this study, IDIs were used to gather information and understand the perceptions, experiences, and needs of seniors in HBMC and those not in care. Furthermore, a FGD was conducted with family members, involving participants from various families. A topic guide was developed for the IDIs, which was pretested, translated (from Dutch to Papiamento and vice versa), and used to explore perceptions, experiences, and social and economic factors. The interviews took place at homes of the respondents. Each interview lasted approximately 45 to 75 minutes. Recordings were made with the respondent's consent, and observations of body language were noted.

The FGD aimed to capture different perspectives and extra information. The discussion was conducted with caregivers and highlighted health service factors, as well as social, cultural, and socioeconomic factors. It lasted approximately 90 minutes. The FGD was in Dutch and Papiamento. Recordings were made, and observations of body language were noted.

Semi-structured interviews were conducted with key informants to provide additional information for triangulation. Key informants included a gerontologist, a psychologist, a manager from WGK, and the chair of Council of Elderly policy.

After conducting the data collection, it became evident that information saturation had been reached, and no additional novel insights emerged, even with the diverse composition of the study population.

Demographics of study population

The study included a total of 10 participants with diverse demographic characteristics. Among them, five were aged 65 to 75, four were aged 76 to 85, and one was specifically 96 years old. Gender distribution was balanced, with 60% identifying as female and 40% as male. Six participants were receiving HBMC, while four were not. The majority, eight participants, identified as Curaçaoan, while two were of South American background. Regarding residential status, two lived alone, five participants lived with children, one lived with a partner, and two lived with a partner and children. Years receiving HBMC varied from 1 to 15 years. Four seniors were not receiving HBMC. Education varied, with 30% having a bachelor’s degree, 20% having secondary vocational education, 30% finished their high school, and 10% with no education (Annex 3).

Five caregivers were invited to participate in a FGD to explore their perspectives, experiences, and perceptions for triangulation and to collect additional information for this study. Caregivers were adult children who take on the responsibility of caring for their aging parents. One caregiver was a husband who takes care of his wife. The elderly who need the care receives additional professional care (Annex 3).

In order to validate and enrich the findings of the study, semi-structured interviews were carried out with four stakeholders who were selected based on their professional experiences in senior care. These experts provided insights and perspectives that informed and enhanced the research outcomes (Annex 3).

Data processing and analysis

The data was grouped into predefined themes and then analyzed with Nvivo software for coding and examination. This approach helped ensure a systematic study, increasing its reliability. Furthermore, findings from FGD were used to validate results and provide extra valuable perspectives, enhancing overall comprehension of the research topic.

Ethical Clearance

The application for ethical clearance for the study titled *"Understanding the Perceptions and Experiences of Seniors and Their Caregivers on Home Based Medical Care (HBMC) in Curaçao"* was reviewed by the Research Ethics Committee (REC) of the Royal Tropical Institute. Following the thorough evaluation and addressing of concerns and questions raised by the REC, the research successfully met the necessary ethical standards. Consequently, the study was granted clearance for implementation (Annex 4).

Limitations

The use of multilingual translation, from English to Dutch and then to Papiamento, and vice versa, may have resulted in the loss of valuable information. Certain words in Papiamento may be challenging to translate accurately due to the emotional connotations they carry, making the translation process complex.

The principal investigator had initially planned to conduct two FGDs, one with a group of male caregivers and another with a group of female caregivers. However, due to time limitations and the availability of caregivers, only one FGD was eventually conducted, combining both male and female caregivers in the same group.

Chapter 4: Results

The elderly needs

This chapter presents the results of the study aimed at understanding the perceptions and experiences of seniors and their caregivers regarding HBMC in Curaçao. To preserve participants anonymity, specific characteristics of the individuals are utilized.

Mental Health Needs

More than half of the participants mentioned feeling lonely. *"Being alone is not good for your thoughts. When you're alone at home, you only think bad things. Going out distracts you. When you go out, you see other people"* (Female, 96 years old, receiving HBMC).

A senior stated that he would like to do nice activities, but he doesn't feel like it. *"Your attitude, exercising, it is necessary, but I don't do it. Going out, being with people. Not me. I don't feel like going dancing and going out. I am not interested. That's not good*" (Male, 70 years old not receiving HBMC).

Some of the participants became emotional during the interview. A 73-year-old woman had lost her son, which made her very sad. Additionally, her husband had passed away 8 months ago at the time she was interviewed. She stated several times that she felt very sad.

Another 72-year-old participant cried during the interview. She expressed emotional distress, possibly related to mental health issues resulting from not working anymore. She wanted to continue working after retirement, but she got sick. She said, *"I thought that when I retire, I can continue visiting people at home. Look at me now, I am the one being taken care of, and I can't be a nurse anymore. I really wanted to keep working after retirement, but I don't feel well enough"* (Female, 72 years old, receiving HBMC).

An expert mentioned in the interview that loneliness is often a struggle for older people, especially those who are highly educated. She said, *"There are hardly any social activities that cater to highly educated seniors. It's often about playing dominoes or bingo. But there are no discussions on specific topics or book clubs, which prevents them from going out and leads to isolation"*(Expert).

Another expert also highlighted that seniors often face a significant barrier when it comes to doing things alone. In her practice, she frequently encounters elderly individuals who are afraid to engage in activities on their own. During consultations, the psychologist empowers seniors to acknowledge and overcome these fears related to undertaking activities alone. Subsequently, she equips them with practical tools to navigate these situations independently. The psychologist has observed that older adults are embracing these tools and increasingly showing a willingness to take steps like dining alone, among other activities.

The interviews with the seniors revealed a prevailing emphasis on maintaining mental fitness and well-being through various proactive approaches. During the interviews, various participants emphasized that a positive attitude among the elderly plays an essential role in well-being and coping with life's challenges. Some participants indicated that negativity could make their lives more difficult and even impact on their mental well-being. By adopting a positive attitude, individuals can better handle challenges, difficult situations, and setbacks. Which they believed can help them approach problems in a more constructive manner, promoting their overall well-being.

"*The importance of a positive attitude in maintaining good mental health highlights positivity and optimism in our lives, especially as we age. It can be a valuable means to promote resilience and well-being in the face of diverse life challenges"* (Male, 70 years old, not receiving HBMC).

A notable aspect that emerged from these conversations was the eagerness of the seniors to engage in activities that stimulate their minds and keep them mentally sharp. Some of the interviewees expressed a keen interest in reading books, demonstrating a desire to expand their knowledge and explore different perspectives on various topics. Additionally, a few participants mentioned their habit of watching news from different countries, indicating a willingness to broaden their understanding of global affairs and cultivate a more worldly outlook. Some participants stated not be interested in news anymore.

Another activity among the seniors that surfaced during the interviews was their involvement in crossword puzzles and mind games. These mental exercises were seen as not only an enjoyable pastime but also as a means to challenge and stimulate cognitive faculties. Some participants found pleasure and satisfaction in solving these puzzles and mind games, perceiving them as a valuable activity to keep their minds alert. *"I do a crossword puzzle every day, my mother loved puzzles and remained mentally healthy until she passed away"* (Female, 66 years old, not receiving HBMC).

