

Policy Research Report

A Gender Lens on COVID-19 and NCDs



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Executive Summary



Executive Summary

As the COVID-19 pandemic unfolded, research from across the globe revealed that like in many other disasters and emergencies, people living with non-communicable diseases (NCDs) were particularly vulnerable. Specifically, the World Health Organisation and the NCD Alliance reported that people living with NCDs were not only at an increased risk of developing COVID-19 but also faced a higher mortality and morbidity rate. Compounding the increased risks were the COVID-19 policy interventions that were introduced to prevent and control COVID-19. These included border closures, restrictions on movements, stay-at-home orders and other such interventions. While these policies were useful in slowing the transmission of COVID-19, in countries across the world, data revealed that these policies affected existing approaches to prevent and control NCDs and thus had a negative impact on people living with these conditions.

In St. Kitts and Nevis, we are highly dependent on regional and international research to inform our public health strategies and with such an unprecedented public health emergency there was a need to understand the local situation as it relates to the impact of the pandemic on people living with NCDs, rather than extrapolate from

global and regional experiences. Therefore, we conducted a qualitative research project that involved an in-depth exploration of how the pandemic affected people living with NCDs. As part of this work, we adopted an intersectional approach that aimed to bring some nuance to this research and explore how the dual identities of NCD patient and gender may influence how a person might have experienced both the pre-pandemic and pandemic eras. We also wanted to determine if the pandemic may have exacerbated the challenges that people with NCDs encountered before the pandemic and if the pandemic created or exacerbated any gender inequalities amongst people living with NCDs.

Our Main Findings

Before looking at the experiences of people living with NCDs during the pandemic, we first conducted an in-depth exploration of their experiences prior to the pandemic to establish a benchmark for their pandemic experience. To our knowledge, there has been no research to understand the experiences of people living with NCDs in St. Kitts and Nevis using a gender lens and thus this data is of significant value in identifying gender inequalities within the NCD patient population.

Prior to the pandemic, people living with NCDs in St. Kitts and Nevis faced a high level of uncertainty about their future because of the unpredictable nature of their NCD. This created a high level of anxiety especially as their NCD affected every aspect of their lives including their physical and mental health, relationships and social connections,

their work and finances. The unpredictable nature of their NCD and its ability to affect all these areas then also made their daily lives, their future and quality of life unpredictable. Therefore, there was a need to make a concerted effort to regain control and this required an intentional application of self-management techniques which, in our population, included adopting a healthy diet, engaging in regular exercise, effective medication management, obtaining adequate rest, developing resilience and coping skills and ensuring patients regularly monitored their condition including regular medical check-ups. Some people living with NCDs were able to successfully control and manage their NCD before the pandemic through these self-management techniques but others found it very challenging to control their NCD, and this affected their quality of life even before the pandemic.

Taking an intersectional approach we were able to determine that in St. Kitts and Nevis there is a strong gender facet to the impact and experience of NCDs, with men and women having a variety, and a different set of emotional, practical, domestic, professional, and biological needs that have historically been unaddressed and need to be considered when developing NCD policies and strategies. Importantly, through our exploration of gender, we found that the most vulnerable groups of people living with NCDs were:

- **Single mothers on a low income.** This group was **managing their NCD while balancing a number of roles and responsibilities with sometimes little or no practical, emotional or financial support.** As a result of this, they were exposed to a high level of stress which exacerbated their NCD.
- **Retired older single women.** This group was **at risk of isolation and loneliness,** leaving them at risk of not having the support they needed if an emergency occurred.
- **Men overall.** This is because **men were found to be more hesitant to seek out help** and were therefore at risk of not receiving the support and medical attention they needed and thus, having a worse outcome than women when it comes to their NCD.
- **Women affected by chronic reproductive health issues and auto-immune and immune-mediated conditions which are more common in women.** This is because there is **a lack of specialist care and support** for these conditions in St. Kitts and Nevis, leaving these women without appropriate medical, practical and psycho-social support.

When we then explored the impact of the pandemic on people with NCDs we identified that overall the pandemic was a significant disruptor creating even more uncertainty and exacerbating the many challenges that patients faced before the pandemic. Specifically, the increased risk that people with NCDs faced when it came to COVID-19 further compounded their anxiety about their health and future, and the COVID-19 policies and protocols in some cases significantly affected patients' ability to engage in successful NCD self-management practices and therefore resulted in a worsening of symptoms.

Conversely, we found that aspects of the pandemic such as the overall slowing down of society, for some patients, provided an opportunity to improve their NCD self-management and enabled some improvement of their health condition. Furthermore, other NCD patients had a very neutral experience where the pandemic had no impact, good or bad, on their NCD. When we delved further, we identified that some of the gender issues that were identified before the pandemic worsened and those groups that were most vulnerable before the pandemic were made even more so because of the pandemic.

Our research highlights that the diversity of needs of men and women living with NCDs have to be considered when developing the federation's disaster management policies and strategies. Whilst we found patterns of difference between men and women, strategies to support people living with NCDs should be nuanced as purely implementing strategies based on a person's gender is not the solution. If we are to ensure that we adequately protect and support all persons living with NCDs during emergencies, then an intersectional approach that considers not just gender but socio-economic factors is needed as people living with NCDs are not a homogenous population but a heterogenous one of varying needs. What our findings reveal is how gendered roles have an impact on how NCDs are experienced.

Embedding an effective, holistic NCD response as part of any disaster management strategy is of utmost importance because of the high prevalence of NCDs in St. Kitts and Nevis. By focusing much-needed attention on this population during emergencies, we can strengthen the disaster management and recovery process by protecting and supporting a key segment of society. This should be seen as a priority because the pandemic and other disasters continue to reveal that people with NCDs are particularly vulnerable when disasters occur.

Recommendations

Based on our findings we present the following recommendations:

1

A specific, holistic and comprehensive NCD strategy is required as part of the disaster management process.

Having a strategic NCD component as part of the disaster management process would ensure that the concerns of those living with an NCD, an important vulnerable group, are a key priority. This strategy should focus on ensuring that NCD patients are empowered to successfully control their NCD during a disaster through self-management and should mitigate the impact the disaster could have on the physical health, mental health, finances, relationships and social connections of people living with NCDs.

2

An intersectional, gender-sensitive approach to NCDs is required during disasters that includes collaboration between the National Emergency Management Agency, the Ministry of Health, the Department of Gender Affairs, Social Services, the Mental Health Association and other relevant government departments and NGOs.

An intersectional approach would ensure that any gender or social-economic inequalities that exist amongst people living with NCDs during a disaster are identified and addressed and that care is taken to focus on protecting and supporting those groups that we have already identified as being particularly vulnerable. An intersectional approach also helps us tailor responses to specific needs or concerns which would mean more effective solutions and more efficient use of limited resources.

3

A Federal NCD Patient Participation Group that is supported through capacity building and training should be formed.

This will enable policymakers to easily consult with people living with NCDs when developing policies that may directly or indirectly affect those living with NCDs. By having an existing consultation group, people living with NCDs can easily be engaged and included in the disaster management process when a disaster is imminent.

4

Employers must meet their duty of care to people living with NCDs especially during disasters.

In this regard, employers must be accountable to the Department of Labour and metrics should be developed to ensure that employers adequately meet the needs of their employees who are living with an NCD. Employers should provide employees with access to medical and psychological support and adapt the roles of people living with NCDs to minimise stress during disasters.

5

Employers should include their staff in the decision-making process when developing their response to disasters. This should include:

- More meaningful staff consultations
- Greater transparency with regards to the decisions made and policies being introduced
- Sufficient notice being provided to employees to enable them to emotionally and practically prepare for any decisions and policies being implemented
- Better and more frequent communication before, during and after a disaster
- Having a specific focus on and strategy for people with chronic illnesses during disasters

6

The government should ensure that any policies developed during a disaster are assessed to determine their NCD and gender impact.

This would involve determining the impact any new policies have on NCD self-management, whether these policies may exacerbate challenges associated with the physical health, mental health, relationships, social connection, work and finances of those living with an NCD, and whether these policies address the gender-based needs of people living with NCDs.

7

The government should introduce special support and relief for people living with NCDs during disasters as their financial, medical, mental health and personal needs are significantly different to the general population.

8

The Ministry of Health and the government should improve monitoring and data collection related to people living with NCDs and their experience and outcomes during disasters to measure the success and impact of the disaster management response for people living with NCDs.

This would enable gaps to be identified and facilitate continuous improvement of the NCD response during disasters and thus allow more effective evidence-based NCD policies and strategies to be developed for future disasters.

9

Front line workers and essential workers living with NCDs must be adequately supported during disasters so as not to create unmanageable stressors that could exacerbate their NCDs.

10

NGOs and faith-based organisations must be adequately supported both in terms of capacity building and finances to support people living with NCDs during disasters.

A grant programme should be established to enable NGOs and FBOs to access funding to support the disaster response, fill the gaps that Governments cannot fill and provide an effective support service for their target groups.

11

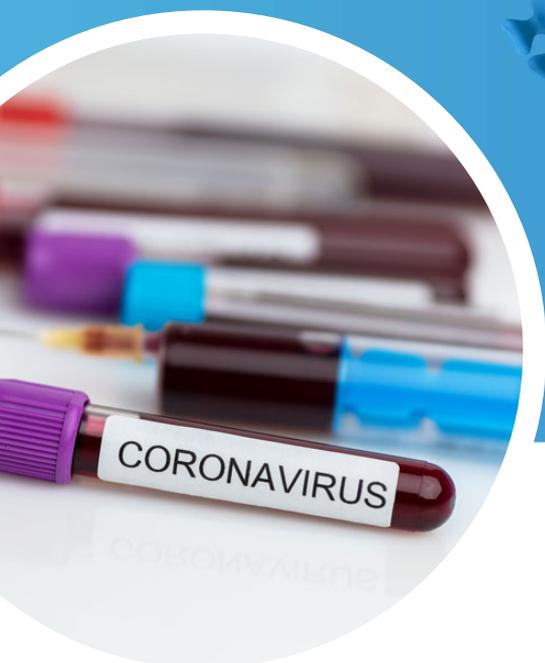
The entire disaster management process including the policy development process must be rooted in empathy, sympathy and kindness towards vulnerable members of society including people living with NCDs. Additionally, a human rights-based approach to disaster management must be considered to protect those who are most vulnerable.

12

An NCD Disaster Wellness Programme should be developed that focuses on protecting the mental health of NCD patients and should include stress management, coping and resilience and mindfulness. This should take into account people's different emotional needs as well as the different social expectations and pressures and the differences in the nature of support men and women tend to have access to.

This research report is part of a series of three documents which include this report, an NCD and Gender Impact Assessment of St. Kitts and Nevis' COVID-19 policies and a framework for embedding the protection of people living with NCDs in the disaster management process. These documents aim to provide policymakers with evidence of the need to develop intersectional and nuanced policy approaches to supporting people with NCDs and guidance to assist their NCD policy development and implementation process in preparation for future disasters and emergencies.

1. Introduction



Introduction

Globally, the COVID-19 pandemic has not only exposed but created many health inequalities, and many of these inequalities have been identified in people living with non-communicable diseases (NCDs). People living with NCDs have been found to be disproportionately affected by COVID-19 (Chang et al., 2020; NCD Alliance, 2020; PAHO, 2020; WHO, 2020). Specifically, they are at a higher risk of contracting the viral infection and have a higher COVID-19 mortality rate (Chang et al., 2020; NCD Alliance, 2020; PAHO, 2020; WHO, 2020). Additionally, data published by WHO and the NCD Alliance revealed that government responses to COVID-19 negatively impacted NCD services and treatment; affected the ability of patients to access nutritious food, medication and support; and exposed the public to NCD behavioural risk factors – lack of physical activity and unhealthy eating (NCD Alliance, 2020; WHO, 2020). This has meant that the COVID-19 pandemic has hindered strategies for the prevention and control of NCDs as government and healthcare providers' priorities shifted to managing the pandemic and caring for COVID-19 patients. It also affected patients' ability to successfully manage their condition, and overall, the pandemic has been shown to have negatively affected the mental health of people

living with NCDs as they try to cope with the COVID-19 restrictions whilst managing their condition and their risk of contracting COVID-19 (Chang et al., 2020; WHO, 2020; NCD Alliance, 2020).

Since the pandemic, there has been no research conducted in St. Kitts and Nevis to explore the above-mentioned issues, so there is not a full understanding of the local impact of the pandemic on people living with NCDs. Exploring this area is of utmost importance because NCDs are the major public health challenge in the federation. Specifically, 54% of adults have at least one chronic illness; the prevalence of diabetes in St. Kitts and Nevis is three times higher than the world average and our hypertension prevalence is 9% higher than the global average. Before the pandemic, the Nevis Island Administration reported that 85% of hospital admissions were NCD-related (PAHO, 2012; Ministry of Health, n.d.); and 63% of deaths in St. Kitts and Nevis are due to NCDs (Ministry of Health, 2021).

With so many people in St. Kitts and Nevis being affected by NCDs, it is important to understand how the COVID-19 pandemic and the measures taken to control the pandemic may have impacted those living with these conditions, especially since the measures that were introduced to contain the virus were much stricter than in other countries. By understanding these issues, we can strengthen future responses to emergencies and protect those within our community who may be particularly vulnerable or marginalised when disasters occur.

When exploring the impact of the pandemic on people living with NCDs, it is important that gender is considered, as there is a gender component when it comes to the prevalence of NCDs in St. Kitts and Nevis. In St. Kitts and Nevis, women are disproportionately affected by some of the most common NCDs – 60% of registered diabetics and 65% of cancer patients are women – and may have specific challenges that may need to be considered as it relates to living with these diseases during this pandemic period. In addition to cancer and diabetes, during the pandemic, some women are enduring challenges related to reproductive health-related NCDs, like fibroids, and similarly, male-specific NCDs such as prostate cancer may be also presenting gender-specific challenges. All of these conditions will need to be explored so that we understand the challenges that the COVID-19 pandemic may be posing to those affected by gender-specific NCDs and also to understand if men and women living with other NCDs (heart disease, lung disease, etc.) have had different experiences during the pandemic. Ultimately, an assessment of these issues will determine whether the pandemic created or exacerbated gender inequalities amongst people living with NCDs and, therefore, enable us to provide evidence-based, gender-balanced policy recommendations for the management of NCDs during emergencies.

2. Study Design and Methodology



Study Design and Methodology

To understand the experience of people living with NCDs during the pandemic, a qualitative research study was conducted and our approach was based on the frameworks and techniques of phenomenology, intersectionality and grounded theory.

Although our primary focus was on gender and NCD status, we did recognise that other factors such as socio-economic status may also impact how men and women living with an NCD may experience the pandemic and therefore we conducted our research to enable these areas to be explored too.

For this project, we conducted one-to-one interviews with policymakers and people living with NCDs. The policymaker interviews enabled us to understand the process that policymakers, business leaders and civil society employed to develop their COVID-19 response, strategies and policies and to determine if this process considered the gender-specific needs of people living with NCDs. Interviews took place between May 2021 and October 2021 and covered experiences of the first three waves of the COVID-19 pandemic. Our analysis of COVID-19 policies was based on the Gender Mainstreaming

Toolkit developed by the European Institute for Gender Equality — this assessment of specific policies is presented in a separate document.

Research interviews for the project only commenced after ethics approval was granted from the Ministry of Health Interim Ethics Review Committee (Ethics approval number: IERC-2021-04-047).

2.1. Participants, Sample Size and Recruitment

We recruited 25 people living with NCDs who were aged 18 and over and residing in St. Kitts and Nevis: 24 participants were based in St. Kitts and 1 participant was Nevis-based. Specifically, participants were aged 29 to 83 and the average age of participants was 55. Six participants were male and 19 were female. Therefore, one limitation of the study is the higher ratio of women to men. Participants had a variety of NCDs including hypertension, type 2 diabetes, chronic respiratory conditions, cardiovascular disease, auto-immune disease, reproductive health conditions, hypercholesterolemia and arthritis. The most common conditions affecting the sample population were hypertension (16 participants) and type 2 diabetes (7 participants), and several participants had multiple NCDs (9 participants) with the most common combination being type 2 diabetes and hypertension (5 participants).

Number of Participants	Number of Female Participants	Number of Male Participants	Average Age of Participants	Age Range of Participants	% of Participants with Hypertension	% of Participants with Diabetes
25	19	6	55	29-83	64%	28%

Table 1: Summary of NCD Participants

We also interviewed 10 policymakers across a variety of sectors including civil society (faith-based organisations and NGOs), the private sector and the government. Of the 10 policymakers, 9 were based in St. Kitts and 1 was based in Nevis. We experienced some challenges in recruiting policymakers, so to address this we sourced information from their organisations, either through public presentations that they had delivered or documents provided on their websites.

2.2. Interviews

All interviews were either conducted in-person or via Zoom based on the participants' preference and the COVID-19 situation (during certain periods of this project, St. Kitts and Nevis was subjected to curfews, stay-at-home orders and a 24-hour lockdown which meant that some interviews had to be conducted via Zoom).

Interviews ranged from 30 to 90 minutes and were semi-structured, with interviewers utilising an interview guide (see Appendix 1 and 2 for the interview guides) to assist in exploring the key topics of the study.

All data collected from the interviews was strictly confidential and the anonymity of participants was upheld. Participants were given an information sheet that explained the purpose of the project, informed consent was obtained and permission to audio record the interviews was acquired prior to the start of each interview. The interviews were fully transcribed soon after the interviews in preparation for data analysis.

2.3. Data Analysis

The collected data was analysed using a thematic analysis and based on grounded theory, phenomenology and intersectionality.

A gender impact assessment was conducted on the COVID-19 policies and this assessment was based on the European Union's Gender Mainstreaming Toolkit and is presented in a separate document.

To ensure the accuracy of the data collection and analysis process, all transcripts and a sample of four coded transcripts were checked by an additional person.

3. Findings



Findings

We began our exploration with participants by trying to understand their experience of living with an NCD before the pandemic so that we could establish a starting point and a simple baseline for comparing their pandemic experience.

In trying to build some context around participants' experiences, we will start our discussion with two areas: patients' perception of the cause of their condition and controlling the uncertainty of living with an NCD through self-management. To these themes, we applied a gender lens to understand how gender and sex impacted these areas and then we explored the impact of the pandemic and any gender (and other identity) implications.

3.1. Patients' Perception of the Cause of their NCD

It is important to understand patients' perception of the factors that may have contributed to the development of their disease as this can frame their actions and mindset around their condition, and thus can dictate whether they believe they can successfully control and manage their condition both in normal times and during the pandemic.

Looking at the perception of the cause of their NCDs, participants reported the following contributing factors:

Inheritance: Some participants explained that they had a fairly strong family history of NCDs and thus they recognised that they may have been at a high risk of developing these conditions.

“

My grandfather had it. My grandmother had it. My mother's grandmother died from it. My aunt has it and my mother has it. My father had it, so it did not surprise me.”