Mental health needs of Caregivers

During the FGD, a caregiver, who takes care of his wife, became emotional and said, *"Being a caretaker is not easy. A lot of emotions are surfacing, and this surprises me. I feel embarrassed, but I am grateful that I could share my story with you all"* (FGD, 72 years old caregiver).

Some family caregivers may find themselves overwhelmed and facing immense pressure in balancing their caregiving responsibilities with other aspects of their lives. Some caregivers stated to have feelings of guilt, as they strive to do everything themselves to ensure the best care for their aging parents. A caregiver stated: *"Until I collapse, I must care for her at home" (FGD, 72 years old caregiver).* The burden of caregiving can take it's toll on the well-being of the caregivers themselves, as discussed in the FGD. *"Yes, your own sanity is also important so that you can continue. We put ourselves aside but we need to take time for yourself. They will also appreciate it because when you take time for yourself, you appear happier. They can feel it too"* (FGD, 56 years old caregiver).

During the focus group discussion, it was mentioned that a family received support from the general practitioner and psychiatrist. If needed, one could make an appointment with the general practitioner for a home visit, which they provide to support the family and patient through a conversation.

Social Health Needs

Nearly half of the seniors mentioned transportation as an important need. It is mentioned that transportation can be arranged through the HBMC as an additional service. During the interviews, most of the participants stated that they need to call one to three days in advance to reserve transportation. They mentioned using transportation to go to the doctor or a medical specialist. Some participants said they would like transportation to visit their family and friends. Additionally, some participants expressed a desire for transportation to be able to attend enjoyable activities. However, the participants stated that this is currently not possible through home care.

"Transportation is difficult. I would like to visit my sister. I miss her. We used to talk on the phone every day" (Female, 96 years old, receiving HBMC).

In the FGD most caregivers expressed a need for transportation. They mentioned wanting transportation, for example, to go to the beach. One caregiver mentioned that they had to rent a bus themselves to take their parents somewhere. They find it too much work to arrange transportation, leading them to prefer staying home with their parents instead. Another caregiver, who takes care of both her father and mother, said, *"We usually celebrate Easter at their home because then we don't have to arrange transportation. They also need to get out of the house; otherwise, they just keep looking at those four walls. Transportation makes it difficult"* (FGD, 56 years old, caregiver).

Nutrition

Some of the interviewees mentioned that access to healthy food is difficult on the island because vegetables and fruits are very expensive. A senior from the western part of the island said, she would like to receive a fruit and vegetable basket each month. She said, *"During the lockdown, we received food packages with vegetables*

and fruits. I miss that. I cannot afford it myself. I would also like other retirees to have it. As a senior, you should eat vegetables and fruits" (Female, 78 years old, receiving HBMC).

The issue of food accessibility emerged as a prominent topic of discussion during the interviews. One interviewee highlighted the importance of food packages, which likely serve as a critical means of ensuring a stable and nourishing diet for some seniors who might face economic constraints or limited mobility. Other interviewees have also mentioned that being alone can have an impact on accessing proper nutritional food.

"When I'm alone, I often lack the motivation to cook elaborate meals for myself. In such cases, I quickly opt for something simple, like a sandwich with a fried egg" (Female, 80 years old, not receiving HBMC).

Knowledge about what constitutes healthy food is a concern according to a 73-year-old senior. He said, *"We eat very few vegetables in Curacao. We consider canned peas and beets as vegetables. We still haven't taught our people to eat more vegetables, and I think the vegetables here are way too expensive*" (Male, 73 years old, not receiving HBMC).

Most participants mentioned receiving help with groceries from their children or other family members. Additionally, their children often cook for them, providing access to healthy food. One participant mentioned receiving an extra service from HBMC where they cook for her for a few days. She also mentioned that her son helps her with cooking on weekends.

In the FGD there was a discussion about delivery services for healthy meals. One caregiver arranged for healthy meals to be delivered to her mother. There were options for food to be delivered or picked up through a hospital. These services were not provided by home care but are often private, as stated by a caregiver in the FGD.

Some elderly individuals mentioned that eating alone does not promote healthy eating habits. They emphasized that sharing a meal with others provides companionship and encourages better eating habits. Eating alone often leads to poor dietary choices and lack of variety in their meals, they said. Others mentioned that they do not bother cooking when they are alone. One participant noted that there is also limited knowledge about healthy nutrition among some seniors. A participant with a stoma who uses Ensure (It is a ready-to-use, complete, and supplementary medical nutritional drink) and brings it along to dinners or gatherings.

In the FGD, it was mentioned that there are no food delivery services like tafeltje dekje “Meals on Wheels“ (is a meal delivery service in the Netherlands). However, one participant shared that their mother receives a healthy meal delivery service from a private provider and eats nutritious meals daily. One caregiver stated: *“My mother used to eat monotonously - bread, yogurt, very repetitive. Eating alone is less enjoyable than when you can eat with others because engaging conversations happen during meals. Unfortunately, we don't have dining halls for the elderly”* (FGD, 48 years old caregiver).

Physical health needs

Most of the participants lead active lives. They engage in physical activities almost daily, mainly involving swimming, gardening, household chores, and walking. One participant talked about a swimming club at Janthiel (a well-known beach in Curaçao). Approximately 20 elderly people gather there every day to swim, usually starting around 7 o'clock in the morning. Another 73-year-old participant mentioned being part of a swimming club with 30 seniors, where he swims three to four times a week, starting at 6 o'clock in the morning. He said, *"You arrive at 6 o'clock, talk to other people, and when you return home, you feel energized and recharged from swimming"* (Male, 73 years old, not receiving HBMC).

An 80-year-old participant, who lives alone, shared that she takes care of many household tasks herself and enjoys gardening. She stays active daily and does things like painting the bathroom and changing the light in the kitchen. She tries to work on her mobility, saying, *"I bend and move a lot. I do notice that I'm getting older.*

In the past, I could get up from the ground without holding onto anything. Now I need something to hold on to. There's a difference" (Female, 80 years old, not receiving HBMC).

Some participants mentioned exercising during their recovery from illnesses. They had positive experiences with an institution that helped them become more mobile. Unfortunately, they are not as active anymore. A 96-year-old participant mentioned that she attempts to walk to the mailbox but finds it challenging to do so alone. Another 78-year-old participant mentioned that he used to go to the gym and do exercises but has stopped because he didn't feel the need for it anymore. Some other participants mentioned that home care services do not offer activities to encourage exercise at home.

During the FGD, it was highlighted that caregivers take an active role in promoting movement. One caregiver, who takes care of his wife, shared that he exercises with her every day. She underwent six months of therapy to regain her ability to walk, and the efforts paid off. So, he continues to exercise with her daily to maintain her mobility. According to a caregiver, if the physical therapist does not notice significant progress in the therapy, they may choose to discontinue it. However, the caregiver emphasized that even small improvements can have a profound and positive impact on the well-being of the elderly. Another caregiver mentioned that her father, who had a spinal cord injury, received private physical therapy at home, which significantly improved his mobility.

One caregiver mentioned that her father, who has Alzheimer's, lost the ability to walk after a year in a nursing home. "*He used to go to Janthiel regularly for swimming, but, unfortunately, he is no longer able to do so"* (FGD, Caregiver, 56 years old).

An expert mentioned a gym that specializes in fitness for 40 plus. It is quite a popular place among the seniors. They get extra support when doing exercise.

Support, social needs and solutions

The majority of the elderly mentioned that they are supported by their children and family. They said they receive help with groceries, hospital visits, cooking, laundry, and other tasks. One elderly person mentioned that they stay at their child's house every weekend with their spouse, and they also go on vacations together. Most of the elderly also mentioned receiving assistance and support from their family and children in making important decisions. *"Especially with my daughter, I can discuss everything. We have already discussed the funeral "(*Female, 72 years old, receiving HBMC).

Another 72-year-old mentioned receiving help from her 15-year-old grandson with bathing. *"I just have to call him, and he comes to help me"*(Female, 72 years old, receiving HBMC).

A few elderly individuals mentioned that they don't receive support from their children because they live abroad. They shared that they receive support from friends and siblings. *"Fortunately, I am positive, and I am happy every day. Thank God, I can talk about hilarious things and laugh a lot. I visit my siblings every day. We have a great time together"* (Male, 70 years old not receiving HBMC).

Another participant mentioned that their daughter is a nurse and helps with their medication. Another participant shared that their daughter keeps an Excel sheet with all their blood test results every six months and accompanies them to the doctor. They further said*, "She asks difficult questions, and at one point, I asked the doctor if she's being difficult, and the doctor said, 'No, that's love"* (Male, 73 years old nor receiving HBMC).

Many participants stated to place great faith in the support they receive from their family and caregivers. *"The relationship between the elderly and their family caregivers is often one of deep trust and reliance" (Male, 81 years old receiving HBMC)*. Some seniors mentioned to be more comfortable entrusting their care to family members rather than professional caregivers, as they believe their loved ones have a better understanding of their unique needs and preferences.

“We aim to visit them every day because they are happy when we are around. And when we want to leave, they ask us to do various things, as they want us to stay for as long as possible” (FGD, 56 years old caregiver).

Various types of communities and clubs were mentioned among the elderly. A 73-year-old mentioned ladies' clubs that go on beautiful trips together. Another participant mentioned fixed groups of friends who have been traveling together for more than 30 years and meet every week. Swimming clubs and craft clubs were also mentioned by the elderly. *"I go to the beach every morning. I chat more with people than I swim. I go to the church every afternoon to meet people"* (Male, 70 years old not receiving HBMC).

A few experts mentioned that there is a group of elderly people who do not have access to social activities. It often boils down to not being able to afford these activities. *"If you can't afford certain things, then a lot is taken away,"* said one expert. Another expert mentioned that there is a group of elderly people who would like different types of activities. Activities with more depth, such as discussions on specific themes. It would be great to have a job agency specifically for the elderly. For example, older people could be linked to another elder who shares the same interests and needs. A caregiver mentioned that Curacao should give older adults a place back in society. *“My mother used to give sewing lessons to young people. She enjoyed it, her ego was boosted, and the young people gained respect for the elderly because they built something together”* (FGD, 48 years old caregiver).

Access to quality health services

Access to information

Health literacy was mentioned by a few experts and caregivers during the FGD. In the FGD, a caregiver mentioned finding it difficult to access information. She said, *"At some point, you start searching for information, but it feels like you have to beg or whatever. I think the information and availability of home care should be clearer"* (FGD, 52 years old caregiver).

The experts stated that health literacy among the elderly is low. One of them said, "Especially among the elderly, there is a significant health illiteracy." While another expert mentioned that there is not much education about healthy aging. He further stated that they are working on a video to improve seniors' attitudes towards health and make it more positive.

Access to care

Most of the interviewed seniors mentioned various services available through the organization that provides HBMC, such as medical assistance and household support, including laundry and house cleaning. Transport was also highlighted as a means to improve access to care.

However, some participants expressed that HBMC services are not available on weekends or when staff members are on vacation. In such cases, no replacement is provided, leaving them without assistance. *"They are short of staff. If they don't come, I don't call to ask where they are. When they have people available, they send someone. Sometimes they send a replacement, but sometimes no one comes"* (Female, 96 years old receiving HBMC).

Perception HBMC

The perceptions of HBMC providers can vary widely among seniors. *“Each nurse brings their unique approach to caregiving, leading to differences in the quality of care provided”* (Female, 96 years old receiving HBMC). *“Some nurses approach their work with enthusiasm and dedication, while others may not feel the same level of passion”* (Female, 80 years old not receiving HBMC). Consequently, some seniors expressed to have positive experiences with HBMC, while others may be left feeling dissatisfied.

Some participants said that there is fear among some elderly individuals regarding HBMC services. This fear could be fueled by rumors or misconceptions surrounding the quality of care provided or concerns about the

privacy and comfort of receiving care in their own homes, stated by some participants. As a result, some seniors mentioned to resist seeking home care services, preferring to rely solely on their family for support.

The caregivers expressed that professionalization is needed in HBMC. *“Having a definite schedule is important, so people know that the nurses will arrive at 8 o'clock. Of course, unexpected events can happen, but try to establish consistency in the nurses assigned to each individual. Currently, the person receives different nurses each time”* (FGD, 52 years old, caregiver).

“I really appreciate nurses, now that I take care of my wife” (FGD, 72 years old, caregiver).

During the focus group discussion, the quality of care was also discussed. Caregivers shared that accessing additional care required a referral letter, obtained through a general practitioner. While some started with government-provided care, they eventually shifted to private care due to better quality. However, it was acknowledged that better care often requires significant financial resources.

A few caregivers mentioned that he had to put in a lot of effort to arrange care at home. Both seniors and caregivers expressed having trouble arranging HBMC the first time through SVB.

Another caregiver, who takes care of his wife, mentioned that they should receive care from HBMC services twice a day, but they only come once a day due to being understaffed. While he doesn't blame them for being understaffed, he feels the impact as they are left without additional support. He also shared that in the past six months, they had seen 14 different nurses, which he found challenging. Other caregivers also expressed that having so many different caregivers affect trust. One caregiver shared a story, *"My father has Alzheimer's and can be aggressive. With so many different nurses coming in, his mood worsened, and he started hitting the nurses. The home care services then stopped the care because they didn't know how to handle it"* (FGD, 56 years old caregiver).

Several seniors also talked about the challenges they face in obtaining necessary aids through the SVB. They mentioned a need for items like walkers, wheelchairs, diabetes strips, and other supportive materials to make it at home easier. Unfortunately, these materials are not readily available, they said. The SVB was mentioned by most caregivers as well, expressing a need for materials that are not readily available. Some caregivers resort to placing advertisements on commercial sites to obtain the needed materials. The caregivers mentioned that nurses indicated that materials are not returned to the SVB (Social Insurance Bank). *“Certain materials remain in possession of elderly individuals who have long passed away, or they are repurposed and used as coat hangers. There is no control or enforcement of materials by the SVB”* (FGD, 72 years old Caregiver).

Furthermore, many seniors mentioned long waiting times for specialist appointments and hospital visits. They also expressed concerns about the quality of care provided by doctors, particularly general practitioners, where meaningful conversations seem to be lacking. “*I find the people from care not dedicated anymore. They don't take the time for the clients like they used to. It feels superficial, like it's more about the money than truly caring about their work. At least, that's how I perceive it”* (Female, 80 years old, not receiving HBMC).