An unhealthy diet and inactivity: Participants also highlighted that an unhealthy lifestyle of poor diet and physical inactivity may have contributed to the development of their NCD.

“

I was not eating correctly anymore, and I stopped walking.”

Stress: Several participants raised the fact that they thought the development of their health condition was stress-related.

“

I think it was the stress that I was under.”

Workplace exposures to risk factors: Another area that participants raised was the work environment which exposed them, over the long-term, to certain factors such as smoke, pollen and stress which they felt contributed to their illness.

“

I think my hypertension really came because of my assignment. It was a very difficult assignment that it just broke my health right down.”

Applying a Gender Lens to the Cause of NCDs



When we apply a gender lens to participants’ perception of the cause of their illness, we see that both biological sex and gender can play an important role. Firstly, looking at biological sex, we see how biological factors can increase the risk of certain conditions. For example, pregnancy increases women’s risk of developing certain NCDs and this was recognised by participants:

“

Gender actually caused this disease. I got pregnant. If I couldn’t have gotten pregnant, I wouldn’t probably have had hypertension. The act of being pregnant made me hypertensive. I’m a woman who’s been lucky enough to have two children, but they left me with two C-section scars and high blood pressure. So, being pregnant twice has brought on something that reminds me all the time I could die. It’s entirely because I’m female.”

It also appears that women are at an increased risk of developing type 2 diabetes as 60% of registered diabetics in St. Kitts and Nevis are women. However, this could be related to the fact that women are more likely to seek help and therefore receive a confirmed diagnosis.



Policymaker View

“On the local level, the number of registered cases at community-based health centres increased by 603 cases over the period 2016 to 2020, reflecting an average of 120 new cases per year. Of the total, **60% are female** and 95.8% of the total registered clients are diagnosed with type 2 diabetes with a 50% death increase from 2015 to 2018.”

- *Hon. Akilah Byron-Nisbett, Minister of Health on World Diabetes Day, 15th November, 2021*

“Men are at greater risk for not just heart disease but dying of heart attacks. Oestrogen which is one of the sex hormones predominant in females is known to offer some type of cardio protective effect — some type of protection from a cardiovascular standpoint. So, there is a difference.” -Policymaker in the healthcare field

Additionally, reproductive health conditions such as prostate, breast and gynaecological illnesses are broadly related to a particular sex, but this classification based on sex can create misunderstanding and disengage risk groups as highlighted by one participant who identified that a condition like breast cancer can affect both males and females.

“

Most males probably would think – males in St. Kitts – [that] hearing about breast cancer is a woman's thing.”



Policymaker View

“My role is just to really try... to let men know that they can get breast cancer too, and to be a little bit more open with their health diagnoses whether it's cancer or anything else to come forward and seek help.” – Policymaker from the NGO sector

Another area that relates to gender, sex and the cause of NCDs was the fact that none of the men in the study mentioned stress as a contributor to their illness. All those that identified stress as a cause were women. When we probed further, we identified the source of the stress that women faced which included work-related stress and family-related stress. With regards to work-related stress, this is related to workload, tight deadlines and the physical demands placed on them. For example:

“

“I just could not cope with the kind of travelling and those kinds of things. It just broke my health down. That's when I developed this hypertension. Maybe it's probably not the best appointment for a woman, maybe. I think I was the first woman who was really on her own in X. It may have had something to do with gender. Maybe if it were a man he would have, I think, been able to deal with it a little better I think than I did.” – Female, hypertensive

With regards to family-related stress, some female participants described their many support and caregiving roles within the family unit which were demanding and overwhelming.

“

The stress level and the pressure on me to always be there for everybody.”

“

My mother had died, and my brother was getting married. So, I was overwhelmed.”



Policymaker View

“There has been acknowledgement of women taking on multiple roles. Not so much men. I think women are predominantly the ones that are seen, in that, they're the persons who have responsibility for caring for families, children, older persons. Also, they have a role within society. The roles that they tend to have in employment tend to be the nurturing and the caring roles.” - Policymaker in the social development field

Owing to the difference in responsibilities that men and women face, we found that generally speaking, men were able to have a more relaxed approach to life.

“

I'm a cool-going person. If you look at me, you might say, 'It doesn't look like nothing really bothers him.'” – Male participant¹

“

They [men] don't carry that kind of stress. They prefer to live their life carefree.” – Female participant

Conversely, women explained that they worry a lot because of the many responsibilities they have.

“

I'm a worrier, in terms of I always worry about everybody. I have to worry about everybody and if everybody's okay and how things are going. It's constant.” – Female participant

“

I just worry. It's all of that worrying. Everything.” – Female participant

The above-mentioned points suggest that some women living with NCDs within our study are more exposed to stress. This stress seems to stem from the multiple roles that women play in society – as breadwinner, caregiver, community leader, etc. These multiple roles are further exacerbated in St. Kitts and Nevis where the majority of single-parent households are headed by women. We know that stress can exacerbate some of the symptoms of NCDs and thus if women in St. Kitts and Nevis are experiencing higher levels of stress this is a gender issue that can put women with NCDs at a higher risk of their disease worsening. Additionally, from a prevention point of view, research suggests that exposure to long-term stress is linked to the development of NCDs and this is attributed to the biological effects of stress as well as stress-related behaviours such as smoking, alcohol consumption, unhealthy eating and a sedentary lifestyle.

“

I was overwhelmed and not eating correctly.” – Female participant

Furthermore, in the context of COVID-19, it's important to know if the pandemic created an extra gender-specific stress-related burden for women living with NCDs, and in subsequent sections of this report we explore this and highlight the increased stress that women living with NCDs face during the pandemic.

Our data does suggest that when it comes to women's exposure to stress, there are a few compounding factors. These include:

- **Age/stage of life** – our study suggests that younger women (below the age of 65) are exposed to higher levels of stress. Women over the age of 65 are retired, have fewer family commitments because their children are no longer dependent on them and through life experience have developed a good level of resilience and good coping skills.
- **Income** – women on a low income seem to be more exposed to stress due to the many financial challenges they encounter.

- **Personal circumstances** – single mothers are also exposed to more stress due to the challenges of raising children on their own.

From this, we were able to determine that single mothers on a low income and under the age of 65 were more likely to be the most vulnerable with regards to exposure to stress and could be more at risk of exacerbating their NCD if they are unable to manage their stress. As we explored this area further, our data did demonstrate that this group of women were significantly more vulnerable during the pandemic and we describe their specific vulnerabilities in later sections of this report.

3.2. Controlling the Uncertainty of Living with an NCD

As we continued to explore participants' experience with NCDs, the unpredictable nature of NCDs arose as an important theme. Some participants described NCDs as deceptive. To expand on this, they described the silent nature of their NCD, explaining that their condition is a possible "silent killer." In this scenario, they felt well but unbeknownst to them their NCD was worsening and culminated in a major health event:

“

You don't even realise that you have hypertension. I don't suffer with any headaches or anything like that. The first time I realised it probably affected me was when I had the stroke.”

They further explained the unpredictable nature of their NCDs where one day, they feel absolutely fine and then another day they can feel very unwell. They recognised that their condition can deteriorate very quickly without warning.

“

Well, one time like I would wake up in the morning, feel a little snuffy and fuzzy and lightheaded. Then during the course of the day, it would just pick up and start making me feel uncomfortable; can't breathe properly and so forth. Another time, I'm just a hundred percent good. So, it has its ups and its downs.”

“

It happened so sudden. It was sudden because I wasn't aware my sugar was that low.”

Related to the ups and downs of living with an NCD, some participants explained that certain triggers exacerbated their NCD and caused their symptoms to worsen. These triggers included:

- **Stress**

“

If I stress, my skin's going to flare up. I get some things on my skin and stuff.” – Participant with an autoimmune-related NCD

“

So, it's very stressful. Sometimes the blood pressure, it goes up and doesn't want to come down.” – Participant with hypertension

“ I used to have a lot of problem with the fellows because sometimes they made it [blood pressure] go up.” – Participant with hypertension

- Environmental factors

“ The dust from the road would come where I’m at, and it would affect me and my breathing problem and so forth.” – Participant with the chronic respiratory illness

“ It brings out the rash on your skin. That’s why they just tell us we mustn’t be in the sun. Yes, fluorescent light and sunlight.” – Participant with an autoimmune-related NCD

“ I had an awful time with that volcanic ash. It was really bad for me. I couldn’t even breathe.” – Participant with an immune-mediated disorder

“ Then I remember a couple of years ago, I went to the swimming pool and I ended up with bronchitis going into a swimming pool, that’s because of the chlorine.” – Participant with an immune-mediated disorder

The unpredictable nature of NCDs means that patients being able to have some control over their NCD is very important as a method of stabilising their condition.



Policymaker View

“It’s a good thing to — from time to time — remind clients/patients that life is unpredictable. You just never know what can happen tomorrow. So, they must live in a way to try to keep abreast with what is happening around them. Don’t have this carefree attitude where, “Cho, don’t worry yourself.” They need to self-care.” – Policymaker in the healthcare field

When it came to NCD control before the pandemic, the picture was mixed. Some participants felt they had their NCD under control and it did not significantly impact their quality of life

“ Before the pandemic, it wasn’t that bad. It wasn’t that bad at all.”

“ I do know how to look after myself. I live a balanced life. Like I said, it doesn’t bother me.”

Some stated their NCD wasn't under control and significantly affected their quality of life.

“

No, it wasn't. If it was under control, if it was under control, I wouldn't have gotten the abscess on my head. I didn't have it under control. As I tell you, it's hard. It's something hard, and you have to live with it.”

Others said sometimes, they felt it was under control, but they had periods when it was very much out of control.

“

Over the past 10 years, not that I'm perfect, but it would fluctuate sometimes.”

“

Sometimes it would be quite out of control. I just did what I needed to do, and followed the instructions in hopes that with time, little bit by little bit it would get better.”

Those that felt their NCD was under control tended to have mastered their condition and developed a plan and strategy to manage it.

“

I was more confident that I knew how to control it. I was happy that the diet had worked so well, and I was really proud of myself.”

Also, they were more likely to be attending the Ministry of Health's Diabetes and Hypertension clinic monthly and were receiving a significant amount of support and guidance.

“

We have a schedule like an action plan that we used to do from the health centre.”

Despite having their condition under control there was recognition that maintaining control required a significant amount of discipline and effort, which can be stressful.

“

Knowing that I have something that I have to actively try to control... knowing that I have to actively try to control it is stressful.”

Finally, there was the recognition that even when patients take control and are diligent with managing their condition, there is an element of the NCD that is not in any one individual's control, i.e., living with an NCD ultimately comes with an uncertainty that cannot be mitigated.

“

I, however, have felt that a lot of people feel that the control of the disease is so much in your hands that you just have to do the right things, and everything will be fine. I lived through doing the right thing every day and things going screwy.”

3.3. Controlling the Uncertainty of Living with an NCD During the Pandemic

Participants' ability to manage their NCD was rooted in their ability to practise certain self-management techniques and in the next section, we will explore these self-management techniques, how participants utilised them before the pandemic and how gender influenced self-management.

The pandemic was a disruptor in the lives of several of our participants and exacerbated the uncertainty that their disease itself creates. This uncertainty affected, to varying degrees, participants' ability to control their NCD. The unpredictable nature of NCDs proved to be challenging in the context of the pandemic, thus making people living with an NCD more vulnerable than the general public when it came to coping during this period. Furthermore, those persons living with an uncontrolled NCD were even more vulnerable during the pandemic, particularly during the 24-hour curfew periods.

In these next sections, we will also look at how participants' ability to implement their self-management strategies were affected during the pandemic, and we will apply a gender lens to their pandemic-related NCD self-management.



Policymaker View

“The diabetic who’s uncontrolled is going to be a lot more vulnerable than diabetic who has adequate control, so too for the hypertensive, so too for the asthmatic, and you’re saying to this person, ‘Go back into the environment, hunker down’ with a disease that literally is like a ticking time bomb.” — Policymaker in the healthcare field

3.4. NCD Self-Management

In the context of living with a chronic health condition, self-management is defined as a patient working with healthcare professionals to better manage the day-to-day challenges associated with their health condition and being active participants in their care and treatment (Loh, 2018). This is the most effective way that patients can take control of their condition. In our study, when it came to self-management, the following techniques were utilised by our participants before and during the pandemic:

- Diet and exercise
- Medication management
- Rest
- Maintaining a healthy weight
- Coping and building resilience
- Regular monitoring and regular check-ups

3.4.1. Pre-pandemic NCD Self-Management: Diet and Exercise

As previously mentioned, people living with NCDs acknowledge the role that diet and exercise play in the development of NCDs and understand that lifestyle factors can affect their NCD and quality of life, or have been advised by a healthcare professional about the benefits of controlling their disease through lifestyle changes. Thus, participants described how important these types of lifestyle changes are in managing an NCD.

“

I know it is vitally important to exercise.”

“*Yes, it helps a lot. That is one of the main stuff the doctors tell you to do — exercise, change your diet, eat right.*”

Before the pandemic, almost all participants had made adjustments to their diet and attempted to increase physical activity as a way of controlling their NCD.

“*As part of my regimen, I would try to get some form of walking in because my doctor told me that that would assist in lowering or regulating my blood pressure.*”

“*I try to eat right and do my exercise. That’s the main thing: eat right and exercise.*”

“*I was drinking a lot of water, eating a lot of fruits and vegetables, doing my exercise, [having] less intake of sugar.*”

Participants attempted to exercise regularly and made very specific changes to their diet such as cutting down on salt, sugar, fatty foods and meat, and eating more fruits and vegetables.

“*I take a walk maybe three days in a week or so or swim or something else – exercise.*”

There was recognition that mastering these techniques (diet and exercise) provided both a sense of comfort and confidence about being able to overcome their condition.

“*They [doctors] can’t give me the kind of comfort that adding that diet did to bring down my hypertension, release me from one of meds, and give me some confidence that I could manage this.*”

The challenges associated with diet and exercise

In trying to apply these self-management techniques, some participants explained that there were some challenges. Some participants explained that maintaining a healthy diet was one the most challenging aspects of living with an NCD especially because most of the food that is available within their community is not NCD friendly.

“*You still want to eat and most of the food I like to eat is sugar, so I have to try to monitor it.*”

“*Most of the food that’s around right now, I still have to keep away from them, but I still have to eat.*”

When it came to diet, two additional challenges were identified:

- **The cost of healthy eating**

“*[The] biggest challenge is just getting the basic food stuffs. Some cost a little more than some, but I try to cope with the price tags that [go] with it. The healthy food is a little more expensive, and I try to cope with it.*”

“*You can't afford it to even buy the things that will be more beneficial for you. You want to be healthy. You want to feel better, but you have to eat more food that is good for you. Sometimes the prices are so expensive, you can't afford it.*”

“*It is very expensive. The diet is very expensive.*”

- **The culture of eating**

Some participants recognised that how they eat is wrapped in their culture and family norms; therefore, there can be a strong emotional tie to eating and this can be very hard to change.

“*And trying to eat right which you know that's a problem because trying to eat right—most of us Black people, we like a lot of rice. Yes, a lot of rice. So, that's basically what's there to eat.*”

“*Most people think that if they don't eat meat, they won't stay alive.*”

“*I'm telling you as boys growing up, it's all like six figs, half of a dozen figs you're eating off. Daddy bring in a bunch of fig in the house; it's gone. Between me and my brothers, it's gone. Go up the mountain looking soursop, I'm eating off a whole soursop. You're telling me now a piece of every portion of everything. I had to adjust, and it took me a while, I must say. It took me years.*”

When it came to exercise, challenges included:

- The **symptoms of their main NCD** or an additional chronic health issue, e.g., pain, fatigue breathlessness

“*I used to exercise, but from I found out about my knee, I can't do a lot of walking.*”

“*I think that was the hardest thing; like adjusting the workouts that may send your body crazy and finding a rhythm that your body will love, that will help you to kind of lose the pounds, that isn't as hard but is gentle enough that you can feel like you did something when you exercise. That was a challenge for me. I, literally, I grieved not being able to jog.*”

- Age

“

To be honest with you, right now my life isn't as active as when I was younger because when I was younger, I had energy.”

- The **busyness of life** and the fatigue after a long day at work

“

I'm supposed to, but sometimes I'm so busy with work.”

“

Trying, but sometimes when you finish work, you're so tired. You just want to go home and lie down.”

“

... sometimes I'm too lazy to exercise.”

There was recognition that exercise requires discipline especially when living with an NCD as there is a need, at times, to overcome the above-mentioned physical challenges in order to exercise. One or two people persisted regardless of their symptoms or restrictions.

“

When I don't feel good, I still take my exercise.”

“

Some people don't believe they can exercise unless they go outside, but I just stay indoors, and it feels so good. I can do everything that they can. I still sweat. I know I'm exercising.”

“

I don't really take it on because when you take on pain, it has you screw down and screw up. So, you have to keep moving and do your exercise.”

Overall, when it came to diet and exercise, it was noted that there is the challenge of some people living with NCDs not appreciating the importance of lifestyle changes until, in some cases, it was too late.

“

The complications that could develop from mismanagement of diabetes, you realise a lot of things can happen, amputation, [losing] your eyesight. To be honest, I don't mess with it. The information that I've gotten wake me up. It's an experience. It's an experience because at first, I didn't quite understand it. I was still doing some of the wrong things, eating the sugary stuff and so on.”

“

He [the doctor] said, 'Yes, you have to be more strict with the changes to your diet and increase in your exercise.' To be honest with you, it's only since I went on this 'no carb' diet and lost these 30 pounds that I understood that, at that time, if I had absolutely removed the carbs, my body might have said, 'This is good' and it might have gone away. I was able to bring it down with the change in the diet now. I might have been able to eliminate it with the change in the diet back then.”



Policymaker View

“So, for me, that is one of my biggest challenges — getting persons to realise that not only medication helps. There are other non-pharmaceutical approaches that they should be embracing to help with their condition. The type of food you eat, how often you eat. Also, the whole matter of exercise.” – Policymaker in the healthcare field

“We have very poor measures to control those diseases. Whether the asthmatic, for example, who lives in a place where grass is constantly burning or whatever the case may be. Or the diabetic patient who doesn’t have access to a proper diet. Or the hypertensive patient who has not cut back on salt because they eat poorly. So many of our patients who suffer with non-communicable disease or NCDs [that] are not adequately controlled. How do we get that type of control? It’s more than just a conversation or an intention. It’s about how can there be a whole-of-society approach to revisit how we eat, how we live, access to exercise.” – Policymaker in the healthcare field

Applying a gender lens to diet and exercise



When applying a gender lens to the self-management techniques of diet and exercise we see that some participants were able to leverage gendered roles to introduce these techniques into their routine. For example, most of the men that we interviewed tended to have professions that were very physical and used this to keep active.

“

That is what I’m doing right now to keep the body going. I still work. I still work” – Male participant

“

It’s manual. It’s physical... very physical.” – Male participant

Also, some men’s role as the provider acted as the motivation to improve their diet. For example:

“

As a man, I just knew that I had to be careful with my diet and stuff like that because I’m now thinking about my health and trying to be healthy. As a man... I have always been the man of the family. When I say that, I did everything basically, in terms of providing the finances. Everything kind of revolves around me.”

Meanwhile, some men tended to be dependent on female family members for their meals and so control of this self-management technique was delegated to someone else.

“

My brother’s wife. She too is very health-conscious, so she knows. Most of the time she very seldom uses salt so salt-free.” – Male participant

“

I mean, support from my sister-in-law. I could get breakfast, stuff like that. My in-laws, I could get lunch.” – Male participant

Some older men did take advantages of the time afforded to them due to their retirement to keep active with household chores and activities:

“

Well, I try to keep the yard clean. Sometimes I sweep and mop and everything. Keep the house or clean the yard. Keep the yard clean and clean the garden and everything.” – Male participant, retired

With regards to women, there was the recognition that some women in St. Kitts and Nevis are a “Caribbean or traditional female” so they are responsible for all the cooking and cleaning in their homes and had full control of these self-management techniques and used this role to introduce exercise or a healthy diet into their lifestyle. Examples are provided below:

“

Do you know that I deliberately don’t have house help, so that I can get exercise... because mopping and sweeping and cooking and folding and doing laundry is actually really good exercise for my hypertension. I’m not kidding.” – Female participant

“

Even when I’m cooking [chicken], sometimes I will just throw little water in the pot and kind of brown stew it. I don’t cook it with a lot of grease and a lot of fry food. I don’t eat this fry food thing. I’ve cut down those things.” – Female participant

“

I sometimes cook without salt.” – Female participant

Regarding exercise, there was the recognition that while men focused mainly on their physical jobs to keep active, women also made more of an effort to adopt an active lifestyle outside of their traditional roles and thus were more likely to participate in structured forms of exercise.



Policymaker View

“I think it’s clearly visible if you walk the bypass on the morning, the ratio of male to female is significantly lower. You see a lot less males than you see females. I think there’s at least five females to every two males that you may see exercising. In terms of the lifestyle habits, those are also important things.” – Policymaker in the healthcare field

Another issue with regards to exercise and women was that some women were balancing their many roles in society which they found to be overwhelming and after they had fulfilled those obligations, it left them feeling fatigued and unable to exercise.

“

Well, I started, but due to the constraints and everything, it was a bit too much. Sometimes when I finish working, I have to come home, prep something for the children. So then, by the time I get to finish, I’m over-exhausted.” – Female participant

Related to this, one participant highlighted that the support of a spouse was very beneficial in getting her active.

“*My husband, realising that I had hypertension, joined me in the exercise. Dragged me out of the house when I really couldn't move some days. We got to keep going. We got to keep moving. So, I was lucky in that regard.*” – Female participant

With regards to diet, some women did have to cook for the entire household and thus the dietary changes that were required because of their NCD also affected members of their household; this wasn't always received well and required adjustment and understanding from their family members.

“*Maybe they don't want it. So, I have to use it in a different way so they could eat it.*” – Female participant

“*That's been a huge challenge for me — really adjusting to healthier ways of cooking and trying to incorporate that in my life with other persons, because I'm not alone.*” – Female participant

It is notable that when it comes to diet women appear to hold more autonomy than men to manage their diet. Despite challenges in trying to cater to the tastes of family members, women still seem to have the authority when it comes to food preparation due to adherence to gendered domestic roles. From the findings, for men with NCDs, their diet management becomes subject to the women who prepare meals for them.

3.4.2. The Impact of the Pandemic on NCD Self-Management: Diet and Exercise

Bearing in mind the importance of diet and exercise in controlling NCDs and the challenges and barriers that participants faced before the pandemic around diet and exercise, we investigated any additional impact the pandemic created on participants' ability to manage their NCD through diet and exercise and any related gender issues.

Diet, Nutrition and Access to Food

Diet and access to food was a major consideration in some participants' preparation for the pandemic because of the COVID-19 restrictions on movement (curfews, stay-at-home orders, zoning and 24-hour lockdowns) and physical distancing, as well as the resulting public panic which affected participants' ability to easily access food.

“*I know many times I leave my house, I don't have anything to eat, and I was like, 'How are we going to do this?' Panic buying was creating too much of a crowd and I didn't want to be in that crowd, so we just stayed away.*”

Therefore, some participants' main concern was having the necessities which included having just enough food to eat, rather than focusing on healthy food which was the main concern before the pandemic.

“*Well, make sure there was enough food there for us to eat. Water, just the essentials.*”

“*Sometimes you worry if you didn't have something to eat, and I had something to eat, so I think I was prepared.*”

There was a feeling that the public may have overreacted to these policies and this compounded the real challenges of the pandemic. Some participants felt they had a more balanced view of the situation and therefore were not worried about their ability to access the food they needed to manage their condition.

“

And the lockdown is just like an ordinary... [day]. Just for the short time when they lockdown, do you know the amount of money people spent just for a couple of days? Do you know the amount of money the supermarkets got?”

When exploring the impact of the pandemic on participants’ ability to manage their condition through diet, the importance of mastering and adopting healthy eating practices before the pandemic was recognised as key to surviving it.

“

Most important I think too, that diet worked so blooming well that I knew that my hypertension was under control at the start of all of this [the pandemic]. If it [my diet] had been bad like it was in 2015 and 2016, I swear I would have popped off.”

Furthermore, the following key themes emerged with regards to the diet of people living with NCDs during the pandemic:

- Food affordability
- Access to food
- Improvements and worsening of eating habits
- Emotional eating

Food Affordability

As mentioned in the previous section, several participants explained that before the pandemic, the cost of healthy eating was already fairly high and since the pandemic, this cost had further increased making it hard for some participants to afford to maintain a healthy diet.

“

Yes, the healthy food is a little more expensive, and I try to cope with it. COVID now, some of them add on.”

“

Yes, the food stuffs you normally have to get is expensive.”

To cope with the increase in prices, those participants on a low income had to economise and find ways to access enough food to sustain themselves and this meant buying more processed and low-cost foods and sometimes forgoing fruit and vegetables. Low-cost and processed foods are more likely to be high in salt, sugar and saturated fat – all of which should be avoided by people living with NCDs.

“

You can cook two macaroni, mac and cheese and a tuna and so. We mix it up and eat. If it’s even little rice and tuna. I say, ‘Sardine and rice is protein suh unuh cook it and eat it and nuh have nuh problem. Drink water after.’”

Others found alternative ways to access healthy foods:

“

What was good is because my brother-in-law is a farmer. Like this morning I cook a half a pack of lentil peas, two sweet potatoes. I had a half of dasheen, so I grated it. That was what I made soup with. That's what I had for breakfast. What I did, I mash up some... when the potatoes boil – mash it to help thicken the soup and then add some coconut milk to it with a lot of garlic and onion and seasoning. That's how we're eating these days.”

Compounding this issue was the fact that some participants had lost their jobs due to the pandemic and had not been working for over a year and this meant that they could no longer afford to maintain a healthy diet.

“

Before the pandemic, as I said, it was easier. It was much easier because I was employed. I could buy the stuff that I need to keep my diet the way I needed it, so it was manageable. Now it's another story.”



Policymaker View

“What we have seen in addition is that some persons who have gotten breast cancer or other types of cancer diagnoses would have lost their jobs. Now, they are faced with the difficulty of buying even food.” - Policymaker in the NGO sector

Access to food

During the 24-hour curfew periods and partial curfew days, participants, like most of the public, because of the restrictions on movement and closure of supermarkets and markets, found it hard to access the food they needed, particularly fruits and vegetables. During these periods, even though there were two partial curfew days every week, the supermarkets were so busy that some participants were not able to access them or, to protect their health, they preferred not to go to the supermarket to purchase food items. This meant that individuals had to manage with the little that they had as described below.

“

No, I'm not going out the road. I'm not going to bundle up in any supermarket line. No, I'm not doing that. I tell them, 'Look here, anything we have in here, that's what we're going to survive off of. Unuh learn fi be satisfied.' I know how to boil so-so food and crush it with butter. Yes, I know how to crush banana, roast a breadfruit, and fry it and drink it with little bush tea and put little salt on it and that's it.”

Senior citizens who felt comfortable visiting the supermarkets did have a less challenging time in terms of the busyness and long lines as all the supermarkets introduced lines specifically for the elderly.

“

No, not with the senior citizens. You go up, you sanitize, you go, and you grab a basket. You go shopping and that's it. No real problem.”

Furthermore, when participants did access the supermarket, they felt there was a need to bulk-buy because of the uncertainty created by the pandemic, but the types of foods they needed to eat could not be bought in bulk because of their short shelf life. This meant they had to temporarily change their diet and in one case this worsened a participant's NCD symptoms.

“

Well, I struggled when we had the lockdown because I eat fresh stuff. So, it's not like I could bulk up my pantry. It was a challenge when we were locked in, and you know fresh fruits don't last as long. I had to literally go back to eating like rice, the basic storage things just to survive. You're thinking about those dry foods. You're thinking about the rice, the crackers, things that I cannot eat. So, yes, I had to eat to survive. I drank a lot of teas, and I got bloated really badly. I think some of the flare-ups took a bit long to subside because I was consuming wheat.”

“

The only thing didn't last is the greens. You know, broccoli, cabbage, and carrots. Otherwise, everything was okay.”

Others did not have any challenges with accessing food which was mainly because they had a family member who assisted them with procuring food or, prior to the pandemic, as a result of limited movement, they had a strategy in place that also worked well for the pandemic. Others were always prepared, even before the pandemic, with adequate food, so the lockdown had no impact on them.

“

I didn't go anywhere because I always stock up. My mom taught me, 'Every week buy the same thing, so when it goes scarce you still have.' So, it didn't bother me at all either. I didn't go anywhere. No panic buying because when we shop, we shop like a month's stuff. It lasts us out.”

Others had a large and close family network and they worked together as a team to access the supermarket and ensure they all had what they needed. A good example is below:

“

Every time there were short days because even though it was a full day, the wait times in lines were long so it was 'divide and conquer.' Your family divided up the list, gave each person some money and then everybody headed for their assigned shopping spot just to get what you needed. You try to call each other as you go along to communicate what is available, what isn't available, and to grab as much as you can.”

To address the lack of access to food and the affordability of food, the Government, political parties, churches and NGOs were offering free food packages to members of the public who were most in need. Several participants reported being a recipient of one of these packages.

“

They brought a bag to me with toiletry and all kind of things, little food, and things. I was grateful. I was very grateful.”

One participant raised the point that while she appreciated the gesture, these packages contained food items that were not appropriate for people living with an NCD.

“

Those that did, they bring you things like rice and macaroni.”



Policymaker View

“We put some baskets together and we put in also nonperishable food and stuff like that. So, in case people have to stay in their home, [they have] like Vienna sausage and sardines, and beef, and macaroni and cheese and stuff like that. Also, in terms of health, we also give out like fruit baskets” – Policymaker representing faith-based organisations

“There were times where we bought some stuff for persons [NCD patients] who were not really mobile. So, we would have bought healthy foods, some fruits, vegetables and so on for those persons. Others who we just gave the vouchers, we just try to encourage them to make sure they buy healthy things, buy things that can help boost their immune system during this period.” – Policymaker in the NGO sector

Within our study, we did have essential workers with NCDs who were still working throughout the curfew periods. One participant explained that before the pandemic, they would purchase food during the day for lunch but with the pandemic, food vendors were closed and they found it hard to access food and for a diabetic, this impacted their ability to control their blood glucose levels.

Improvements and also worsening of diets

One theme that was raised about the pandemic and eating habits was that the scarcity did lead to an improvement in some participants' diets. This was due to a reduction in the purchasing of unhealthy snacks, participants' inability to eat out at restaurants and their increased consciousness about the need to be healthy during the pandemic as people with NCDs were at increased risk of developing severe COVID-19.

“

I was aware that I couldn't do the things that I would do normally to try to maintain the level of exercise and so forth. I was really mindful in how much I was eating, how often, and the construction of meals. I think I ate more greens and raw vegetables during the pandemic than before because the Ministry of Health highlighted how important it was to make sure that your vitamin levels were high and your sodium and so forth were low.”

“

“The only good thing that really would have come out of the lockdown and maybe the chronic illness is that most of the stuff we would normally buy like the ice-creams and that kind of stuff, we were limited. So, it made a difference in terms of my diet. I was able to put a halt on the snacking.”

Conversely (as described in the previous section), because of the increase in the cost of food and their inability to access the foods that they normally consume to manage their NCD, some participants had to select unhealthy foods which had a negative impact on their NCD.

Emotional Eating

We did find evidence of emotional eating amongst our participants which could have had a negative effect on their NCD. Some participants had a heightened state of fear and anxiety because of the realisation that they were more at risk of developing COVID-19 and this led to stress eating.

“*Watching your diet and not getting depressed and wanting to eat all kinds of crazy crap which I did go through.*”

Additionally, there was evidence of boredom-related eating, where people turned to eating as a way to occupy their time during the lockdown periods.

“*[I] find all kind of things to watch on the phone, chat on the phone, just eat. I think that is why so many persons in St. Kitts are obese today.*”

“*Staying at home all day makes you eat. Not being able to hit the street makes you eat. So, I gained weight. Not a good thing but it is what it is.*”

Gender, Food and Nutrition During the Pandemic



Applying a gender lens to these food-related issues reveals that single mothers on a low income were most affected as the pandemic worsened food affordability. Their financial state was due to job losses, reduction in work hours, increase in food prices and to having to provide additional food for children who were spending more time at home.

“*Well, the children eat too much. While they're home, they're always hungry, versus when they're at school, they will eat breakfast; they're at school all day [so] when they come home, you will just make them some supper. They bathe and then they go in their bed. But when they're home all day, they have nothing to do.*” — Single mother with an NCD

Additionally, women – particularly single mothers – had to shoulder the burden of the long lines at the supermarkets, and doing this whilst having an NCD could be more challenging to them than to the average person due to NCD symptoms like fatigue, pain, respiratory symptoms and sunlight sensitivity.

“*You had to be out in the hot sun standing up for two hours sometimes, and you know sometimes you have to eat.*” – Single mother with an NCD

“*Sometimes you go to the shop, and you have to stand up in a long line. Knowing that sometimes you don't feel good, and you have to be in a line. I had to go myself. I pray when I wasn't feeling good. All I could do was tell them, 'Bring me the bed let me lay down on the landing.' As I said, this sickness has no regards.*” – Single mother with an NCD

Overall, men seemed to be shielded from some of these issues because cooking for the family and grocery shopping fell on women — men tended to have family members who could shop on their behalf during the pandemic. If men did visit the supermarket during the lockdown period, they had to face the reality of shopping which they had been previously shielded from.

“

“I think as a female I had an advantage because shopping is something that most females do regularly whereas some of the men that I encountered in the grocery store, it was very clear that they hadn’t bought groceries in a long time and they didn’t quite understand how to cook. So, their strategy was to get things they didn’t need to cook. So, I felt like I was at an advantage and quite advanced in comparison to males. This is one of the areas where being a female, at least a Caribbean or traditional female would have given you an advantage to most.” – Female participant

Older women with NCDs also tended to be shielded from long supermarket lines as they had family and friends who shopped on their behalf and provided them with hot meals, or they could access the senior citizens' line at the supermarket. There was a slight gap for older women who were partially dependent on family and friends — these were women who cooked for themselves on some days and on other days had food delivered by a family member or friend. The gap occurred when they may not have had the energy to cook for themselves on the days where they did not receive support.

“

The only problem with that sometimes was a meal, a meal together. There were the odd days when I didn’t feel I wanted to do any cooking, you know? Something like that. Then on Sundays particularly, it kind of worried me for a bit.” – Older female participant

With regards to emotional eating, this did seem to affect women more, but there was some evidence that whilst women were more likely to turn to food to manage stress, men were perhaps more likely to turn to alcohol.

“

...maybe stress from the situation, the pandemic and what we were going through, also drinking... Yes, I drink to ease my mind of the stress.” – Male participant

“

[Men] will more go drink.” – Female participant

There were some benefits for women around cooking: The scarcity of ingredients and availability of time meant they could get creative with meal preparation which led some to enjoy cooking more and feel a sense of accomplishment at mastering creative, healthy dishes.

“

When I’d have cravings, for some of them, I would test out recipes and I’ve noticed that a lot of things that I would spend quite a bit of money on [,] I could make it just as good or maybe even better but ... with a lot less calories or a lot less fat or a lot less sodium and a number of other ingredients that would affect my blood pressure. I’d make it without it sometimes because I didn’t have it.” – Female participant

“

One of the things it has done, it has made me take a keener interest in cooking. Since I’m preparing my meals, I now go on the computer and I look for another way of doing this or doing that, or sometimes just breeze through the thing. I have now tried different ways of cooking things. Having done that, I’ve also shared it with one or two people some of the things I’ve tried.” – Female participant

Exercise

When exploring the impact of participants’ ability to manage their NCD through exercise during the pandemic, there were

three main effects:

- A reduction in the amount of exercise;
- An increase in exercise; or
- Maintenance of pre-pandemic levels of exercise

Firstly, looking at those who were able to take part in more exercise, this stemmed from the fact that the pandemic-related restrictions on movement created more time for them to exercise at home.

“

I actually got a little bit more exercise than I normally would because I was home. So, yes, that worked.”

A key factor in enabling some participants to continue exercising during the pandemic was the fact that they had the space at home to exercise – they either had a significant amount of yard space or internal space to exercise.

“

I was lucky because I had space. So, when we were in lockdown, I could go out onto my veranda. I could go down into the garden, and I could dig holes.”

“

We have a big yard, so we could walk through the yard.”

“

Yes, because when it started and we got locked down, I was using the yard 10 times.”

“

Yes, I still exercised because it still came on... the exercise on TV, 3ABN.”

One participant recognised the advantageous position she was in compared to others who may not have as much space and highlighted that if she didn't have the space to exercise this would have negatively impacted her NCD.

“

I do wonder because like I said to you, I feel I was lucky because I had space. I do remember thinking, 'Wait, if I didn't have space, I'd be in trouble' because I wouldn't be able to exercise. So, it would be really important for the next time that they actually plan on rotating space for people to exercise outside of their home.”

When we explored this further, this was the case for some people who did not have the space at home to exercise.

“

I would strongly desire the chance to go for a walk. So, most mornings I would go to the gate and look out as though I was a prisoner for as long as possible. After a while, feeling somewhat defeated, I'd come back inside. Then I was concerned that the stressors from the pandemic along with lack of exercise – well, for me, meaningful exercise – would cause spikes that maybe medications couldn't control. So, that would then cause me to worry about my blood pressure altogether.”

Others who did not have the space but had the financial means to do so invested in home exercise equipment or already had such equipment and used these to maintain adequate levels of physical activity.

“

I bought a bike. It's in my bedroom, so yes, I still try.”

“*I have a stationary bike, so I try to go a half an hour daily.*”

Additionally, another important way that participants were able to continue exercising was by making use of either online or TV-based exercise programmes. Online classes were a nice discovery for one participant who stated that she would not have considered this as an exercise option if it were not for the pandemic.