One participant mentioned traveling to Colombia for medical care due to long waiting times locally. The cost of the trip is covered by the SVB, he said.

The rehabilitation Centre received praise, from all participants, including the caregivers, for providing professional and excellent care. It was considered a professional model that other institutions could learn from, according to one caregiver.

It was also mentioned in the FGD that with a referral letter from the general practitioner, one can have access to a psychologist, and through the hospital, one can engage in a conversation with a social worker.

In the FGD, it was mentioned that a specific rehabilitation center offers the possibility to have conversations with a psychiatrist. *"My wife had a session with her psychiatrist there."* (FGD, 72 year old caregiver).

Many caregivers mentioned the need for quicker access to care for the elderly. They expressed frustration with long waiting lists and the feeling of being pushed back. One caregiver said, *"For an older person, it's very*

frustrating. You are already limited in things you can do, and this has an impact on the elderly" (FGD, 52 years old, caregiver).

Another caregiver shared an example of her neighbor who never greeted her when they saw each other in the garden. Later, she found out that the neighbor had to wait a long year for her hearing aid.

The experts brought up various aspects that could impact the access to quality care. Most of them discussed the potential benefits of having care facilities located near the elderly, clustered within a neighborhood. They mentioned a model used in Cuba, where various services are available, such as physiotherapy, social workers, general practitioners, and community centers offering social gatherings for the elderly. They expressed a desire to have a similar approach in Curaçao, making healthcare easily accessible for the elderly. One expert explained that some seniors might prefer different care that are not located in the neighborhood. So this model is not always applicable for all seniors.

An expert also mentioned that addressing staff shortages in home care would improve the quality of care. However, they acknowledged the challenges of shortages across various working fields. Moreover, most experts noted that there is a lack of collaboration among different organizations involved in elderly care on Curaçao. *"This has an impact on the care. There is no coordination, no proper referrals. Everyone is operating independently"* (Expert).

Another expert, who teaches at a nursing faculty, observed a lack of enthusiasm among students. They shared that intrinsic motivation for nursing work is lacking due to various personal problems, such as financial and social issues, leaving them with little motivation to pursue the profession beyond monetary reasons.

An elder who has been receiving home care for 15 years expressed a desire to have a monthly conversation with a manager from the home care organization. She emphasized that the home care services should pay more attention to the elderly. She also shared, *"I would like to have the opportunity to evaluate with the manager. What is going well and what needs improvement. What are the aspects missing in the care. Give us more say in the matter. Let our voices be heard louder. The elderly should have a greater say in the care they receive"* (Female, 96 years old, receiving HBMC).

Some experts also emphasized this aspect, stating, *"The elderly should have a voice in the care process, collaborating with healthcare providers to optimize the care for elderly"* (Expert).

Improving the Quality of Care

One of the key aspects that experts emphasized is the need for nurses to receive specialized training in geriatric care. *"Professional caregivers should be equipped not only with technical skills but also with a compassionate and humanistic approach to elderly care. Courses and workshops in humanistic care should be an integral part of their training, focusing on building meaningful connections with the elderly and treating them with dignity and respect"* (Female, 80 years old not receiving HBMC).

It is essential to understand that caring for the elderly goes beyond merely providing medical treatment. It is about establishing a bond of trust, creating a comfortable environment, and engaging in meaningful activities with them stated by several experts. *"When elderly individuals feel valued and respected, they are more likely to open up and cooperate with their caregivers, leading to a more positive care experience"* (Expert).

Perception of Nursing Homes

Some seniors stated to have a positive view of nursing homes, seeing them as safe havens that offer professional care, companionship, and various engaging activities. Some caregivers stated that receiving care from a nursing home is stigmatized, leading older adults to avoid seeking such services, even when they might be beneficial. "*Others would have placed her in a nursing home long ago stated by a caregiver. With heavy hearts, we placed him in a nursing home*" (FGD, 56 years caregiver).

However, a participant did raise concerns about nursing homes for the elderly, stating that it is becoming a commercial issue on the island. He said, *"Everywhere, you have nursing homes where someone thinks they can*

make a profit. They take ten elderly people and charge them 500 guilders. Those elderly people are just left there with nothing to do. If you put 20 elderly people in a house and only have two people to take care of them, it won't work out well." (Male, 73 years old, not receiving HBMC).

Positive Experiences with HBMC

Several seniors reported positive experiences with HBMC services. They praised the dedication and proficiency of the nurses, who attended to their needs. One interviewee particularly highlighted the excellent care provided by the nurses, referring to him affectionately as the "broeder van wijk" (Male nurse of the hood"). The attentive and compassionate nature of these caregivers left a lasting impression on the seniors, making them feel well-cared-for and valued.

Similarly, the interviewed seniors expressed appreciation for the WGK and their positive encounters with them. The WGK was commended for its competent and empathetic approach to medical care, leaving seniors with a sense of confidence and reassurance.

In addition to the positive experiences mentioned above, some seniors expressed satisfaction with the overall HBMC services they received. Furthermore, certain seniors emphasized the importance of nurses getting to know them on a personal level. When nurses took the time to understand their preferences and needs, seniors felt more at ease, and the quality of care improved significantly. The importance of establishing a personal connection with the elderly was highlighted in various interviews. Seniors appreciated nurses who showed genuine interest in their well-being and treated them with dignity and respect.

Challenges and Gaps in Care

However, not all experiences were seamless. Some seniors reported occasional lapses in care, with professional caregivers forgetting to provide timely assistance. While these instances were not frequent enough to warrant a formal complaint, they did cause some inconvenience and led to difficulties in planning daily activities stated by some seniors.

A few seniors shared fewer positive experiences with healthcare professionals, including a negative encounter with a general practitioner and complaints about the attitude of certain nurses.

Experiences Caregivers

Most caregivers have had a bad experience with HBMC. Half of the participants in the FGD took action, but the institution providing HBMC did not respond to the action taken. *"I had a complaint. There's a specific number you can call for complaints. So, I called and filed a complaint. Another time, the same thing happened. I called the number again, but they had not registered the previous complaint. They had not registered the previous complaint"* (FGD, 56 years old caregiver).

"My father has Alzheimer's, it depends, sometimes he is aggressive, and sometimes he is affectionate. Sometimes he recognizes this nurse, and sometimes he doesn't. The HBMC started complaining that if our father is aggressive, they will no longer come. They began threatening with this. At one point, they called me 2 or 3 times since I am the contact person. They kept calling because my father hit one of the nurses. Now they can't come anymore" (FGD, 56 years old caregiver).

"My wife had to go to rehab center for treatment on a stretcher. I am sitting next to the driver, and he falls asleep. The colleagues know who it is, but nobody takes action. I am getting goosebumps" (FGD, 72 years old caregiver).

Another caregiver is positive about the staff of HBMC. *"I cannot generalize. I have an aunt, my brother's sister, for whom I sought the help of WGK. WGK came to offer assistance, and some of them were very kind. At some point, I developed a friendship with one of the nurses, and I still have their contacts"* (FGD, 56 years old caregiver).

Healthcare system

Multiple caregivers indicated that you need to know someone to receive the appropriate care. They referred to this acquaintance who helps you as a *"kruiwagen"* (Dutch for "wheelbarrow," a term used to describe someone with access to help,who can assist or influence you in getting what you need).

The caregiver mentioned that he did not receive a referral from the doctor to go to a rehab centre, even though his wife couldn't walk after a hospitalization. He asked a friend who used to be the director of the rehab center to assist him in scheduling an appointment at the facility. *"It may sound very unpleasant, but here in Curaçao, you need a 'kruiwagen.' If you don't know anyone within the institutions, you won't get far. My wife had an intake at the hospital, and they said she didn't qualify for rehabilitation therapy. Luckily, through an acquaintance of ours who is an ex-director of the rehab centre and a good friend of mine, he managed to arrange for her to go to the rehab centre. Thanks to God, she can stand on her feet now"* (FGD, 72 years old caregivers).

"Here in Curaçao, you definitely need a kruiwagen. Unfortunately" (FGD, 56 years old caregivers).

The majority of caregivers utilized a "network connection" to facilitate access to care.

Most caregivers mentioned that they pay out of their pockets to arrange proper care for their seniors. Almost all caregivers pay for better care. A few seniors mentioned that they purchase and pay for extra help themselves.

"Through word of mouth, we found a male nurse who has been coming every Friday, Saturday, and Sunday morning for two years now. My father is sometimes aggressive with him, but he is a strong and experienced nurse, and he handles it well. But again, we pay for this from our own pockets" (FGD, 56 years old caregivers).

"I couldn't handle this system. People from HBMC (presumably a healthcare service) came twice, but then I told them not to come anymore. I took charge and arranged everything myself. But again, I could afford it financially" (FGD, 52 years old caregiver). The caregiver had difficulty with the variable timing of the HBMC's visits. It was a different time every day, which she couldn't handle.

"The care provided by certain institutions is not organized based on the recipient's needs but rather to facilitate the organization" (Expert).

According to most experts, it is crucial to have a policy for elderly care. As there is no policy for the elderly, there is no enforcement or control.

"The division within the ministries[4] is set up in a way that they need each other to develop policies, but they don't work together. One ministry develop the policy, and the other oversee it. With this approach, there will never be a policy" (Expert).

"It's simply a matter of money. What you can afford. You need to establish standards and enforce and inspect them. You should kick out those money-driven individuals in the healthcare sector. They are all about money and not about quality, all about money" (Male, 73 years old, not receiving HBMC). The participant elaborated that these initiatives are privately started nursing homes without proper licensing.

Several seniors and caregivers have shared that they feel like elderly people no longer matter in society. *"When you reach a certain age, they don't do much for you anymore. They think that as elders, we can't contribute anything to society anymore. It hurts me deeply. They forget what we have done in the past and how hard we have worked. And now that we need help, they talk to us like this. Let us live our lives until God says it's enough"* (Female, 72 years old receiving HBMC).

[4] The Ministries: the expert is referring to The Ministry of GMN and the Ministry of SOAW.

"Seniors are not considered a good investment. They are pushed aside and not taken seriously in the care system when they have certain needs. It is very important for us as children that our parents age happily and without worries," (FGD, 56 years old caregiver).

Chapter 5: Discussion

Variation well-being seniors

Research conducted worldwide indicates that most seniors living at home report feeling reasonably healthy (3). A study conducted in Norway among older individuals living at home highlighted the importance they place on being healthy, maintaining independence, financial autonomy, engaging in social activities, and fostering meaningful relationships (10). Nevertheless, in this research, a notable variation is observed within the study population, particularly concerning the well-being of seniors. The seniors, not receiving HBMC, who manage to remain physically and socially active tend to have a more positive outlook on life. Nevertheless, there is a concerning pattern among seniors who receive HBMC. These seniors appear to be less active and have fewer opportunities for physical activity and social interactions, largely due to limited access to resources, especially healthcare resources.
Mental health surfaced as a significant issue, with feelings of loneliness and social isolation impacting the well-being of seniors who are beneficiaries of HBMC.
Several participants who live alone tend to have less healthy eating habits. Sharing meals with others contributes to improved eating behaviours. Furthermore, the cost of healthy foods such as vegetables and fruits is high in Curaçao. Consequently, many seniors choose more convenient and affordable, yet unhealthy, dietary options.
It is worth mentioning that some participants receiving HBMC have expressed difficulties in accessing essential services, such as the rehabilitation centre. This issue arises because specific seniors do not receive the proper indication, resulting in a lack of referrals. Additionally, there are limitations in transportation options. Paradoxically, this centre plays a critical role in improving mobility and enhancing the overall quality of life for seniors relying on HBMC.
Within the field of innovative technologies, there are several impressive applications available in the market that have the potential to enrich the well-being of seniors. Commonly known as virtual assistants, these applications have the capability to provide assistance in various ways. For instance, they can motivate seniors to take a stroll or participate in activities that promote their well-being. Moreover, these virtual assistants can facilitate interactive experiences such as engaging in cognitive games or initiating conversations with other seniors (46).

Caregivers and their well-being

Research conducted in Curaçao with 435 seniors, who are not in care and living independently, regarding their Needs and Networks reveals that 68% of the respondents believe that children who have moved abroad have a responsibility to financially support their parents. Additionally, over 80% feel that children, regardless of their location, should help their parents. The only exception is if their own children have small children; in such cases, they may not be expected to take care of their parents (7). Caregivers feel responsible for the care, caregivers were involved in almost all the seniors' lives. A few seniors did not have support of their children, but that was because their children do not live in Curaçao. All caregivers in this research expressed that it can be extremely challenging. They often report never receiving any help and may have taken care of their parents for an entire year. Some caregivers find the responsibilities overwhelming, especially when they must perform medical tasks without adequate training, leading to concerns about the quality of care provided. The caregivers feel that the caregiving support is insufficient, and due to the lack of personnel and the quality of care provided, they hesitate to seek additional assistance.

HRH Shortage

The HRH shortage presents a complex challenge that requires urgent attention from the Ministries and HBMC organizations. During vacations or when HBMC nurses fall ill, there is no adequate replacement. Consequently, some seniors do not receive the care they need. Additionally, HBMC services are often unavailable on weekends, compounding the issue further. The severity of the problem has reached a point where seniors refrain from reporting the absence of care altogether. Caregivers submit complaints, but these are not being documented by the HBMC. The inspection authority is not operating as effectively as it should. This is due to a shortage of staff and an unclear vision. The presence of outdated legislation and the lack of clear policies and

vision result in a lack of sufficient authority to carry out and enforce effective control measures (29, 44). When seniors themselves cease to make the effort to file a complaint, it becomes difficult to recognize and rectify areas that need improvement in the care being offered. As a result, the overall quality of care can be impacted. Addressing this HRH shortage is crucial to ensure the well-being and proper care of the elderly population.