“*I think a benefit for me [was] just home workouts, having those videos online. I followed a few groups that did online exercising over Zoom. That really helped. I wouldn't have thought of that outside of the pandemic, really and truly. I wouldn't have.*”

A significant number of participants reported that their level of physical activity and exercise reduced significantly because of pandemic-related restrictions and therefore, during the lockdown period some were completely inactive. These participants tended not to have the space to exercise or simply lost motivation.

“*I wasn't getting to go out to do as much exercise.*”

“*Now and again, I would do some of it but not as much. I haven't been walking as I used to. That's all. That's the only change.*”

“*When you're home, you get lazy. You don't want to do nothing but eat and sleep and maybe walk around the house and stuff. If you can't go outside to go across the road, to me, it's hard.*”

When exploring the issue of exercise during the pandemic it is evident that those from a higher socio-economic background had the means, time and opportunity to exercise, including internet access for online options.

Gender and Exercise During the Pandemic



Overall, we see that for women the restrictions created by the pandemic afforded them the time to exercise, but from an intersectional viewpoint when factoring in socio-economic background and personal circumstances, single mothers on a low income were again most likely to be at a disadvantage. Whilst they may have had more time at home, some were in administrative positions and had to work from home while caring for children and assisting with their homeschooling.

“*I had to juggle. I would have to put off my work just to make sure my daughter gets in what she's supposed to be getting in [in her class].*”

Additionally, men who depended on their physical/manual jobs to keep active were also at a disadvantage as the restrictions on movement meant they could not engage in these activities unless they were essential workers.

It is important to note that it did appear that exercise was an activity that women were more intentional about and made time for as a self-management option, making them more likely to engage in exercise during the pandemic.

3.4.3. Pre-pandemic Self-Management: Medication

Participants reported that as well as diet and exercise, medication was a very important part of managing their NCD before the pandemic.

“

I mean, a major part of dealing with hypertension is taking your medicine and being disciplined in taking them. I imagine once you do that, you the individual should be okay.”

“

I take a regular set of pills every day. I think that is what's keeping me going and trying to eat healthy.”

Depending on the NCD, these medications were taken daily.

“

Generally, I've been living on pills every day.”

Whilst the majority of participants were advised to take their medications daily, some persons expressed discomfort with having to depend on medications over the long term. The discomfort stemmed from concern over the side effects and the possible long-term health effects of medications.

“

I refuse to take it because doing research and looking up what does, it does more harm than good to the body.”

“

I learnt about how the tablets deal with you and I didn't like it either. I said probably that's one of the reasons why I was feeling like how I was feeling.”

Furthermore, one participant stated that her goal with regards to medication was:

“

At some point in time, I want to get rid of the medication. I don't want to always have to be popping pills.”

This hesitancy in taking medication resulted in some participants exploring herbal medications to manage their condition.

“

Then I started learning about herbs. I didn't know much about it before, but then I just adapt more into it and take it as part of my life. Most of the herbs I deal with bitter but they work. There are a lot of bush that I use. Trust me, a lot.”

When it came to the challenges or issues associated with medication, five main challenges were identified. Firstly, some participants found it hard to remember to take their medication or forgot to take the medication as prescribed.

“

My biggest challenge was taking my medication. I would forget.”

“

Once or twice probably I took my insulin and forgot to eat.”

The second medication-related challenge was the side effects and then having to deal with those side effects which can be uncomfortable or disruptive.

“

I didn't like them. I didn't like how they used to make me feel. I would take it in the morning and then in the afternoon I would feel funny.”

Another challenge, although not common before the pandemic and only reported by one participant, was running out of medication and this was only an issue with this participant because two members of the household were living with the same NCD and sharing medication.

Before the pandemic, most participants always had an ample supply of medication on hand.

“

I go to the drug store. I make sure I get two months' supply, so I would not have to run out of what I need.”

An additional challenge related to medication was patients developing treatment resistance where their NCD, unbeknownst to them, was no longer responsive to their prescribed medication. This issue was compounded by the fact that some patients were not aware this was possible and therefore, were not having regular reviews with their doctor about the effectiveness of their medication.

“

I was looking at my blood pressure being constantly high even though I was taking my meds. I was blaming my anxiety and my rise in my hypertension on things that were external to me but which I thought about a lot, only to find out that there is such a thing as your medication can stop working.”



Policymaker View

“There was another issue where some patients, it's like they go to the doctor once, and they feel that the medication that the doctor gives them at that first visit is what they'll be on for the rest of their lives.

They might need a dose change or a different tablet is put in the mix depending on how they're doing. If they're doing well, they might keep the same medication. If they're not doing well, they might get some changes. If there is no assessment, there's no way of knowing.” – Policymaker in the healthcare field

“I say to you, ‘Well, how do you get your medication?’ ‘Well, I go to the pharmacy, and they just repeat it for me.’ How do you know that the same dose of medication five years ago is still working for you, that your heart has not increased in size, and you need new medication? You know what I mean. So, those are some of the things.” – Policymaker/Doctor

Finally, a minority of participants highlighted the costs associated with accessing medication as a challenge and this was either the cost of obtaining medication on island but also shipping medication into St. Kitts and Nevis.

“

Sometimes I would order it. Clearing it is more expensive than buying it. That is the problem.”

“

When it comes to buying stuff and buying medication, that's the hardest part.”

“

You can't afford to be buying these medications because it adds up. If you have to check up for whole year times 12, the amount, it adds up.”

Despite this being raised as a challenge for a small minority, the majority of participants did commend the Ministry of Health for the affordability of medications at the health centres and also for providing free medications to the older population.



Policymaker View

“Some of them are on some expensive medications, so they're trying to see how best they can stretch the money. Well, one of the things the pharmacy does, it gives a discount, but the discount is restricted to people who are 65 and over.” – Policymaker in the healthcare field

“In St. Kitts & Nevis, we do provide some level of essential medicine support to individuals. So, there is still that buffer where persons would be able to obtain their essential medicines at a lower cost through the health centre pharmacy.” – Policymaker in the healthcare field

“The government has done a fantastic job, I think, in ensuring that the stock of medication at the hospital, at minimal cost to most individuals, is available.” – Doctor/Policymaker

Gender and Medication Management Before the Pandemic

We found the following gender-related issues with regards to medication. Firstly, it was noted that

“

Men don't like to take medication. They don't like to take medication, so it will really bother them a lot. But if I have to take it, I just take it.” – Female participant

Supporting this statement from a female participant, we did find that there appeared to be more hesitancy around taking medication amongst men and this was because of the reasons mentioned previously – a concern over side effects and the health impact of being on long-term medication.

Furthermore, another issue that was raised around medication was the gender-specific side effects of some of the medication which, as raised by a policymaker, can be very sensitive to discuss and therefore may not get addressed.



Policymaker View

“Some of the men, the side effects of some of the medications, they don’t seem to give the doctor all the information. For instance, erectile dysfunction. Some of their medication can cause that, and they would come to me one-way and say, ‘I taking this. This is what is happening to me.’” – Policymaker in the healthcare field

Another issue was related to body image with some medication leading to weight gain and hair loss which was more of a concern to women.

“

And they do so much damage to you. My hair was nice and long and thick and all that and flowing and going. Then they come so thin. That is just one of the side effects of taking the pills. Being a woman, being all coming from glamour zone to getting diabetes and you get this... the belly. Before, I didn't have this. It really makes you go like, 'Really? So, what happened to all the sexy?' Sexy took a walk.” – Female participant



Policymaker View

In terms of a medical condition, the females, I think their big challenge tends to be more with obesity and weight control. They are more conscious of it. There are those who want to put on weight because they might be on some medication that is causing them to lose weight. There are some who put on weight because a certain medication causes water retention, and they get a little bulk.” – Policymaker in the healthcare field

The Impact of the Pandemic on Medication Management



Prior to the pandemic, most participants were in the habit of ensuring they had ample amounts of their medication and therefore when the pandemic started several participants were very prepared in this regard.

“

When the pandemic started, I had three months' worth of meds. I wasn't worried about running out of meds.”

“

I buy my medication in bulk, so I don't have an issue.”

“

I always prepared. I always make sure I have adequate.”

With the onset of the pandemic with its restrictions on movement and the uncertainty about the future, most participants became even more vigilant with stocking up on their medication especially as this recommendation was regularly being reinforced by the COVID-19 Task Force, the Ministry of Health, the health centres and doctors.

“ I made sure to stock up real good with my medication and thing.”

“ Initially, my only thought was, ‘Be careful to go to the pharmacy’ and ‘Get as much medication. Stock up with as much of your medication as possible.’ So, I think on the day that it was announced, I went to the pharmacy and I got three months’ worth, and I thought that that would be sufficient and that by the time that was finished that everything would have cleared up.”

“ That advice [from the Ministry of Health]? Well, make sure that you have what you need, your medication. Make sure you don’t run out of medication, so make sure you have a proper supply of your medication.” That advice [from the Ministry of Health]? Well, make sure that you have what you need, your medication. Make sure you don’t run out of medication, so make sure you have a proper supply of your medication.” I made sure to stock up real good with my medication and thing.”

Additionally, doctors and the health centres accommodated patients’ desire to stock up on their medication and they promptly facilitated bulk-stocking of medications.

“ They made sure that they gave me all the medication that I would need during that time and really and truly, I didn’t run out of anything. So, I wasn’t hysterical or worried or had a problem with anything.”

The most vulnerable period with regards to medication management was during the 24-hour lockdown as during these times pharmacies were closed. However, the majority of participants were very much prepared, so this vulnerability was mitigated. Only one person ran out of medication – the same participant who reported running out of medication before the pandemic. The nature of this participants’ condition (a chronic respiratory condition) meant there was a negative effect on the participant’s NCD management and there was a need to improvise to ease symptoms.

“ I tried controlling it for the time being. Sometimes I would use paper bags. It depends.”

During the 24-hour lockdown periods, there were two partial lockdown days per week and these were partly introduced to allow people living with NCDs to replenish their medication and/or visit their doctors or their nearest health centre for any medical attention that they may have required. Our study shows that these two days were used by participants for that purpose.

“ Well, when they had the partial lockdown days and I could come out, I would go to the supermarket or the pharmacy, get what I needed and then go back home.”

Outside of the 24-hour lockdown period, there were curfews and physical distancing requirements which created long lines at the pharmacy and this is where some challenges occurred, leading to more participants running out of medication. Most participants were stocked up but when their stock of medication was running low and some attempted to obtain a refill, the long lines at the pharmacy prevented them from filling their prescriptions and they ran out of medication.

“*The lady at the pharmacy abuse me and all. It [running out of my medication] wasn't intentional... the long lines.*”

“*I had to go to get medication. I ran out. I went to look in the week, but I didn't get it where I went, and I came home. I finally didn't have any, so I had to go. I had to end up over Valu Mart. I went over there like seven [a.m.] and the line was long.*”

To overcome this issue, others, particularly older participants, asked family members and friends to assist with getting their medication and they would ensure that they did not run out of medication and would visit the pharmacies regularly on their behalf.

“*As I said, the family and friends were very supportive. They made sure that I had everything that I needed so that I would not be in want over the medication.*”

“*I had all my medication, she puts it in advance. She doesn't like me to run out of things.*”

Additionally, all pharmacies had a line specifically for older people to make it easier for this age group to access the pharmacy and refill their medications.

“*At Pharmcarre, we had two lines: senior citizens and the regular — people who are not senior. I used to go in the senior citizens' line, so I used to get through kind of quick.*”

When probing participants on medication management, it was clear that medication was perceived as a bit of a lifeline during the pandemic and provided participants with a sense of comfort and stability within a very challenging and uncertain period. Participants in various ways explained that medication management was one of the only aspects of the pandemic they could control; everything else came with some level of uncertainty, e.g., changes in food prices and inconsistencies in the availability of food.

“*The only thing I could do was make sure that I had my medication and any essentials that I needed so that I could just be in a settled state of mind. Well, as settled as you could possibly be when nobody knows what's going on.*”

“*Well, it's just a matter of getting your medication. I'd say that's the important thing. As long as you're getting your medication, it keeps you as good as normal I would say.*”

In contrast, for one participant the disruption in daily routine caused by the pandemic led to the disruption of medication management. Prior to the pandemic, this participant had established a routine for medication management which included a structured balance between herbal medication and conventional medication. The pandemic-related disruption to schedules, mealtimes and working hours disrupted this balance and impacted their medication management, resulting in their NCD becoming uncontrolled.

Furthermore, as described, the issue of medication resistance arose with another participant but because of the

restrictions of the pandemic, there was a delay in identifying this issue which meant their NCD was being insufficiently managed during this period.

“

I should have [gone to the doctor] because then he had to change like one of the medications.”

When looking at those that were more at risk of running out of medication during the pandemic, our study suggests that those on a low income who could not afford to bulk buy were at risk. They simply bought what they could afford.

“

I went to both the supermarket and the pharmacy just to restock on what was there and not buy bulk, but just to replace what was used.”

Additionally, older persons living on their own were also at risk of having challenges accessing the medications they needed, but as mentioned previously, all were able to get some support in this regard through friends and family.

Gender, medication management and the pandemic



When we apply an intersectional gender lens to the issue of medication management during the pandemic, we again see that single mothers on a low income were most at risk of having issues with accessing medication. Additionally, men who prior to the pandemic were hesitant to take medication were at risk of facing challenges with their medication during the pandemic because it created additional barriers to accessing medication. This was identified in one male participant where a combination of hesitancy of taking medication, disruption to his daily activities and the restrictions of movement affected his ability to successfully manage his NCD and his NCD became uncontrolled, whereas before the pandemic, his condition was fairly well managed through a combination of pharmaceutical and non-pharmaceutical measures.

3.4.4. Pre-pandemic Self-Management: Rest

As we continued to explore the self-management techniques that participants employed to manage their NCD before the pandemic, a few participants highlighted the importance of rest.

“

I go to sleep because sleeping is very important.”

“

When it's 12 o'clock, I have to lay down.”

“

When I don't feel good, I relax.”

The challenge with rest was participants finding the time to get adequate rest. Older, retired participants had the opportunity to carve out time for rest, but younger participants who were working and balancing domestic life found it harder to do this.

“

I used to mostly be in my garden. I have a sling, so sometimes I go in it and I swing. Go in my garden [and] relax.” – Older, retired participant

Gender, NCDs and Rest Before the Pandemic



Our data suggested that working mothers, in particular, found it hard to set aside time to rest which may have a negative impact on their NCD.

“

The way we work the long, long hours, the very few breaks in a year, that kind of thing... So then you end up always in the not-so-much-downtime as maybe the disease could do with.” – Female participant, working mother

“

I just put my best foot forward because I just feel so tired sometimes. I know I have to do it. If I don't do it, who's going to feed my kids?” – Female participant, working mother

“

It was a lot of stress. Finding the time to relax, finding the time to just be comfortable, being alone and have me-time.” – Female participant, working mother

The Impact of the Pandemic on Rest

When we look at how the pandemic affected rest as a self-management technique, we see in some cases that the 24-hour lockdown, the restrictions on movement and the slowing down of society provided some participants with the opportunity to get more rest than they had been able to obtain before the pandemic. Participants spoke about using the 24-hour lockdown period to practise some self-care.

“

I was not bored. Not one day because I enjoy reading books. So, it was an opportunity for nobody to call me... I'll be reading my book. Yes. I lie in my bed and read my books.”

“

Oh, I was more on the Internet, Facebook, watching TV and Netflix and different things. I just relaxed myself.”

“

I got a little more rest: TV or read a book.”

Those who were able to get more rest during the pandemic tended to fit into a group of people whose employment was not significantly affected and therefore they generally had peace of mind about the future and were able to make the most of this quiet time to recuperate. They reported that this period was beneficial to their NCD and improved their symptoms. Although some of these participants were working from home, the pace was slower.

“

I worked to a sense if they send in anything. It's more calming. You don't have anybody to be calling you on the phone to tell you, 'Oh, don't forget to do this.' 'Oh, don't forget to do that.' Or emails coming in. I mean, you work at your own pace, so you're calmer.”

Others were unable to rest during this period as their minds were consumed with the anxiety of the pandemic and the impact it was having on their lives and livelihood. Also, for some, the pandemic brought extra caregiving roles and responsibilities (looking after children, grandchildren or older family members) which prevented them from getting the rest that others were able to get during the curfew periods.

“

Stressful, erratic. Well, the whole nature of the arrival of the pandemic meant that there was a lot of unknowns, followed by a lot of fears. Followed by lots of information around the pandemic that said that if you had hypertension, you were at a higher risk with certain challenges.”

“

The pandemic turned me into a caregiver. It wasn't planned.”

“

I haven't worked since March last year.”

“

Well, honestly, I did not like it [the lockdown]. To be honest, I was kind of scared because I know I have hypertension and it was not going down at all for a while there.”

Additionally, some participants' personal circumstances and living arrangements made it challenging to rest at home during the curfew.

“

Honestly, I know it's a place to rest your head, but then at the end of the day, you still have problems because you aren't comfortable. It's just a lot of things. So, I believe more likely it's the living arrangements.”

For some of the above-mentioned persons who weren't able to rest during the pandemic due to the anxiety of their circumstances, they reported that this exacerbated their NCD.

“

I feel like it created many spikes in my blood pressure.”

Gender, Rest and NCDs during the pandemic



An intersectional lens revealed that single mothers on a low income (as well as grandmothers caring for grandchildren) were at a disadvantage and unable to rest during this period as they had to balance working from home, childcare, homeschooling, household chores and their NCD. Also, male essential workers who were involved in manual jobs during the pandemic had significant physical demands on them – they were on call and this disrupted their ability to rest and thus manage their NCD.

3.4.5. Pre-pandemic Self-Management: Maintaining a Healthy Weight

Another theme that emerged with regards to the way in which participants managed and controlled their condition was weight management. There was a recognition of the need to maintain a healthy weight as an important strategy to controlling an NCD.

“Right now, I’m down to 205. I want to lose 20 more pounds. So, I’m working towards that. I’m doing the work. I’m putting in the work. I need to get down to at least 180 pounds.”

“I was a little thicker than what I am. Then eating special food, you’re going to lose the weight and then I started to exercise more.”

Maintaining a healthy weight did become a bit of a conundrum for some patients with specific NCDs as one of the side effects of certain medications is weight gain, or their NCD itself caused weight gain.

“So, I decided, even though the insulin helps you to gain weight, I prefer to gain weight than to lose my kidneys.”

“A huge part of my condition* is the crazy weight gain.”

The Impact of the Pandemic on Weight Management

When it came to weight management during the pandemic, some participants explained that the pandemic affected their weight. Some participants explained that they had lost weight either because they opted to, or because of the circumstances (explained previously), they were forced to make healthy lifestyle choices during the pandemic.

“It has cut calories and caused some well-needed weight loss to occur.”