Galiña bieu ta traha un bon sopi

In Curaçao we say, “Na punta di kabuya bieu mes ta konopá nobo” (we must continue building on the experience of our grandparents). “Galiña bieu ta traha un bon sopi” (an old chicken makes a good soup). Both expressions emphasize the importance of learning from the experiences of our grandparents and building upon their wisdom and knowledge. In my personal perception and experience, the elderly are highly respected and valued in Curaçaoan society. I have grown up with the belief that seniors hold a prominent and honoured place in our culture. However, it is disheartening to hear that some seniors express feeling marginalized and undervalued in the care they receive. Despite the cultural respect for the elderly, the context of care seems to present a different perspective. Healthcare providers may not always treat seniors with the seriousness and attention they deserve, possibly seeing them as less relevant or disregarding their needs. One possible explanation for this disparity could be the absence of a dedicated policy for elderly care on Curaçao. Without specific guidelines and support, the elderly may not hold a prominent position in the care system. Implementing well-defined policies that prioritize elderly care and address their unique needs could help ensure that they receive the respect and attention they deserve in healthcare. It is a crucial need to offer healthcare providers training on engaging with the elderly in a compassionate and human-centred approach. By doing so, we can bridge the gap between cultural reverence for the elderly and their actual experiences in the care system, ultimately creating a more equitable and supportive environment for our seniors.

Equitable Access to Health

The absence of a dedicated policy for elderly care worsens the inequities in providing care for seniors. Such a policy can provide seniors with protection and support. The current insurance system further compounds the issue, as it allows medical specialists to prioritize privately insured individuals over those insured by SVB. SVB-insured seniors do not receive the same level of priority in their care. The insurance regulations restrict medical specialists from charging additional costs during treatment for SVB-insured individuals, while privately insured individuals can access such benefits, creating an inequitable situation. Additionally, some seniors resort to unofficial payments to foreign caregivers to access quality care, adding to the financial burden of receiving proper care. This unequal scenario divides access to care based on financial capacity, with better options available to those with greater financial resources.

Relevance of framework

Based on literature research and my knowledge and experience in sexual health, it becomes apparent that sexuality and relationships are not addressed as essential aspects in Sima Ghasemi's framework. Research reveals that sexuality impacts the well-being of seniors, as does the presence of relationships. According to this research, seniors in a relationship tend to experience less loneliness than those without (27). Moreover, a sexologist shares insights from a prospective study indicating that seniors who engage in sexual activity at an advanced age tend to live approximately five to ten years longer (28). Recognizing and addressing these aspects in the framework would be valuable in providing comprehensive care and support for seniors, acknowledging the role that sexuality and meaningful relationships play in enhancing their overall quality of life.

Strengths and limitations

One of the strengths of this research excels in giving seniors a strong voice, delving into their experiences and perspectives with utmost sincerity. This consideration is critical when formulating policies that cater to the needs of older adults effectively. Involving older adults and their families in the policy-making process is essential for a comprehensive approach. An important strength of the study lies in the profound engagement achieved during the interviews with seniors. This level of engagement fostered a strong sense of trust, allowing for a more open and meaningful exchange of information. The seniors greatly appreciated these conversations and expressed a sense of contentment, feeling truly listened to and understood. This positive rapport with the participants not only enriched the data collection process but also added a heartfelt dimension to the research, emphasizing the value of their perspectives and experiences in shaping the study's outcomes.

Throughout this research, the seniors have consistently voiced feelings of being neglected and experiencing prolonged waiting periods before receiving care at the hospital (CMC). Moreover, they expressed less satisfaction with their experiences with general practitioners. The experts in elderly care who were interviewed during this study are specialists in this field, and their focus on the well-being of older adults is driven by their expertise. It would be interesting to incorporate the viewpoints and experiences of other healthcare providers, such as nurses, general practitioners, and specialists from CMC, concerning aging and their practical approaches to caregiving.

Another limitation of this study is the focus on seniors who receive care and those who can access it. Seniors who need care but encounter challenges in entering the healthcare system were not included in this research. Examining the perspectives of these older adults could provide a different insight into their experiences and perceptions of care. Therefore, conducting research with seniors who require care but face difficulties accessing it would be recommended.

One of the notable challenges encountered during the research was the lack of sufficient existing literature. Finding peer-reviewed sources, particularly on healthcare in Curaçao, proved to be challenging. Consequently, there was a scarcity of prior research that had specifically concentrated on this particular topic. However, the information obtained from this study reached data saturation in relation to the specific aspects investigated. Despite the scarcity of literature, the research process continued, leading to the extraction of valuable insights from the data collected.

Chapter 6: Conclusion and recommendations

The findings of this study reveal the complex and multifaceted nature of elderly care on the island of Curaçao. Mental health emerged as a prominent concern, with loneliness and social isolation affecting the well-being of seniors receiving HBMC. The lack of tailored social activities and the need for more accessible information about HBMC services were also highlighted.
Social health needs to include the importance of transportation in maintaining social connections and participating in enjoyable activities. The role of family and friends in providing social support was acknowledged, but some seniors expressed feelings of neglect by the society.
Nutritional health needs were emphasized, with the cost and accessibility of healthy food options being a significant concern.
Physical health needs were met through regular engagement in physical activities, but challenges in obtaining necessary aids and long waiting times for medical specialist appointments were identified.
The study also shed light on the crucial role of caregivers in elderly care. Caregivers require more support and resources to balance their responsibilities while maintaining their well-being.

This study reveals a range of issues affecting elderly care, including the availability and consistency of HBMC services, variations in the quality of care provided by nurses, and difficulties in obtaining necessary aids and materials. Long waiting times for healthcare specialist appointments and hospital visits, along with a perceived lack of dedication and meaningful conversations with healthcare providers, also impact the overall care experience for seniors.

The shortage of staff in HBMC services poses challenges for seniors and caregivers, leading to gaps in assistance and support. Additionally, the lack of collaboration between the two Ministries, the HBMC service providers and among other organizations involved in elderly care highlights the importance of creating a more integrated and comprehensive approach to address the needs of the elderly population effectively.
Seniors' voices and preferences should be given greater consideration in the care process, and efforts should be made to foster a closer connection between healthcare providers and the elderly.

The health system in Curaçao faces challenges related to coordination, funding, and enforcement. The lack of a comprehensive policy and legislation for elderly care underscores the need for collaborative efforts among policymakers, healthcare providers, and caregivers.

Recommendations

Based on the findings of this study, several recommendations can be made to enhance elderly care in Curaçao:

To the Curaçaoan Ministry of GMN and Ministry of SOAW:

1. Promote collaborative efforts with seniors and elderly care organizations to co-create a comprehensive policy addressing mental, social, nutritional, and physical health needs, ensuring consistent and high-quality services for the elderly.
2. Take proactive measures to address the HRH shortage and the inequitable access to care by regularizing the employment of qualified foreign healthcare providers and working with HBMC organizations to implement strategies for attracting and retaining skilled professionals.

To the HBMC organizations:

3. Collaborate with the Ministry of GMN and SOAW to address the HRH shortage, seeking ways to recruit and retain qualified staff.
4. Provide enhanced support and resources to caregivers to help them balance their responsibilities with their well-being.
    - Online Caregiver Communities:

   Create online forums or social media groups where family caregivers can connect, share experiences, offer advice, and find fellowship in others facing similar challenges.
5. Involve seniors representatives in the governance of HBMC organizations by creating advisory panel to give them a voice.
6. Develop and launch a patient-centred mobile application featuring a virtual assistant, aimed at facilitating communication regarding HBMC service hours. The app should also provide information about available services, provide for healthy food deliveries, along with a platform for submitting feedback, complaints, and suggestions. Furthermore, the application can serve as a tool to engage seniors in daily activities, enhancing their overall well-being.