“The only good thing that really would have come out of the lockdown and maybe the chronic illness is that most of the stuff we would normally buy like the ice-creams and that kind of stuff, we were limited. I was able to put a halt on the snacking. I’ve gone from eating a lot of junk to right now I have a big bag of almonds on my table and a big bag of cranberry. That’s why I am losing the weight.”

Others were unable to maintain a healthy lifestyle and this led to weight gain, and this was compounded by the fact that some NCD medications led to weight gain.

“Staying at home all day makes you eat. Not being able to hit the street makes you eat. So, I gained weight. Not a good thing but it is what it is.”

“I was a whale. I was bloated.”

The Pandemic, Gender, NCDs and Weight Management



Weight control appeared to be more of a concern for women as all those who raised the issue of weight management before and after the pandemic were women. Those who raised this issue felt they were or had been overweight prior to

the pandemic and this correlates with published data which states that a higher percentage of women in St. Kitts and Nevis are overweight or obese compared to men. Additionally, our study highlights that there are female hormonal conditions that cause weight gain; weight gained in this way (i.e., due to hormonal diseases) is harder to lose and this presents an additional challenge for women as this places them under unrealistic pressure when it comes to maintaining a healthy weight.

“

He mentioned losing weight, and obviously we try all of the things. It's a hormonal imbalance so it's not as easy as doing exercise or whatever [to lose the weight].” – Female with a chronic hormonal reproductive NCD

Therefore, when it came to the pandemic and weight gain, this primarily affected women. Women both benefited from and were most disadvantaged when it came to weight management. We see in some circumstances women being able to lose weight that they had not been able to lose prior to the pandemic, but at the same time, other women gained weight. Both of the scenarios were a combination of the personal circumstances women found themselves in – women’s socio-economic situations, women’s increased risk of being overweight or obese, women’s responsibility for grocery shopping and meal preparation, the side effects of medication and/or being affected by a hormone-related NCD.

3.4.6. Pre-pandemic Self-Management: Coping and Building Resilience

Throughout our interviews, the theme of coping and resilience emerged and appeared to be an important aspect of successfully living with an NCD. Some participants spoke about accepting their condition and how that acceptance came with a matter-of-fact attitude around managing it and not letting it defeat them.

“

I think the main thing [is] I have accepted [it]. I think this is what has helped me. I accept my condition, and I just decided to deal with it. That's it.”

“

I got it under control. I just try to balance it. I look at diabetes as you know basically in the future it might take you down, but I try to be strong for whenever... you have a strong mind... I'm still living normal. I know how I'm supposed to eat.”

“

I try not to let—you can't take it on. You just do what you know is right.”

Impact of the Pandemic on Coping and Building Resilience

In our study, we found that older people were better able to cope with the pandemic and were fairly resilient. When we explored this, it appeared to be due to a combination of factors.

1

Retirement/Semi-retirement – Being retired meant their movements were already limited before the pandemic and a few mentioned being ‘already locked down,’ therefore the imposition of restrictions and curfews had no significant impact on their quality of life and they already had processes in place to manage long periods of being at home or alone.

“

Well, I didn't feel no way because what really happen is that I don't go any place, so I was home. It was good.” – 74-year-old participant

“

That's what I do all the time, so it wasn't anything to me. It didn't affect me at all.”- 67-year-old participant

“

I lock down every day. It didn't affect me.” – 62-year-old participant

2

Keeping busy — Some older participants decided to keep themselves busy and continue doing some type of work to maintain some level of normalcy.

“

As I said, it doesn't really bother me. All the time we were working. I was still at work. We work by shift. As I said, I don't really take on those things.” – 72-year-old participant

“

But I really did not allow it to get me depressed. I worked against that. I said, ‘Here are the things I can do.’ So, I kind of got myself involved in doing things.” – 83-year-old participant

3

No dependent children – Older participants also explained that their children were now adults and less reliant on them, therefore, they did not have the added worry of caring for children during this period. In fact, their adult children (or other family members) were caring for them and making sure they had everything they needed during the pandemic.

“

The thing is you don't have any young children to harass you. All of them big.” – 72-year-old participant

4

Positive outlook – Older people seemed to have a positive outlook – they anticipated that better days would come and therefore did not let the pandemic wear them down or worry them unnecessarily. This positive outlook seemed to stem from life experience and the lessons they had learnt throughout their lives, especially from living through scarcity and overcoming previous hard times.

“

I don't let certain things bother me. Older than me just don't take that on.” – 78-year-old participant

“

It's going to happen. The place is going to come back to normal.” – 62-year-old participant

“

For me, if you know me, I like to simplify my life not complicate it. That's when the problems start, and you can't find the solution. It's complicated. When you keep it intact, simple, you could always touch base with it and say, 'I know. I can choose.' I keep my life simple. Maturity.” – 71-year-old participant

“

Of course, I'm used to it. I know how to boil so-so food and crush it with butter. Yes, I know how to crush banana, roast a breadfruit, and fry it and drink it with little bush tea and put little salt on it and that's it.” – 62-year-old participant

“

I remember the days when I was growing up with daddy and mommy, we couldn't afford electricity and so on. But daddy bought a lot of vegetables. Where do you think he put the vegetables? Underground. The ground used to preserve the carrots, the sweet potatoes. He just covered them, and every time mommy's ready to cook, she just called me. I dig out what she wants, and they're perfect. The coolness of the ground.” – 71-year-old participant

5

Religion – A core part of older people's life was spirituality and religion – most were regular church-goers before the pandemic. They had a strong faith and this provided a sense of comfort, peace and hope.

“

Yes, I'm not crying because the more you cry, the worse it is for you. You give God all, and God will provide.” – 78-year-old participant

“

You just have to continue praying for the best.” – 62-year-old participant

“

God gives me strength. Oh my God. I talk to the Lord.” – 74-year-old participant

In contrast, some of the middle-aged and younger participants – because the pandemic affected so many aspects of their lives – had a challenge coping with these additional burdens and ensuring their NCD remained under control during the pandemic.

“

Well, sometimes it would trigger [the NCD] off because you're there studying. I can't go outside or go anywhere or to talk to anybody. It's just like I'm in there panicking like I do somebody wrong. Why am I locked down? I didn't do anybody anything.”

“

I ended up going to a doctor and he said my heart was skipping beats or something like that. It was just a little hectic.”

Before the pandemic, middle-aged and younger participants spoke about acceptance as a method of coping with living with an NCD, but the pandemic prompted participants to try new techniques to cope with the additional burden and challenges. These techniques included:

Breath work: *“I learned to breathe. I did try to do some mental—learn to breathe and destress in the moment. I have actually, I think, mastered that. I can actually hold on to myself a little tighter and give things up.”*

Building mental resilience: *“My main thought was that I needed to control my emotions and my mind because when your mind goes, everything else goes thereafter. A lot of my energy went into conserving energy, and that's where I am right now even though we've had the pandemic for more than a year. I'm still very much in 'conserve your energy' [mode], which means, try to limit anything that would fluster me. Try to limit anything that would spike worry because for me, if any of those two things spike, then the next thing to spike would be the blood pressure.”*

Social support: *“The only thing I was able to do was just call my family.”*

Religion and Faith: *“But at the same time, I'm a godly man. So, I try to be positive. Speak to your higher power about it and just move on.”*

Reframing their thoughts and drawing on acceptance, contentment and gratitude:

Reframing: *“I've had to literally focus my thoughts to not let it run wild because you are seeing something else in the present and you want to remain as optimistic and reframe as best as possible. But that has been a challenge.”*

Acceptance: *“I have to live with it because it's already there. There is nothing I can do about that. During the pandemic, because of the lockdown you can't get certain things. You have to always be on top of the ball.”*

Contentment: *“I don't need much. I satisfy because I was raised with my grandmother and she told me, 'Take little and live long.’”*

Positive thinking: *“But sometimes you have to think the positive and not the negative.”*

Gratitude: *“You have people that have it worse than me. So, I should be at least thankful enough to be okay in the situation.”*

Gender, NCDs and the Pandemic: Coping and Resilience



Applying a gender lens to coping and resilience, before and during the pandemic, it did appear that men were more likely to worry less about their illness and the pandemic, and therefore they appeared to be coping better and presented themselves as more resilient compared to female participants. However, this could be due to the low rate of help-seeking often seen in Caribbean men; perhaps some men were internalising their concerns and not addressing important issues like how they were feeling about their health.



Policymaker View

“The way our Caribbean male has been raised to sort of endure pain, to not cry, to ‘man up,’ so to speak. I think that has done untold damage to the way in which we approach care as males, as Caribbean males.” – Policymaker in the healthcare field

Women are expected to play multiple roles in society much more so than men, causing women, justifiably, to feel overwhelmed. Their NCD compounded the stress that they are under and the pandemic further worsened this stress.

“

The stress and anxiety, it didn’t change. They were compounded [by the pandemic].” – Female participant

We did find that older women seemed to be coping better and appeared to be more resilient than younger women; this seemed to be due to the reasons explained previously (age, experience and being at a stage in life where they have fewer commitments).

“

I don’t have an issue. I thank God for life. I don’t really have any issue. It’s just okay for me. I don’t have any complaints or anything. I’m just a cool-going girl. I don’t let anything trouble me... [It’s] age and experience, and I get good teaching when I was small.” – Older female participant

3.4.7 Pre-Pandemic NCD Self-Management: Regular Monitoring and Medical Check-ups

Finally, when it comes to the self-management techniques of regular monitoring and medical check-ups, some participants explained that before the pandemic they regularly saw their doctor, or if they had diabetes and/or hypertension, they attended the Diabetes and Hypertension Clinic at the community health centres.

“

I do regular check-ups once a year where they send you to do the tests, and that’s about it.”

“

I go to the clinic every month.”

“

I see my doctor once or twice a year.”

At their appointments, patients received a full health review and their doctor arranged all the necessary tests to determine the status of their NCD.

“

Every six months the doctor would send me to have like my EKG and the whole full blood work to make sure everything—my organs— [is] good: my kidneys, my liver, stuff like that.”

In between appointments, some participants monitored their own condition by measuring their blood pressure and glucose levels.

“

I try to check regular. The pressure is good. The sugar is being good. Everything is good. The only thing I can't check on my own is the cholesterol.”

“

We bought the monitor and we keep checking to make sure it's normal.”

“

I always check my sugar first thing in the morning before I eat.”

“

Because I have a machine at home, I was able to keep on top of it, do my own checks.”

When it comes to challenges associated with monitoring and medical check-ups, some participants highlighted that time and cost were challenges. For example, with regards to the cost, one participant explained, “I supposed to have done gone for the next check-up, but the money not there,” and when it comes to finding the time, another participant stated the following:

“

I had lapsed on it for a while through the job that I do because every first Monday it's clinic. Then sometimes it's me alone working, and by the time I get settled, it's 12 o'clock. I just committed myself, from now, every month, I will try to attend the clinic as much as possible.”

Additionally, another issue that created a barrier to making regular appointments with their doctor was the fear of what the doctor might say about their NCD. For some participants, all these issues meant that they only visited their doctor when something serious occurred:

“

But you know, we only go doctor if something happens to us.”

Furthermore, with St. Kitts and Nevis being a small country, the issue of privacy was raised:

“

A lot of people don't use [the health centres] because they think that they don't have any privacy.”

Finally, the need to constantly monitor their NCD did affect some participants' mental health as, depending on what their results were, this could affect their mood and emotions.

“ Sometimes I just don't want to know if it's high. If it's low, then I'll be in a good mood, but if it's high, it's on your mind.”

Gender and Medical Check-ups



Several participants, both male and female, explained that men were less likely to keep up with their medical check-ups.

“ You know some men don't really like doctors. They got to be very sick to go. They don't want to hear like oh you have this, you have that.” – Female participant

“ I think we as women, we're more open to going to the doctor as soon as anything happens to us compar[ed] to our male counterparts. They hate doctors, and when they do get to the doctor, it's too late for them.” – Female participant

“ Well, majority of men mostly, only when something happens to them, they rush to go to the doctor.” – Male participant

“ It's a man that don't go doctor unless I feel sick.” – Male participant



Policymaker View

“I've always found that males are a lot more reluctant to seek help. So, you usually find when you do intervene when it comes to a male with an NCD, it is usually from the standpoint of curative thing. There's already a disease process that already set in, versus females who, I think, you have more time to actually adopt preventative measures in females.” – Policymaker in the healthcare field

When we explored men's low rate of help-seeking, some of the reasons that emerged for their reduced likelihood of having regular check-ups included:

The perceived motivation of their doctor

“ I am not certain whether that has to do with a genuine wanting to see me so that they could make a hundred dollars or he's genuine in that I really should come and see him so that he can have a look at me; I see that as a ploy to get you back in the office so that you can pay one hundred dollars for a visit.”

“ When you look at it, sometimes when you go to the doctor, the doctor set you up.”

Not seeing the need to visit their doctor

“ I don’t see it as necessary because I have the apparatus he has. I’m speaking about that gadget that takes your vital signs. I have one at home, so why go and see him when I could strap up myself daily and know what’s going on and can monitor myself? I do monitor myself daily.”

“ Well, I was supposed to go last month, but I felt good. So, I didn’t go anywhere. I know I have to go.”

Preferring to manage their own health

“ Well, I’m supposed to be taking a regular check-up, but sometimes it just slips me, and I just do my thing.”

The Impact of the Pandemic on Regular Monitoring and Medical Check-ups

Throughout the pandemic, several participants explained that they still tried to maintain some type of contact with their doctor so that they could monitor their NCD.

“ I was visiting the doctor to check up on the pressure.”

Some doctors were very proactive and made themselves readily available to their patients. For example, one elderly participant explained that her doctor contacted her regularly to ensure that she was able to manage her NCD, especially during the 24-hour curfew periods.

“ And I must say, my doctor, he checked on me quite regularly. Well, he would ring and he would come. He always said, ‘If you feel anything or you have any problem, just call and I will come and see you.’”

The most difficult period was during the 24-hour lockdown periods which created some anxiety for patients.

“ Then I might create scenarios: ‘Well, if it got really high, I couldn’t access the care that I would want to have because my doctor is on lockdown as well.’”

Others explained that they had a good relationship with their doctor and were reassured by the fact that the nature of their relationship meant that they could reach out to their doctor at any time if they needed any medical advice or support.

“ I have good relationships with my doctors. So, yes, I can call them. I can pick up my phone and ask a question.”

“ I have a good relationship with my doctors and my caregivers in my community, so I don’t ever have a problem or issue.”

Outside of the 24-hour lockdown periods, to protect their health, some participants continued to stay at home and stayed away from what they deemed to be high-risk areas, and that included their doctors' offices.

“

No, [I didn't visit my doctor], I just kind of kept at home and everything like that.”

There were participants who before the pandemic either did not have a regular doctor or who did not regularly visit their doctor and would have benefited from being under a doctor's care. This is because the pandemic either exacerbated their health condition, they had a challenge during the pandemic, or when they eventually saw their doctor their medication needed changing.

“

No. I didn't want to go to the doctor for him to tell me it's high. Maybe I should have because then he had to change like one of the medications.”

“

I realised that my doctor would prefer if I come and see him more often.”

Additionally, some participants were at a disadvantage during the pandemic because St. Kitts and Nevis lacks the specialist care that they need and due to border closures they were not able to travel to access this care.

“

I don't have a specialist doctor here to talk to and to help me go through the pandemic. My normal doctor, I would say he isn't giving me that much advice. If it were a specialist, he would have been able to give me better advice.”

“

I was to go back to St. Lucia to visit my specialist, and I was supposed to go to either Jamaica or Barbados to visit another specialist but because of the pandemic I didn't get to go, so I had to miss my appointments.”

Participants who attended the Diabetes and Hypertension Clinic before the pandemic for the most part continued to regularly attend and thus visit the community doctor and still get regular check-ups. Additionally, the clinic was a good source for COVID-19 related information and participants reported being provided with guidance on how to keep safe during the pandemic, prepare for the lockdown and successfully manage their NCD throughout the pandemic.

“

Yes, when you go to the health centres, the nurses explain things to you. They tell you different things. Even if you don't want to ask, they will ask you how you're coping and so forth.”

Gender and Regular NCD Monitoring and Check-ups



The pandemic with all its restrictions on movement and activities added an additional help-seeking barrier for men who were already hesitant to visit their doctor.

Additionally, female participants with particular types of NCDs such as hormonal and auto-immune conditions that required specialist care overseas were at a disadvantage because borders were closed.

3.5. Impact and Challenges of Living with an NCD: The Picture Before and During the Pandemic

Another theme that emerged from this study was the overall impact of living with an NCD and the challenges associated with living with these chronic health conditions. When exploring the areas within which NCDs impact a person's life, the following arose:

- Mental and physical health
- Relationships and social connection
- Work and finances
- Daily activities

In this section, we will look at each of these areas and explore whether the pandemic exacerbated or attenuated these effects.

3.5.1. NCDs and Mental Health

Participants explained that before the pandemic there was already a certain level of fear and anxiety associated with living with an NCD. One participant described the source of their anxiety below:

“

I was to go back to St. Lucia to visit my specialist, and I was supposed to go to either Jamaica or Barbados to visit another specialist but because of the pandemic I didn't get to go, so I had to miss my appointments.”

Several participants expressed that some of their anxiety and fear was a result of feeling that their NCD may result in their premature death.

“

Okay, I'm going to die from this thing. I'm just going to drop dead one day.”

“

Well, sometimes I feel like I'm leaving them. Yes, like going on to the glory land.”

“

You know basically in the future it might take you down.”

“

It's frightening because when you come through, you realise you could have been gone if nobody was around.”

Additionally, other sources of anxiety, fear and discomfort included concerns about developing complications, uncertainty about their NCD and their future, and the impact of their NCD on their physical health, families (particularly children), income, career and working life.

“

I think a huge mental health one is anxiety. Even if you don't want to think about it, I literally went to a period like, why isn't my body working? What is up with my body? There is that anxiety about 'Will it ever work as it used to?' That's a huge thing to process. So, for me, it manifested itself in anxiety.”

Furthermore, for some people there was a sense of shock and disbelief at being diagnosed and a significant period of time was needed to fully accept that they now had to live with an incurable condition.

“

So, it was a surprise, and it was a kind of shock. I just think it was such a shock.”



Policymaker View

“We are mindful that other conditions – diabetes, hypertension, cancer, you name them, they can affect the person’s mental wellbeing. However, we decided to narrow our focus more on mental health [in general].” – Policymaker in the healthcare field

The Pandemic, NCDs and Mental Health

Some participants explained that the pandemic exacerbated the stress and anxiety of living with an NCD

“

The stress and anxiety — it didn’t change. They were compounded.”

The main pandemic-related factors that affected participants’ mental health included:

- Their **increased risk** of developing COVID-19 and of developing severe COVID-19

“

Frightening because you have to make sure you follow all the protocols so that you don’t become sick or sicker because you’re sick already. So, you don’t want to add another disease upon what you have already.”

“

Well, to be honest, at first, I was kind of scared because they were saying persons with diabetes and hypertension have a greater risk of catching it.”

“

Honestly, I was worried. One, knowing that I had a respiratory problem. Now realising they’re telling you, that’s how it starts. It affects you most through your respiratory organs and you can’t breathe. It was scary.”

- Concern about the impact of **pandemic-related stress** on their NCD and health

“

Everything that causes me more stress makes me think I have to remember to take better care of myself because I have something [hypertension] where stress may kill me.”

- The **uncertainty** about COVID-19 and the future

“After the three-month period passed, then there was really an increased sense of uncertainty and just recognising that I would have to figure out a way to calm myself because this thing might be around for a while.”

“Well, the whole nature of the arrival of the pandemic meant that there was a lot of unknowns, followed by a lot of fears, followed by lots of information around the pandemic that said that if you had hypertension, you were at a higher risk with certain challenges.”

“It was just a little frustrating because you don’t know who has what, where to go, how to turn, and try have different things.”

- Pandemic-related **job, business and income losses**

“It reduced business which meant we had to reduce staff. We reduced staff, and the staff that were there weren’t ideal. So, it was more stressful. So, yes, that’s the pandemic fault too.”

“Yes, it affected me mentally because the fact that I’m not working, and I have to now depend on my kids... is the hardest thing.”

- The **loneliness** created by the lockdown and other restrictions on movement

“I would say I was kind of sad. I wasn’t getting to talk to people. I had to stay where I was, and I couldn’t talk to anybody. I felt like in isolation, like I was in a kind of jail. Nobody to talk to.”

“There were times when I said, ‘I wish this thing would just go away’ so that somebody could come and see me.”

- The **sadness/depression** created by the effect of the pandemic on society, locally and internationally

“I was almost going into a depression. It’s not just from St. Kitts point of view, [but] the whole world. You can’t travel. You travel; you got to be quarantined. The whole thing. It was getting to me. It’s how it was affecting my mind. Not only from that point; economically, you realise a lot of people are out of a job. People begging. People robbing. Look how it’s affecting the society in the world. You’re hearing so many things, domestic violence. So many things you hear coming from this thing and you realise, ‘Boy, it’s affecting people.’ I said, ‘Boy, no, this ain’t me.’ I had to get out of it. Yes, I kick myself out of it. It’s the first time. I’ve never experienced anything [the depression] like that.”

- Grave **concern about family members**, particularly parents/grandparents worrying about their children/grandchildren

“

I say, ‘Lord Jesus, I hope she don’t contact with nobody out there because I don’t know how I would deal with the three of them here.’”see me.”

“

As soon as I read it, I dialled him. I said, ‘Boy, where are you?’ He said, ‘Mommy, I not there.’ I said, ‘Okay.’ I was frightened because I know I can’t take on anything right now. I want everything to remain smooth.”

- Having to **manage serious personal challenges** during the pandemic. These included challenges such as divorce, surgery, studying and caring for a terminally-ill family member.

“

Then I had the uncanny situation of being in the middle of an academic program while we were in the lockdown in the thrust of the pandemic. So, I was just stirred beyond any kind of stirring.”

Conversely, as explained in the self-care section, some participants explained that aspects of the pandemic had a positive impact on their mental health. In some cases, the 24-hour lockdown, the restrictions on movement and the slowing down of society provided some participants with the opportunity to rest, spend time with family, explore new hobbies and recuperate from the physical and mental toll of their busy schedules.

NCDs, Mental Health and Gender



Some of the factors that affect the mental health of people living with NCDs are connected to gender identity and gendered roles. For example, for men, some of the anxiety and fear created by their condition was related to the pressure of being the breadwinner of the family and their NCD affecting their ability to provide for their families:

“

I have always been the man of the family. When I say that, I did everything, basically, in terms of providing the finances. Everything kind of revolves around me.”

Additionally, some men had to come to terms with how having an NCD would impact their identity as a man.

“

It used to feel funny. You’re a young man coming up and everybody telling you about what your future life will be like, so it kind of messes with your head a lot. As a young man, it messes with your head a lot.”

Meanwhile, for women with younger children, there was a lot of concern about their children and a heightened state of worry about their premature deaths and leaving their children behind at a time when they most needed their mothers.

“

But sometimes when I think about it, I think about my daughter and so forth. Sometimes I think, ‘What if I have to depart, leave her young?’ I would like to see her reach at least the age of adulthood because I don’t want to depart and then somebody’s here knocking her about and so.”

“

Well, sometimes I feel like I'm leaving them. Yes, like going on to the glory land. Yes, and I really and truly don't want to do that, leave my daughter.”

Also, as mentioned previously, working mothers in particular – because of the multiple roles they had to fill whilst still managing an NCD – were exposed to more stress, and this stress would leave them feeling anxious, overwhelmed and fatigued.

The Pandemic, NCDs, Mental Health and Gender



When we look at the pandemic and the gender-related impact on mental health, we see that for some men the pressure from being the breadwinner was amplified. The pandemic created extra anxiety and pressure due to the reduction in income created by business and border closures.

“

Once the pandemic came on, everything was difficult. We were not making the kind of monies that we normally make so that in itself might have put some mental stress on me.” – Participant working in the tourism industry

For some women, we see that the multiple roles that they played prior to the pandemic increased significantly because of the pandemic and they had to balance even more responsibilities. This exposed them to even more stress and anxiety. Women acquired additional caregiving roles during the pandemic. For example, some of them had to care for elderly parents because their paid caregivers' movements were restricted.

“

In March all of a sudden, we have a pandemic, and [the paid caregiver] can't come anymore. Then we never saw her again. That was stressful. The pandemic turned me into a caregiver. It wasn't

Women also had more childcare responsibilities because their children were spending more time at home. Some women were separated from and received less assistance with childcare from family members who had previously provided this support.

“

Lord, [it was] stressful. Because I'm a single parent. Was me and she alone. Sometimes I used to feel frustrated, but I just used to ask God for forgiveness and move right

While at home with children, women had to assist with homeschooling whilst also working and managing their NCD.

Finally, women expressed a significant amount of concern for their children during the pandemic, and furthermore, our data highlighted that women shouldered a lot of the burden of any challenging circumstances that arose during the pandemic such as deaths in the family, unwell family members, studying, the fallout of a divorce, etc.

“

Mind you, there would have been some stress once we knew daddy was sick anyway. There would have been stress: my father-in-law had a stroke. There would have been stress: poor staffing. Yes, all those things would have still been stressful, but yes, the pandemic made them that much worse.” – Female participant

3.5.2. NCDs and Physical Health

Participants highlighted that living with an NCD presented several physical challenges related to the symptoms and nature of their condition. This included pain, breathlessness, limited vision, limited mobility, speech problems, loss of consciousness, menstrual issues and a wide range of other physical health challenges, and these issues then impacted all other aspects of their lives.

“

I have breathing challenges; when you cannot breathe, that is something else. It's just like the world crumble down on you.” – Symptomatic participant

“

It's like it's affecting all the joints in your body especially if you don't take your medication. If you don't take your medication, you'll feel all kinds of pain. You get sore on your foot and things like that. it's a hard, hard thing to deal with.” – Symptomatic participant

Conversely, a significant number of participants experienced no physical symptoms.

“

You don't even realise that you have hypertension. I don't suffer with any headaches or anything like that.” – Asymptomatic participant

“

It was going all right. I didn't have no problem.” – Asymptomatic participant

The Pandemic, NCDs and Physical Health

Looking at the impact that the pandemic has had on respondents' physical health, participants highlighted that they felt that the stress of the pandemic triggered physical symptoms, some of which they had never experienced before. This included:

- **Exacerbating hypertension**

“

I feel like it created many spikes in my blood pressure.” – Participant with hypertension

- **A mild stroke**

“

As to what was the cause of that mild stroke, I can put it down to two things: maybe stress from the situation, the pandemic and what we were going through and drinking.” – Participant with hypertension

- **Asthma attack**

“

Well, sometimes it [the lockdown] would trigger it [asthma] off because you're there thinking, I can't go outside or go anywhere or talk to anybody. It's just like I'm in there panicking.” – Participant with chronic respiratory condition

- Acne

“

“During the pandemic, I broke out with hormonal acne. I think it was a combination of pandemic stress, work stress, staying at home. All of the things to send your hormones crazy. But for the first time in my thirties, I had acne. I couldn’t understand this. Obviously, everyone is stressed from this pandemic, and it has affected us all, but I saw it physically on my face. When I saw it on my face, I freaked out more.” – Participant with a chronic hormonal reproductive condition

Additionally, as explained previously, the change in lifestyle due to the pandemic (diet, exercise, etc.) physically impacted some participants. Depending on the lifestyle change, whether it was an improvement or worsening of their lifestyle (i.e., healthier or unhealthier habits), this led to an exacerbation or an alleviation of NCD symptoms.

NCDs, Physical Health and Gender

There were certain complications of NCDs that affected patients’ physical health which were related to biological sex, some of which were very sensitive reproductive and sexual health issues. For example, prostate issues for prostate conditions, menstrual health and fertility challenges for women with gynaecological conditions and an increased risk of developing vulvovaginal candidiasis for diabetic women were some of the complications highlighted.

“

Facial hair, painful periods.” – Female participant

“

The prostate. When you think about prostate for men, urinary—you cannot pass your urine.” – Male participant

“

As a woman, you end up with thrush easily, vaginal thrush. Everything gives you vaginal thrush once you get diabetes.” – Female

All of these sexual and reproductive health issues can then put a strain on intimate relationships and can also be difficult to discuss with family members, friends and even healthcare professionals. They can therefore remain unaddressed, leaving patients feeling isolated.

“

So, I didn’t know who to turn to in terms of just getting that nutrition or education for it. It was lonely and it was very overwhelming.” – Female participant

When we look at gender-related physical NCD symptoms that created challenges for participants during the pandemic during the 24-hour lockdown period, two female participants experienced serious, debilitating physical symptoms. One participant had an auto-immune condition that affects mainly women. During the lockdown, this participant experienced a serious bout of pain.

“

I was feeling a lot of pain. I had like joint pain, couldn’t move. I had basically all the symptoms that I normally have, so I had to call my doctor.”

The second participant had a chronic hormonal reproductive health issue and during the 24-hour lockdown experienced severe pelvic pain as well as spotting, symptoms she had never experienced before.

“

I had episodes of intense pelvic pains. It scared me because it wasn't PMS. It wasn't my period. It was outside of that window. Then for the first time during this pandemic, I began spotting. I'm like, 'What is this? This has never happened to me.' The pelvic pains were intense. I didn't know what that meant.”

It was recognised that because people were spending more time at home some of these sensitive reproductive health issues which may have been hidden from family members and not discussed would inevitably surface and there needed to be support for family members to have these discussions in a sensitive way.

“

That would have not necessarily been a bad thing because those briefings were... I mean, the whole population seem to have hung on to every word. It would have been good for some men to understand that menstruation is a problem. Can you imagine living with a PMS sufferer? It probably would lead to a bout of anxiety.”

3.5.3. NCDs, Work and Finances

NCDs and the work environment appeared to have a cyclical connection where the symptoms of participants' NCDs affected their ability to either attend work or to fulfil their work obligations if they did attend work. This created some stress and tension in the workplace due to misunderstanding and lack of empathy. Further, independent work-related stress (workload, deadlines, long working hours, etc.) exacerbated NCD symptoms.

“

Sometimes I'll have my bad days where I won't be able to work. Some days I could work. So, I would have my good days where I could work and other days, I won't be able to work.”

“

I had to stop working because it was something I had to deal with on a day-to-day basis, so it prevented me from going to doing my daily work.”

“

My livelihood was driving. So, I could no longer do the driving part of the work. My work was restricted to just giving narrations. So, that was difficult for me.”

“

Sometimes when you're working and so, it'd be a lot stressful.”

“

The only thing I've been going through is that I've been getting sick on a regular basis where I have to be on various sick leaves. Sometimes when I reach[ed] out to certain people like to tell them how I feel, they didn't believe me. They feel like I'm just faking sick and stuff.”

An important point that some participants raised was the lack of support and empathy from their employers.

“

I have to work, people wouldn't want me to miss work a lot. So, it's kind of difficult for me.”

“

They would tell you plain up, that's your personal issue. That has nothing to with them. That's what happens in these Caribbean islands. The employers don't ever put things in place for the employee when it comes to health and wellness and stuff like that. They can because they have the means to.”

“

At least show me you care because, at the end of the day, it's your work I'm doing, regardless of if you're paying me.”

Living with an NCD also significantly impacted individuals' finances. Healthcare costs placed a significant burden especially on participants who were on a low income. The NCD-related costs included medications (as discussed previously), doctor's appointments and medical procedures.

“

It's hard. I got a hospital bill here to pay – a thousand something. I'll have to pay a thousand nine (\$1900). I don't know where I going to get money to pay it. Being in the hospital, and I don't have money to pay my hospital bill, and doctor fee and things like that.”

“

It took, what, how much? It took 20 something—I think 20 thousand dollars.”

Persons on a low income found it hard to meet all their financial obligations and also cover the costs associated with managing an NCD (healthy diet, medication, etc.)

“

Every week, I get \$200. I have to give him [the landlord] one. So, that only leaves me back with one. Then I have to make sure the children have stuff and everything. Right now, it's kind of frustrating because, to be honest right now, nothing's really in here to eat like that.”

A final point related to finances was that some persons with NCDs had to stop working and this reduction in income was challenging.

“

I had to stop working. After six months you would not receive a salary from your job, so you had to be placed on invalidity. So, it was kind of a challenge economically, financially.”

The Pandemic, NCDs and Work

When we explored the impact of the pandemic on the working life of people living with the NCDs, the following themes emerged:

- **Pandemic-related unemployment (permanent and temporary)** – Several participants worked in the hospitality industry and with the closure of this industry, they lost their jobs and thus their only source of income.

“

I haven't worked since March last year when the pandemic closed down the hotel industry.”

Participants working in other industries temporarily lost their jobs due to lockdowns, border closures and restrictions on movement which meant there was little or no business activity.

“

I wasn't working for maybe about two and a half months.”

- **Business Closures/Reduction in Business Income** – Business owners experienced significant reductions in income which meant they had to close their businesses permanently or temporarily and this also meant making the difficult decision to let some of their staff go.

“

It reduced business which meant we had to reduce staff. We reduced staff, and the staff that were there weren't ideal. So, it was more stressful. So, yes, that's the pandemic fault too.”

“

So, when the country closed in March, my business closed as well, and because of the nature of my business, it has remained temporarily closed. So, that has definitely depleted resources.”

“

Once the pandemic came on, everything was difficult. We were not making the kind of monies that we normally make so that in itself might have put some mental stress on me.”

- **Workplace vaccination mandates** – Many workplaces introduced a mandatory vaccination policy and this was a concern to some participants particularly those with compromised immune systems who could not take the COVID-19 vaccine.

“

That is not right. They're not thinking about people who have a severe immune condition like me.”

Additionally, in some companies, unvaccinated employees were relieved of their duties and one participant explained that this increased the workload of the remaining staff. This participant explains the impact of this below, and since stress is a trigger for many NCD symptoms, this has had a negative impact on this participant's NCD.

“

Right now it's stressful. They're laying off people who aren't taking the vaccine. Then who's there working feeling the strain because they have to do everybody else work. The work stressful, you're hypertensive.”

- **Remote working** – Some participants who remained in employment during the pandemic were able to work from home. This was a good option as it allowed employees to retain their jobs and it proved to be a more relaxing way of working in what has been a very stressful period; this was of benefit to persons with NCDs.

“

I had to work from home, but then, it wasn't as bad. It's more calming.”

Working from home did pose some challenges which did create some anxiety. The challenges raised by participants included:

- Having to balance working from home with homeschooling children
- Poor implementation of remote working by employers. This included not providing staff with adequate tools and resources to work from home, not compensating employees for additional utility costs incurred by working from home, lack of adequate training to transition to online/remote working and failing to understand the demands on parents.
- **Reduction in Wages** – To keep businesses running, some employers decided to reduce the wages of their staff. This was very difficult for participants especially those who were already on a low income.

“

The pandemic started in late March like the ending of March. April, maybe, we were home. May, they do everything. But that's when they cut the pay. Bad because I mean, you done don't get anything and then to see them cut what you don't get. I mean, you have responsibilities and all that.”

- **Employers' Response to the Pandemic** – Before the pandemic, some participants expressed that there was a lack of compassion and understanding from their employer when it came to their NCD and that the pandemic further revealed that more attention is required from some employers to the wellbeing of their staff. Participants spoke about the lack of care and concern about staff even during the pandemic despite having worked with organisations for a significant period of time.

“

My boss has never, or nobody, until this very day ask me, 'How you do?'"

“

They don't care.”

Participants also highlighted the lack of communication and transparency when important decisions were made that directly impacted them. These included decisions about vaccines, pay cuts, lay-offs and the introduction of COVID-19 protocols. This lack of communication and transparency meant participants could not mentally and practically prepare when policies were introduced.

“

“[They just] send a memo saying, 'This is what we're going to do.'”

“

They hadn't communicated with anybody. They called a meeting. We went in; they gave us a letter to take to the labour office that would enable us to get our redundancy. Outside of that, it wasn't x, y, z, nothing at all.”

“

I mean, you have to think about people in the long run. You can't just do things drastically. It affects us.”

- **Essential Workers** – One participant who worked in the essential services described how assisting to keep the country running was physically and mentally challenging particularly when living with an NCD.

“

I was out all the time, and it took a lot out of us. People don't know what it takes. There are times when everybody lock down, we have to be in the mountain.”

All of the previously mentioned work-related issues had an impact on participants' health, primarily due to the stress and anxiety created by these pandemic-related work challenges. These issues contributed to the exacerbation of the physical symptoms described in the previous section – increased blood pressure, mild stroke, etc. – and also affected participants' mental health.

Additionally, the loss of income created significant financial challenges for some participants.

“

It [the pandemic] left me without a job, financially broke. Then after the job finished, the savings that I had for about a year depleted just like that because it had everything attached to it. So, I don't have a savings account anymore.”

“

Well, when I was not working, the bills started rolling in. I wasn't working for maybe about two and a half months.”

“

Once the pandemic came along, I was not able to provide for my family like I used to because obviously, the funds are not coming in. What you had there on savings are depleted because having to go more than a year without making monies, it just puts a different spin on things.”

This financial vulnerability then meant some participants could not afford to implement self-management techniques such as healthy eating, medication management, treatment and attending regular doctor's appointments.

“

Well, as I said, the biggest challenge for me is the bills. I got to find that money to pay the hospital bill because I don't want when I get sick again, I can't go back to the hospital.”

“

You can't afford to be buying these medications because it adds up. If you have to check up for whole year times 12, the amount, it adds up.”

NCDs, Work, Finances and Gender



When applying a gender lens to the impact that living with an NCD has on work, career and participants' professions, we identified that the physical nature of the roles that some men hold in their workplaces was a concern with diabetics. This is because such jobs can increase workers' risks of developing diabetic wounds and ulcers which could lead to serious complications like amputations.