To the Council of Elderly Policy:

7. Encourage the provision of specialized training in geriatric care for healthcare providers, with a focus on adopting a humanistic approach to caregiving. This initiative will enhance the quality of care provided to the elderly population.
8. Foster a positive and inclusive societal attitude towards the elderly, by starting a *campaign "Respect our seniors"* valuing their contributions and experiences, and creating aging-friendly communities.

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Annex 1: Topic guides for seniors (in care), Seniors (NOT in care), caregivers and experts

Seniors (in care)

Interviewer name: Start time:

Date: End time:

Location:

Introduction

My name is Thirza and I will conduct interviews to get a better understanding of the perceived and experienced on Home based medical care. By conducting this interview, I would like to gain a better in-dept understanding of the experiences, needs and perception in Home based medical care, therefore there are no right or wrong answers to the questions asked. You are able to withdrawal the interview at any time and are not obligated to answer questions that make you feel uncomfortable. The interview will take thirty minutes to an hour. To be able to re-listen to the interview, it will be audio-recorded. Any information derived from this interview is confidential and will be analyzed anonymously.

Do you give permission to start the interview? Do you have any additional questions? If not, I will start the interview and recording. **[Start recording]**

—----------

First, I will start the interview by asking some general questions.

Demographics

- What is your age?
- How do you identify your gender?
- What is your residential status?
- What do you consider as your ethnicity?
- What is your education level?

Now, I will ask some questions about your perception, experience and needs on HBMC.

Perceptions	• **How do you feel about your health?** • **How do you feel about your home situation?** • **When did you start receiving care at home?** • **Why did you choose for HBMC?** • **How do you feel about receiving help from HBMC?** • **What are the main factors that influence your decision to seek help for HBMC?**
Experiences	• Are there any difficulties orhelp that you have experienced when seeking help? • What are the main difficulties and or help you have experienced when seeking help? • How was that first HBMC experience for you? • Do you have any experience you want to talk about that touched you in a way? • How do you think your caregivers would react if you asked for assistance with health related problems? • What do you think about receiving care from a male or female health professionals? • How confident do you feel in receiving HBMC?
Needs	• Why do you need HBMC? • What kind of care do you need? Mental, social, Physical and HC, SS needs?

	• Who are the important persons in your life whose opinions or actions might affect your choice of seeking help? • What factors do you think would make it easy or difficult for you to receive HBMC? • What is/was your expectation towards HBMC? And why? • Are these expectations met? And how?
Other factors	• How do you think other seniors feel about receiving HBMC? • In what ways do you think your culture or background might influence your attitude on receiving HBMC?
Closing	Thank the participant for their time and willingness to participate in the interview. • Do you have any questions or something you want to get off your sleeve? • Or any recommendation or feedback for the HBMC?

Seniors (NOT in care)

Interviewer name: Start time:

Date: End time:

Location:

Introduction

My name is Thirza and I will conduct interviews to get a better understanding of the perceived and experienced on Home based medical care. By conducting this interview, I would like to gain a better in-dept understanding of the experiences, needs and perception in Home based medical care, therefore there are no right or wrong answers to the questions asked. You are able to withdrawal the interview at any time and are not obligated to answer questions that make you feel uncomfortable. The interview will take thirty minutes to an hour. To be able to re-listen to the interview, it will be audio-recorded. Any information derived from this interview is confidential and will be analyzed anonymously.

Do you give permission to start the interview? Do you have any additional questions? If not, I will start the interview and recording. **[Start recording]**

—----------

First, I will start the interview by asking some general questions.

Demographics

- What is your age?
- How do you identify your gender?
- What is your residential status?
- What do you consider as your ethnicity?
- What is your education level?

Now, I will ask some questions about your perception, experience and needs on HBMC.

Perceptions	• **How do you feel about your health?** • **How do you feel about your home situation?** • **How would you feel about receiving help from HBMC?** • **Why would you choose for HBMC?** • **What are the main factors that influence your decision to seek help for HBMC?**
Experiences	• How do you think your caregivers would react if you asked for assistance with health related problems? • How confident do you feel in receiving HBMC? • Do you have any experience of receiving HBMC? If yes, how was it? • What do you think about receiving care from a male or female health professionals?
Needs	• What kind of assistance would you like from HBMC? • What would your need for HBMC be? Mental, social, Physical and HC, SS needs? • Who are the important figures in your life whose opinions or actions might affect your choice of seeking help? And why? • What factors do you think would make it easy or difficult for you to receive HBMC? • What is your expectation towards HBMC?
Other factors	• How do you think other seniors feel about receiving HBMC? • In what ways do you think your culture or background might influence your attitude on receiving HBMC?

Closing	Thank the participant for their time and willingness to participate in the interview. • Do you have any questions or something you want to get off your sleeve? • Or any recommendation or feedback for the HBMC?

Caregivers FGD

FGD names:

Start time:
Date:

End time:

Location:

Introduction en Welcome

Good … and welcome to our session. Thanks for taking the time to join us. My name is Thirza and I will conduct FGD to get a better understanding of the perceived and experienced on Home based medical care. By conducting this FGD, I would like to gain a better in-dept understanding of the experiences, needs and perception in Home based medical care for your families, therefore there are no right or wrong answers to the questions asked. You are able to withdrawal the FGD at any time and are not obligated to answer questions that make you feel uncomfortable. The FGD will take forty-five minutes to an hour. To be able to re-listen to the FGD, it will be audio-recorded. Any information derived from this FGD is confidential and will be analyzed anonymously.

Do you give permission to start the FGD? Do you have any additional questions? If not, I will start the FGD and recording.
[Start recording]
Discuss some ground rules
- Everything we discuss stays in this room
- Respect each other's opinion
- Privacy (no pictures without permission)

—----------

Let's begin. I'd like to begin with a little introduction around the table. Let's find out more about each other. Tell me your name and where you live, and would you also like to tell me who is in care in your family. Now, I will ask some questions about your perception, experience and needs on HBMC.

Perceptions:
What are the main factors that influence your decision to seek help for HBMC?
How would you feel about receiving help from HBMC?

Experiences:
- Are there any barriers or facilitators that you have experienced when seeking help?
- What are the main barriers and facilitators you have experienced when seeking help?
- How was that first HBMC experience for you as a caregiver?
- Do you have any experience you want to talk about that touched you in a way?
- What do you think about receiving care from a male or female health professionals?
- How confident do you feel in the care HBMC is providing?

Needs:
- What is your need for HBMC?
- What kind of care do you need for your family members? Mental, social, Physical and HC, SS needs?
- What factors do you think would make it easy or difficult to receive HBMC?
- What is/was your expectation towards HBMC?
- Are these expectations met? And how?

Closing:
Thank the participants for their time and willingness to participate in the FGD.
- Do you have any questions or something you want to get off your sleeve?
- Or any recommendation or feedback for the HBMC?