“

You have to be careful in terms of getting cut, nail dig. My work still surrounds a lot of these things, so it slows you down. It makes you think a lot when you're working.” – Male participant with diabetes

During the pandemic, we see that the issue around men and the physical nature of their jobs was compounded by whether men were in roles considered to be essential. One participant explained that, as an essential worker, the demands of his job increased during the pandemic, further increasing the risk of a diabetic injury, and this “took a lot out of [them].” And, as mentioned previously, the significant disruption to his normal routine negatively affected the self-management of his NCD. Additionally, men in manual jobs could not work from home and thus were unable to retain their jobs. This had a significant effect on their identity as the family breadwinner, and was concerning since NCDs can be exacerbated by the stress of financial challenges.



Policymaker View

“If you're speaking about one of the measures that you're taking is remote work, the construction worker cannot work remotely. The guy who is doing landscaping can't work remotely. The guy that's a truck driver cannot work remotely. That person, when they go home, they're out of a job and a pay cheque with a family to feed. But the receptionist can. The person that's an office clerk, an executive assistant can do those things. So, that I think created a real disparity.

It was really taking away a man from his very traditional [breadwinning] role. For men, I found they were a lot more reluctant to simply just go home and hunker down. They felt like they had to protect their kid. They had to provide, and their skillset was one that was purely manual. It's not knowledge-based. Therefore, it's not something that can be transferred online.” – Policymaker in the healthcare field

With regards to women, NCDs and the work environment, some auto-immune conditions are significantly more common in women (9 out of 10 people affected by the auto-immune condition discussed in this study are women³) and fluorescent lights in offices can exacerbate this

“

It [causes] flare-ups [on] the skin. Yes, sun and fluorescent light.” – Female participant with an autoimmune condition

Additionally, several single mothers raised the challenge of balancing work, caring for their children and managing their NCD.

“

When I finish working, I have to come home, prep something for the children. So then, by the time I get to finish, I'm over exhausted. I used to go walking some of the times but...” — Female participant

With regards to the pandemic, women continued to have to balance the demands of working from home with their multiple other roles, including additional roles such as caregiving for elderly parents or grandchildren and homeschooling children. In some cases, women benefited from the pandemic and restrictions on movement as it meant they could work at a slower pace and this alleviated some of their work-related stress and thus enabled better management of their NCD.

Another theme that emerged centred on older women who had lost their jobs because of the pandemic. One participant described encountering gender discrimination when seeking a new job, explaining that there was less opportunity for older women in the job market compared to men of a similar age and experience.

“

Less opportunity. For instance, I haven't worked since March last year. I have since sent out some applications, and I'm wondering if my age has to do with it because some of the responses I get is that they don't see me growing with the company. I guess because of my age. Yet, the same men in my age group are finding work to do.”

Not being able to find employment affected this participant's mental health and this was compounded by the feeling that this was a result of her gender. Additionally, it has made her financially vulnerable, much more so than her male counterparts.

“

It's hard for me because from an early age of 10, all I know is hard work. It's really hard just sitting around doing nothing. It doesn't resonate well with me. Women on a whole seems to be taking the backburner to a lot of things, and it's people in my age bracket. So, it's very hard. It left me without a job, financially broke. That's it.”

From this experience we see that where age, unemployment and gender intersect, NCD self-management – which is reliant on consistent income – may be more challenging for older women who experience greater challenges finding gainful employment.

Finally, when looking at finances, our study suggests that single mothers living with an NCD were the most financially vulnerable. They tended to be on a low income and had numerous financial obligations such as household bills and expenses and costs related to raising children. When you factor in the cost of NCD treatment, care and management this exacerbated their financial vulnerability.

“

I don't have money to pay my hospital bill and doctor fee and things like that. Well, I supposed to have done gone for the next check-up, but the money not there because I still have two small children. It's hard. It's really hard.” — Female participant

3.5.4. NCDs, Relationships and Social Connection

Some participants explained that living with an NCD has had an impact on their relationships. Firstly, living with an NCD impacted intimate relationships.

“

... sometimes you don't want to be in a relationship. I don't know if it's your emotions change when you get this condition or if it is just a mind thing. I don't know. I'm yet to find out. I don't have an issue with snapping at people or anything like that. But that sexual thing, yes. They don't understand.”

“

It affected my relationship. We broke up because he couldn't deal with me trying to process this condition. The possibility of not having a child. He was head-on for marriage and having a family, and at that time I interpreted this condition as 'Oh my goodness, you will not be able to get children,' all the painful things.”

Additionally, family members had to play a caregiving role and look after participants and this was a change in the dynamic of the relationship which took some adjusting to, and at times could be traumatic when medical emergencies occurred. Thus, their NCD also affected the wellbeing of their family members.

“

There's the little one that says, 'Granny, you don't take your tablets.'

“

She heard, like, breathing hard. I was gasping for something because my sugar was going down. She fly down in my room and she called quick the ambulance and everybody. She saved my life. I always tell her I owe it to her. She saved my life about three times.”

“

My son came, and he went to the hospital with me because I couldn't walk. That is how bad it was. I couldn't walk, so he came in. He said he never heard about it. He's only heard people say how dangerous it is.”

“

It affect them bad because I had to be in the hospital and it's like nobody's there to watch them, and it affected them.”



Policymaker View

“Some persons maybe now require more care especially, for example, persons who may be terminally ill from cancer, or persons who require daily insulin shots for diabetes and [may] not be able to administer them themselves. So, that's where I will say that strain on the family support would be.” – Policymaker in the healthcare field

Another theme that arose was the social isolation that could occur, even before the pandemic, for people living with an NCD. Some participants, due to restrictions on their movement either because of the physical effects of their condition or because their doctor recommended that they no longer drive, found themselves isolated and there was recognition of the importance of having company both from a safety (in case of a medical emergency) and a mental health point of view.

“

I was a bit active doing all kind of things with the church and so on. Since the stroke, I've really not been out much. I have to learn to live with my four walls. Having a computer that I can do things on, I go on there and do a few things myself. Look at TV now and again. Doing crossword puzzles. Keep myself occupied that way. I can now see that there may be a benefit in not being a single person because you're all alone. There's nobody to talk to. There's nobody to share anything with at all. It's just you. I continue to say it's just me and my four walls.”

“

They keep me company. He keeps me company that is very important, somebody to keep you company.”

NCDs, Relationships, Social Connection and Gender



The impact of NCDs on relationships before the pandemic did seem to be more of a concern for women as all the participants who raised the tensions created in their relationships (particularly intimate relationships, but also other relationships) because of their NCD were women. These tensions were related to the pressures placed on women within their relationships and the challenge of fulfilling their expected societal roles when living with an NCD. This included the challenges of meeting fertility, sexual, body image, domestic and professional expectations.

“

Your life didn't stop. He knows that you have an NCD, but he doesn't understand what you're going through.” – Female Participant

“

You don't even know her issue health-wise. You're probably watching a woman gaining weight and thinking she's lazy, she doesn't eat right, when she's probably doing all of the things, but she's struggling with an NCD, and she doesn't know how to say it.” – Female participant

The Pandemic NCDs, Relationships and Social Connection

During the pandemic, some participants expressed that it had a positive effect on their relationships and this stemmed from the fact that participants were able to spend more time with their household members and connect in a way they had not been able to in a long time.

“

COVID-19 meant we got to spend more time together. For that, I'm grateful. If there's a silver lining to anything.”

Others expressed that their household worked really well together in terms of navigating the challenges that the pandemic presented and this created a sense of togetherness, as explained below:

“

Your family divided up the list, gave each person some money and then everybody headed for their assigned shopping spot just to get what you needed. You try to call each other as you go along to communicate what is available, what isn't available.”

Participants also explained that the pandemic brought their community together; their neighbours and friends were checking in on each other more frequently and assisting each other where needed.

“

I had a friend who was a nurse. She told me the days when there were lockdowns, she would come and—well, if I needed anything just call her because she'd be able to come.”

“

There was a sense of gratitude for what you did have and a sense that you need to try to help somebody else.”

“

We try help one another in the village that we live because we're lockdown sometimes the bread van comes. If I have anything, I put them in a bag and I hang it up on the gate. They will see it. They will come take it up. I think we should help one another because we're in it all together.”

The closeness that some participants felt with their family members, friends and community was of immense benefit to participants because this meant they had a network of support they could reach out to during difficult days with their NCDs.

Single participants, especially older single participants, and those participants who did not have friends and family in St. Kitts and Nevis were at a significant disadvantage. They expressed that the restrictions, particularly the 24-hour lockdown, separated them from extended family members and friends, and although they were in contact via phone, this separation was difficult.

“

I would have liked to have my parents around.”

“

There were times when I said, 'I wish this thing would just go away' so that somebody could come and see me.”

“

It was difficult adjusting to not seeing family because one of the huge reasons why I moved back was because of my family so I can visit them. Just drive across and visit them, but I couldn't do that. That was an added stress.”

The Pandemic, NCDs, Relationships, Social Connection and Gender

The issue of the pandemic and relationships seemed to be more important to women than men as more women discussed relationships and the need for emotional connection. Therefore, in this regard, the pandemic was of benefit to women as they appreciated the opportunity to spend more time, especially quality time, with their spouses, children and other household members.

“

My husband was at home. I like staying at home and I like when he's at home, so it was good.” – Female participant

“

They're home with me. We play games. We talk, and that was a good idea because certain things they will talk with you that they never talked about before and experience.” – Female participant

However, women who were single were at a significant disadvantage as described in previous sections and we found that older, retired single women living with an NCD were more vulnerable to isolation.

“

I can now see that there may be a benefit in not being a single person because you're all alone. There's nobody to talk to. There's nobody to share anything with at all. It's just you. I continue to say it's just me and my four walls. Being a single elderly person, it might have been different if you had even another elderly person in the house with you. It doesn't have to be a man. Or you had a niece or a nephew or somebody. You had somebody to interact with.” – 83-year old female with hypertension

“

Only me alone. I live alone.” – 67-year-old female

In our work, single older men did not report being alone or feeling isolated, as those that fit this category were either living with family members or were still working and thus had regular social interaction.

3.5.5. NCDs and Daily Activities

Overall, some participants felt that living with an NCD affected their quality of life and disrupted their daily activities. As mentioned before, others felt that their NCD had not had a significant effect on their quality of life.

“

It slowed down my life a little. It has slowed it down because a lot of what you used to do you know you can't do now.”

“

It keeps you back a lot. Things you could do, you can't do it anymore. You feel uncomfortable.”

It was interesting to note that those who stated that their NCD had not disrupted their daily activities and quality of life tended to be older and retired and were therefore at a stage in their life where they had fewer commitments and responsibilities that could be impacted by their NCD.

“

As I said before to me personally, I don't know if it's because I'm not working; to me, it's not really bothering me that much.” – Retired participant

NCD, Daily Activities and the Pandemic

When we overlay the pandemic on the NCD experience, we see that the pandemic, with all its restrictions, uncertainty and in particular the increased risk it posed to people living with NCDs, further disrupted the lives of some participants. The ways in which their lives were disrupted have been discussed previously, including effects on simple daily tasks like grocery shopping, exercise and eating habits. All of these activities had either a positive or negative impact on persons' NCDs.

The pandemic did force some participants to develop new skills and hobbies which led to some personal development and improvements to their mental health. Additionally, the pandemic transformed how they could engage in certain activities and led people to make better and more use of technology to maintain some sense of normality.

“

So, it opens somebody to try something different like a new hobby. For me, it has made me look into cooking.”

“

I think a benefit for me [was] just home workouts, having those videos online. I followed a few groups that did online exercising over Zoom. That really helped. I wouldn't have thought of that outside of the pandemic, really and truly. I wouldn't have.”

NCDs, Daily Activities and Gender



When looking at daily activities through a gender lens, some women highlighted some of the traditional gender-based activities that were disrupted or impacted because of their NCD. This included activities like cooking, cleaning and looking after their children. This created some anxiety as it meant that if they did not have the support they needed to fulfil these roles, they had to force themselves to complete these tasks and this was physically and mentally draining.

“

Well, I like to turn corn. I like fungi. I can't do it. I like a lot of different cooking, baking and so that I can't do anymore.” – Female participant

“

I couldn't do most of my household chores per se because I was kind of weak and so on.” – Female participant

Some men mentioned activities that could be related to gender roles that were disrupted because of their NCD. This included their ability to drive, as well as physical tasks related to work and recreation that were not mentioned by women. This significantly affected their identity, purpose and livelihood which then had some effect on their mental health.

“

For me personally, once I had the stroke, it meant that I could no longer drive. My livelihood was driving.” – Male participant

Both of the above-mentioned issues were exacerbated by the pandemic and created further anxiety for men and women as it relates to their identity, purpose and ability to carry out important daily tasks.

3.6. Support

Another theme that we explored was whether people living with NCDs felt supported and/or had access to the support and information they needed to manage their NCD before and during the pandemic. Overall, participants reported feeling fairly well-supported before the pandemic and they received wide-ranging support such as practical, medical, moral and financial support from the following sources:

1. The Diabetes and Hypertension Clinic at the health centres

The Diabetes and Hypertension Clinic was a good source of support for persons living with these conditions. Our data suggested that those who attended the clinic were more empowered, were managing their condition well, and were in fairly good health and had good regular access to a doctor who could identify any medical challenges early and address them promptly. Additionally, the Diabetes and Hypertension Clinic was able to provide some emotional support and advise participants on domestic and psycho-social issues, thereby providing a holistic support system for patients.

“

There is a doctor in the community every Thursday. Once a month, they do clinic for diabetics and stuff like that. I do attend. That is how I stay on top of my diabetes and stuff like that. They help me to manage it.”

“

Today, I must say thanks to the clinic because I was very ignorant to diabetes. The information you got from the nurses, the doctors wake me up.”

“

Well, the nurse just encourages me to keep my stress level down. Try to relax. Focus on like the positive things. Eat properly. And she talks to me privately about the situation that I’m currently facing.”

Additionally, during the pandemic the clinic has been a good source of information for COVID-19 related information — participants reported being provided with guidance on how to keep safe during the pandemic, how to prepare for the lockdown and how to successfully manage their NCD throughout the pandemic and vaccination.

One major challenge would be to encourage more participants to access this service. One participant provided a reason for people’s hesitancy to access the Diabetes and Hypertension Clinic:

“

The clinic, a lot of people don’t use it because they think that they don’t have any privacy.”

Another challenge is also organising the clinics at a time that is convenient for those who are working who may not be able to attend during work hours or may not be able to handle the long waiting times.

“

I have the time on my hands, so I don’t mind sitting and waiting for my turn.”

Gender lens



When it comes to the Diabetes and Hypertension Clinic, a participant made the observation that men are less likely to attend the clinic

“

Even coming to the clinic, it’s like you got to preach to men to go and get check up especially when they reach a certain age.” – Male participant

The Diabetes and Hypertension Clinic During the Pandemic

- Good source of evidence-based COVID-19 information
- Provided patients with information on how to keep safe during the pandemic
- Provided evidence-based information on the COVID-19 vaccine
- Provided advice on how patients could prepare for the lockdown
- Provided advice on how to successfully manage during the lockdown
- Free or low-cost access to medical care and medication
- Easily accommodated patients with stocking up on medication during the lockdown

Patient Challenges

- Slight negative public perception of the clinic
- Encouraging more patients to attend
- Accessing services during the 24-hour lockdown

Gender-related issues

- Men are less likely to attend this clinic

2. Doctors

Doctors can also provide a good source of support and information, but due to cost, some patients were not visiting their doctor as regularly as they should. The cost of care was addressed through the establishment of the Diabetes and Hypertension Clinic as through these clinics people with these conditions can see a doctor for free. However, others who do not have these conditions or who do not access this service repeatedly mentioned the cost of attending doctors' appointments.

Gender lens



As mentioned previously, men are less likely to visit their doctor and while the reasons for this were highlighted in a previous section, it is worth repeating that this seemed to be related to a lack of trust in their doctors, not seeing the need to attend so regularly and wanting to manage their own illness. Women, on the other hand, were very open to visiting their doctor, but the key challenge for women was the cost of appointments and finding the time to go.

Another gender-related issue was access to male or female specialists for conditions that were of a more sensitive nature. This affected women living with NCDs in particular as in certain fields of medicine there is an underrepresentation of female doctors.

“

It was a male doctor. I was already scared to go to a male doctor. I literally told my friend like a month ago, 'Okay, I see someone who is new who is a female. I want to try this out.' When I have to do my annual check-ups, I'll definitely go to her.”

Another issue is that, for certain conditions, St. Kitts and Nevis lacks specialists in these areas and this means patients do not have easy access to the medical expertise that they need and have to travel overseas for treatment and care.

“

St. Kitts doesn't have a specialist to help, treat, or prevent problems. So, I think if we get a specialist* doctor, that would be kind of good. That's a very big, big problem in St. Kitts right now. My normal doctor, I would say he isn't giving me that much advice. If it were a specialist* doctor, the specialist* would have been able to give me better advice.”*

“

We don't have any specialists. He referred me to a specialist* in St. Lucia. She did like a proper assessment and she diagnosed me with the same condition* along with something to do with the skin. I can't remember the word.”*

“

In Barbados, I felt really prepared. I trusted my doctor there. I thought that she was super smart, and she broke it down to me so well. When I came back home to St. Kitts I wasn't satisfied, to be honest. He's excellent. Obviously, he's a good doc, but I just feel like he didn't understand my condition. Maybe he's not sensitive because it's maybe such a small group that comes to him on the island at least.”*

Gender lens



The participants who mentioned the issue of the lack of specialists to manage their condition were all women. One participant had a chronic reproductive health issue and the other two had conditions that are more common in women. This suggests that women's health may need some more attention in St. Kitts and Nevis.

Doctor Support During the Pandemic

- Some doctors made themselves very accessible during the pandemic
- Doctors facilitated patients' requests to stock up on medications by fulfilling prescriptions and working with pharmacists to make that process as smooth as possible
- Doctors provided useful advice on COVID-19, vaccination and how to manage NCDs during the pandemic

Patient Challenges

- The cost of care compounded by pandemic-related job losses, lower income and increase in the cost of goods and services
- Gaining access to doctors during the 24-hour lockdown

Gender-related issues

- Men were less likely to visit their doctor
- Lack of specialist doctors for some women's health issues
- Single mothers on a low income were less likely to be able to afford to see a doctor

3. Family and friends

Family and friends were able to provide participants with moral, financial, practical and even medical support as some participants had friends and family working in the medical field.

“

So, the children and the husband would chip in for the different daily chores.”

“

I had a friend who was a nurse and she suggested to me that she can come to my house if I'm more comfortable and do it for me, which she did.”

“

My daughter would be like, 'Mommy, you all right? Mommy, are you feeling well?' Then she would give me water. My mother would be like, 'You need to come go to the hospital. You have your inhaler?'"

“

My sister is a nurse, so she stays on me with it like she's my mother.”

“

She travelled with me. Of course, she made one or two contributions as well.”

Support from family and friends can be particularly helpful for older people, single mothers and those on their own.