Interview Key informant

Interviewer name: Start time:

Date: End time:

Location:

Introduction

My name is Thirza and I will conduct interviews to get a better understanding of the perceived and experienced on Home based medical care. By conducting this interview, I would like to gain a better in-dept understanding of the experiences, needs and perception in Home based medical care, therefore there are no right or wrong answers to the questions asked. You are able to withdrawal the interview at any time and are not obligated to answer questions that make you feel uncomfortable. The interview will take thirty minutes to an hour. To be able to re-listen to the interview, it will be audio-recorded. Any information derived from this interview is confidential and will be analyzed anonymously.

Do you give permission to start the interview? Do you have any additional questions? If not, I will start the interview and recording. **[Start recording]**

—----------

First, I will start the interview by asking some general questions.

Perceptions	**How do you feel about the HBMC for seniors in Curacao?** **What are the barriers or facilitators of seeking HBMC?** **How do you perceive the view of HBMC?**
Experiences	What is the overall experiences for HBMC? Are there any barriers or facilitators that you have experienced when patients are seeking for HBMC? Do you have any experience you want to talk about that touched you in a way (HBMC)? Gender and providing care as HP, what experiences do you have?
Needs	What is the overall need for Mental, social, Physical and HC, SS needs? And HBMC? What factors do you think would make it easy or difficult to receive HBMC? What is/was your expectation towards HBMC?
Closing	Thank the participant for their time and willingness to participate in the interview. • Do you have any questions or something you want to get off your sleeve? • Or any recommendation or feedback for the HBMC?

RESEARCH ETHICS COMMITTEE

Informed consent form

Hello, My name is Thirza Stewart I am from Royal Tropical Institute (KIT). We are currently conducting research. By means of this research, we map out the current experiences and needs of the seniors and care givers, and how care can be improved. The research consists of in-depth interviews with seniors and focus group discussion with family members of seniors. We will also interview experts who are active in the care for seniors in Curacao.

Procedures including confidentiality.
If you agree we would like to interview you about the care that is needed for the seniors and how we can improve the care. We will talk about how they meet the needs of the seniors; what you think could be improved or changed.

The interview will take place in a private space where no body can hear us and last about an hour.

To make sure that we do not forget or change what you are saying I will tape record the answers you give, if you permit. Everything that will be said, written down will be kept totally confidential. Your name will not be recorded or written down. Notes will be kept in a locked place. Only the team of researchers will have access to the notes.

In publications, the findings will be attributed to the services in general and not to your particular area so that nobody can recognise the setting. Tape recording will be destroyed 6 months after finishing the study.

Risk, discomforts and right to withdraw
You are free to refuse to answer any question for any reason. Refusing to take part or withdraw during the interview will not in any way affect the services you receive or the performance review by your employer.

Benefits
This study will not help you directly but the results will help to improve services.

Sharing the results
The results will be available in written form through our organisation. If you would like to receive a copy of the report, please let us know and we will make this possible for you.

Consent and contact
Have you got any questions that you would like to ask?
Are there any things you would like to be explained further?
Repeat: If you do not want to take part in this interview you can refuse to do so, you can refuse to answer any questions and to stop the interview at any time. You will not be penalised in any way if you refuse to participate

CERTIFICATE OF CONSENT: TO BE SIGNED BY THE RESPONDENT GIVING CONSENT

Agreement respondent
I agree to participate and understand that I can ask further questions, can refuse to answer any questions and stop the interview at any time.

DECLARATION: TO BE SIGNED BY THE RESPONDENT

Agreement respondent
The purpose of the interview was explained to me and I agree that …….. (name of person) is interviewed.

_____

Signed Date

WITNESS SIGNATURE

_____

Signed Date

If you have any questions or want to file a complaint about the research you may contact:

Contact information organization	Contact for Ethics Committee

Annex 3 Tables Demographic Characteristics

Table 6. Participant demographic Characteristics (n=10)

Characteristics	**n (%)**
Age	
65 to 75	5 (50)
76 to 85	4 (40)
Over 86	1 (10)
Gender	
Female	6 (60)
Male	4 (40)
Receiving HBMC	
Yes	6 (60)
No	4 (40)
Ethnic Background	
Curaçaoan	8 (80)
South American	2 (20)
Residential status	
Lives alone	2 (20)
Lives with children	5 (50)
Lives with partner	1 (10)
Lives with partner and children	2 (20)
Years receiving HBMC	
Not receiving	4 (40)
1 years	2 (20)
2 years	1 (10)
3 years	1 (10)
8 years	1 (10)
15 years	1 (10)
Education	
Bachelor	3 (30)
Secondary vocational education	2 (20)
High school	3 (30)
Primary school	1 (10)
No education	1 (10)

Table 7. FGD Participants Characteristics

Number Caregivers	Care	Extra Professional Care	Gender	Age
1	Father passed away 6 years ago at the age of 84, had a spinal cord injury	She managed everything independently	Female	52 years
2	Mother passed away 1 year ago, 14 years after father's death.	They received additional assistance	Female	48 years
3	Father, 91 years old, has Alzheimer's in a wheelchair, and mother, 88 years old, mentally fit but psychical live together with daughter	They receive additional assistance	Female	56 years
4	After a diabetes attack, the husband takes care of his wife at home, who has developed bedsores.	WGK provides daily assistance (in the morning) instead of twice a day as indicated	Male	72 years
5	Mother 91 years has dementia	Mother goes daily to day care	Male	62 years

Table 8. Experts interviewed

Number of Experts	Discipline	Years of experience	Organization
1	Internist - Geriatrician	10 years	Curacao Medical Center
2	Psycho-gerontologist	19 years	Psychological consultancy
3	Manager and Board member	25 years	WGK, Alzheimer foundation
4	Board member and Geriatrician	25 years	The Raad van Ouderenbeleid (Council of Elderly policy)

Annex 4 Clearance letter

KIT Royal Tropical Institute

RESEARCH ETHICS COMMITTEE

Contact: Sandra Alba
s.alba@kit.nl

To: Thirza Stewart
By E-mail: TStewart@soaaids.nl

Amsterdam, 8 June 2023

Subject Decision Research Ethics Committee *S-118*

Dear Thirza Stewart,

The Research Ethics Committee (REC) of the Royal Tropical Institute has reviewed your application for ethical clearance for a study on Understanding the perception and experiences of seniors and their caregivers on home based medical care (HBMC) in Curaçao that was originally submitted on March 13, 2020.

The Committee has reviewed the adapted protocol and has taken note of your amendments and clarifications and is pleased to see that you have addressed our concerns and questions to our satisfaction.

The Committee is of the opinion that the proposal meets the required ethical standards for research and herewith grants you ethical approval to implement the study as planned in the aforementioned protocol.

The Committee requests you to inform the Committee when substantive changes to the protocol are made, important changes to the research team take place or researchers are added to the research team.

Moreover, the Committee requests you to send the final report of the research containing a summary of the study's findings and conclusions to the Committee, for monitoring purposes by the REC.

Wishing you success with the implementation of the research,

Dr Sandra Alba

Co-Chair
KIT Research Ethics Committee

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Royal Tropical Institute