“

Only [I] live here. So, he comes by me regular.”

Some participants who were on their own with no family and friends in St. Kitts and Nevis did not have this type of support and they expressed that they felt overwhelmed.

“

I don't really have family here. It's only me—my daughter was in St. Kitts here, and she brought her children. Then she left them here and went back. So she went back, and she left me with them.”

“

Basically, it's just me and my kids. I'm not a Kittitian by birth. So, basically, it's just me and my kids... It's stressful on me. It's very stressful.”

Gender lens



Those who reported being in St. Kitts and Nevis without friends and family were women. This was a gendered phenomenon because our data showed it was women who migrated and their migration was related to marriage and/or childcare. When circumstances changed such as with a divorce or a family emergency in their home country, this unexpectedly created significant socio-economic and personal challenges and because they were not surrounded by their family unit, they lacked a support network. Combined with a pandemic, these changes significantly compounded their challenges.

Friends and Family During the Pandemic

- Excellent source of financial, practical, moral and medical support for people living with NCDs during the pandemic
- Some participants were able to spend more time with family members which improved their mental health
- The pandemic strengthened family togetherness and community cohesion for some

Patient Challenges

- Some families were separated for long periods during the pandemic
- Lack of support for single people living with an NCD during the 24-hour lockdown when medical emergencies arose
- Young children had to deal with the medical emergencies of their parents which could be traumatic

Gender-related issues

- Single women, particularly older women, or those who had migrated to St. Kitts and Nevis for marriage/ childcare reasons were vulnerable to isolation and loneliness

4. Social Security

Social Security was a good source of support for retired participants through its pension scheme. In addition, for participants who were unable to work due to their NCD, Social Security's invalidity benefits scheme was also a good source of support. Participants described the process as fairly straightforward, and appreciated that payments were paid directly into their bank accounts. This was particularly beneficial for those with mobility issues.

Gender lens



When applying a gender lens to this issue, it was highlighted that more women apply for Social Security invalidity benefits than men and this could be due to a combination of issues such as the higher prevalence of some NCDs in women (e.g.,

60% of registered diabetics are women) and the difference in help-seeking behaviour between men and women.



Policymaker View

*“Between January 2021 to May 2021, just for diabetes alone, we had a total of 59 new claims for Social Security. Some between the ages of 25 to 29 and the **heightened cases we are seeing are amongst women.** That may not be because women are not eating more healthily but **maybe it could be because women more often go to the doctor to seek medical attention as opposed to men.**”*

“So, we’re seeing increased numbers and just for that period alone, between January to May 2021, we would have expended EC \$44, 417.53. Mind you, this information is for diabetes only. So, if we could look at other NCDs, you could recognise that the numbers are increasing and it is a tall wage bill.”

– Excerpt from the St. Kitts and Nevis Social Security Board presentation at ‘Living with NCDs: Solutions to Patient Challenges’ webinar, September 11th, 2021

Social Security During the Pandemic

- Seamless, uninterrupted support for those already receiving Social Security benefits before the pandemic
- Good source of support for the elderly, those with a disability and those recovering from treatment and surgery
- COVID-19 relief was helpful to those on a low income

Patient Challenges

- Lack of understanding and transparency around the eligibility criteria for COVID-19 relief
- The perception that patients with NCDs affected by the pandemic (by job losses) did not receive enough financial support through the COVID-19 relief fund

Gender-related issues

- More women with diabetes accessed invalidity benefits during the pandemic

5. Church/religion

Several participants reported turning to religion or their church for support during the difficult times of their condition and this was a good source of comfort and support.

“

God gives me strength.”

“

I take it to the Lord in prayer.”

“

I pray every day. I thank God.”

Church Support During the Pandemic

- Churches checked in on elderly and vulnerable people living with NCDs
- Provided food packages to elderly and vulnerable people living with NCDs
- Transitioned to online services and Bible studies, which provided a sense of normality, spiritual connection and support

Patient Challenges

- Food packages were not always appropriate for NCD patients
- Some participants felt that churches could have done more during the pandemic to support those in need
- Elderly patients were significantly affected by church closures as in-person church services were their main method of social connection
- Those without internet access were unable to access online church services

Gender-related issues

- Gender-specific NCD responses were not part of churches' COVID-19 response strategy
- Churches did not have the capacity to implement gender-specific responses



Policymaker View

“We gave the people a message of hope. In some areas, we were able to hand out to the less fortunate in terms of packages that will help them be able to get a meal to eat. We put a programme, a radio programme in place to speak about healthy lifestyle or like eating healthy from God’s pharmacy. We educate the people about healthy lifestyle because the immune system is your first defense against diseases.” – Policymaker representing faith-based organisations

6. NGOs

Some participants also reached out to local charitable NGOs for support in managing their NCDs. NGOs were able to provide information, guidance, financial support and mental health support.



Yes, they provided a lot of support. Sometimes you have your down days, and you go, and you listen to somebody else’s story.”

NGO Support During the Pandemic

- NGOs provided financial support in the form of food vouchers and food packages and made contributions towards treatment and medication

Patient Challenges

- Finding NGOs who would be able to assist them with their specific NCD
- Some food packages were not appropriate for NCD patients

Gender-related issues

- Gender-specific NCD responses were not part of NGOs’ COVID-19 response strategy
- NGOs did not have the capacity to implement gender-specific responses



Policymaker View

“We have seen somewhat of a steady – let me say steady – to rising increase in requests [for] therapy support or treatment support [since the pandemic]. We have given support in terms of food vouchers. We’ve seen the request for support to get medication. Those persons who would have lost jobs, we would have given them financial support to help a little bit in some way as well.” – Policymaker in the NGO sector

Vulnerable Persons

We did identify specific groups of people living with NCDs who may not be receiving the appropriate amount of support or who could have been or are at risk of not receiving appropriate support both before and during the pandemic. This included:

1. Participants with rarer NCDs or NCDs that did not fall under local, national and regional priorities

When it comes to NCDs locally, nationally and regionally, the priority tends to be on the four most common NCDs: cardiovascular diseases, respiratory diseases, diabetes and cancer. Thus, persons who do not have these conditions can often be overlooked or feel neglected and find it hard to access information, support and guidance. We did find evidence of this in our study.

“

You don't really hear much about the disease that I have—people supporting it in St. Kitts.”

“

I didn't know who to turn to in terms of just getting that nutrition or education for it. It was lonely. It was overwhelming to see so many young women experience this in the silence and they're just looking to see another woman has something similar.”



Policymaker View

“I realised that we only focus on the four areas in terms of our NCD activities. Those are the main areas of focus when it comes to non-communicable diseases. I could understand we can't focus on everything. So, that's understandable, but even with proper planning, we would be able to carve out those areas where we could focus on different things so that persons would understand that we do take your specific concern or condition into consideration because it is a chronic condition. So, that's one of the challenges, just the fact that we only focus on these areas.” – Policymaker in the healthcare field

Gender lens



When applying a gender lens to this issue, we identified that cancer awareness campaigns in St. Kitts and Nevis tend to focus more on female-related cancers, e.g., breast and cervical cancer and there is a need to focus on male-related cancers like prostate and testicular cancer as breast and prostate cancer are the two most common cancers in St. Kitts and Nevis. Additionally, in our target group, women raised the issue of having NCDs that were not the focus area of local and regional public health policies (see the previous section about this). This included chronic reproductive and immune conditions.



Policymaker View

“From the NCD perspective, one of the things I realised is that even within observance or our awareness campaigns and strategies, we tend to focus a lot on the female-based conditions, especially in the realm of cancer. I can see it with cancer because there’s a lot of awareness on breast cancer. There’s a lot of awareness on cervical cancer. We don’t do as much on prostate cancer, so I think that’s one of our gaps for sure in terms of making the population aware of the various types of cancers and making sure that we cover all types equally.” – Policymaker in the healthcare field

2. Single older women

As mentioned previously, our project suggests that older, retired single women living with an NCD were more vulnerable to isolation, leaving them at risk of not having the support they needed if an emergency occurred

3. Middle-aged working participants on a low income.

Our project suggests that this group was more vulnerable to financial challenges and tended to fall just outside the requirements to receive certain types of support. For example, they were either not old or young enough for certain concessions and they were employed so they were not able to receive the financial support they needed.

“

Not because we aren’t old to get a percentage off. I mean, this is every month thing we have to buy. Not because we’re not senior citizens.”

Gender lens



In our study, as mentioned previously, within this group, the most financially vulnerable tended to be single mothers on a low income.

4. Men

As we highlighted earlier, men are less likely to reach out for support – medical or psycho-social – which means that they are vulnerable to late diagnoses of NCDs and therefore worse outcomes. Additionally, they are at risk of being underserved when it comes to support services especially during significant shocks and disasters like a pandemic.



Policymaker View

“We [men] are very secretive about our conditions when it comes to our health. We don’t go to the doctor unless we are crawling on the ground and can’t move. So, when it comes to cancer, we find that 90% of the requests are from women. It does not necessarily mean that it’s 90% of the population in terms of cancer that is women, it’s just that women tend to come forward more and ask for support. Women are more open with their health conditions and so on while men seem to kind of hide that. So, while we would have helped men before, they’re very few and far between over the years that I’ve seen. Primarily, it’s the women who come forward and ask and seek that support, whether financially, emotional, and so forth.” – Policymaker in the NGO sector

5. People living with NCDs in general

We did hear from several participants that there needs to be more of a focus on NCDs in general and that there is a need for more education and support that is NCD-specific. There was a sense that this focus needs to be maintained despite the development of any emergencies or disasters as during these situations people living with NCDs become extremely vulnerable. This was highlighted during the pandemic where research eventually demonstrated that people living with NCDs were more likely to develop COVID-19 and be more severely affected if they contracted the virus. It was felt that during disasters and emergencies, NCDs tend to be overlooked and this creates an inequality and causes further vulnerability.

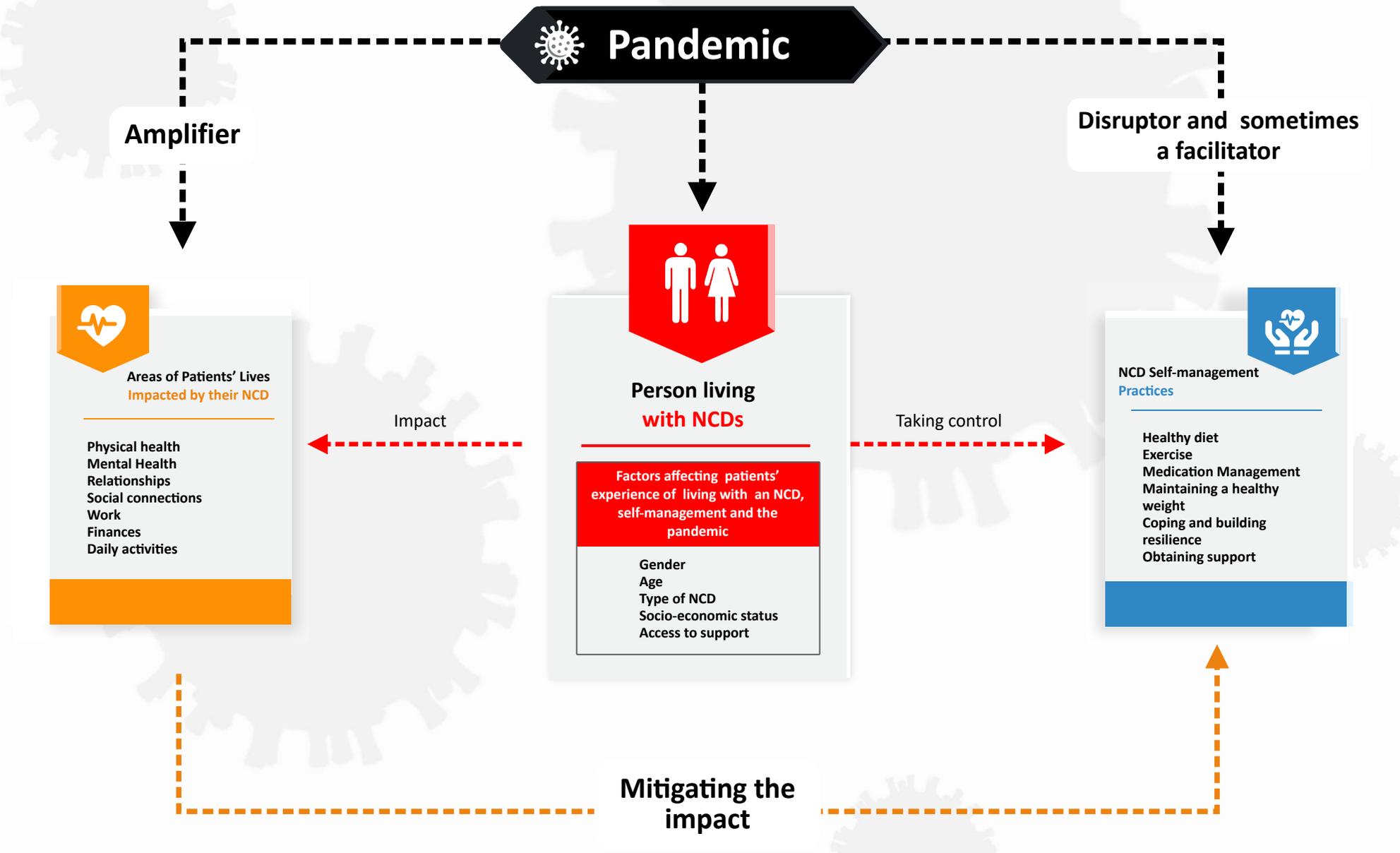


Policymaker View

“COVID has definitely overshadowed cancer in general. It has really pushed cancer for sure to the backburner.” – Policymaker in the NGO sector

“Initially the thought was it was the elderly. Being old does not necessarily speak to being diseased, so we thought that age was a factor. So, we started speaking to that. But once information started becoming more structured, and I think there were more data points to pull from, it appeared that there was a select group of individuals who were particularly vulnerable [to COVID-19], and those were the individuals who had non-communicable diseases, underlying conditions.” – Policy maker in the healthcare field

An overview of the impact of COVID-19 on people living with NCDs



4. Conclusion



Conclusion

Our research findings align with research conducted globally over the past 18 months that found that the pandemic exacerbated the challenges that people with NCDs faced before the pandemic.

Before exploring the experiences of people living with NCDs during the pandemic, we first took an in-depth look at their experiences prior to the pandemic to establish a benchmark for their pandemic experience. To our knowledge, there has been no research to understand the experiences of people living with NCDs in St. Kitts and Nevis using a gender lens and thus this data is of significant value in identifying gender inequalities within the NCD patient population.

Through our project, we identified that prior to the pandemic, people living with NCDs here in St. Kitts and Nevis faced a high level of uncertainty about their future because of the unpredictable nature of their NCD. This created a high level of anxiety especially as their NCD affected every aspect of their lives including their physical and mental health, relationships and social connections, their work and finances. The unpredictable nature of their NCD and its ability to affect all these areas then also

made their daily lives, their future and their quality of life unpredictable. Therefore, people living with NCDs saw a need to make a concerted effort to regain control and this required an intentional application of self-management techniques which included adopting a healthy diet, engaging in regular exercise, effective medication management, obtaining adequate rest, developing resilience and coping skills and ensuring they regularly monitored their condition which consisted of having regular medical check-ups. Some people living with NCDs were able to successfully control and manage their NCDs before the pandemic through these self-management techniques but others found it very challenging to control their NCD, and this affected their quality of life before the pandemic.

Taking an intersectional approach, we were able to determine that in St. Kitts and Nevis the issue of NCDs is highly gendered, and men and women have a variety of emotional, practical, domestic, professional, and biological needs that have historically been unaddressed but which need to be considered when developing NCD policies and strategies. In particular, through our exploration of gender, we found that the most vulnerable groups of people living with NCDs were:

- **Single mothers on a low income.** This group was managing their NCD while balancing a number of roles and responsibilities with sometimes little or no practical, emotional or financial support. As a result of this, they were exposed to a high level of stress which exacerbated their NCD.

- **Retired older single women.** This group was at risk of isolation and loneliness, leaving them at risk of not having the support they needed if an emergency occurred.
- **Men overall.** This is because men were found to be more hesitant to seek out help and were therefore at risk of not receiving the support and medical attention they needed and thus, having a worse NCD outcome than women.
- **Women affected by chronic reproductive health issues and specific auto-immune and immune-mediated conditions which are more common in women.** This is because there is a lack of specialist care and support for these conditions in St. Kitts and Nevis, leaving these women without appropriate medical, practical and psycho-social support.

When we then explored the impact of the pandemic on people with NCDs, we identified that overall, the pandemic was a significant disruptor creating even more uncertainty and exacerbating the many challenges that patients faced before the pandemic. Specifically, the increased risk that people with NCDs faced when it came to COVID-19 further compounded their anxiety about their health and future, and the COVID-19 policies and protocols in some cases significantly affected patients' ability to engage in successful NCD self-management practices and therefore resulted in a worsening of symptoms.

Conversely, we found that aspects of the pandemic such as the overall slowing down of society, for some patients, provided an opportunity to improve their NCD self-management and enabled some improvement of their health condition. Furthermore, other NCD patients had a very neutral experience where the pandemic had no impact, good or bad, on their NCD. When we delved further, we identified that some of the gender issues that were identified before the pandemic worsened and those groups that were most vulnerable before the pandemic were made even more so because of the pandemic.

Our research highlights that the varying needs of men and women living with NCDs have to be considered when developing the federation's disaster management policies and strategies particularly when emergencies like pandemics occur. If we are to ensure that the needs of all vulnerable members of society are met during emergencies, then a nuanced and intersectional approach is needed for people living with NCDs as they are not a homogenous population but one of varying needs.

Embedding an effective NCD response in any disaster management strategy is of utmost importance because of the high prevalence of NCDs in St. Kitts and Nevis. By focusing much-needed attention on this population during emergencies, we can strengthen the disaster management and recovery process by protecting and supporting a key vulnerable segment of society. This should be seen as a priority because the pandemic and other disasters continue to reveal that people with NCDs are particularly vulnerable when disasters occur.

5. Recommendations



Recommendations

1. A specific, holistic and comprehensive NCD strategy is required as part of the disaster management process.

- Having a strategic NCD component as part of the disaster management process would ensure that the concerns of those living with an NCD, an important vulnerable group, are a key priority. This strategy should focus on ensuring that NCD patients are empowered to successfully control their NCD during a disaster through self-management and should mitigate the impact the disaster could have on the physical health, mental health, finances, relationships and social connections of people living with NCDs.

2. An intersectional, gender-sensitive approach to NCDs is required during disasters that includes collaboration between the National Emergency Management Agency, the Ministry of Health, the Department of Gender Affairs, Social Services, the Mental Health Association, other and relevant government departments and NGOs.

- An intersectional approach would ensure that any gender or socio-economic inequalities that

exist amongst people living with NCDs during a disaster are identified and addressed and that care is taken to focus on protecting and supporting those groups that we have already identified as being particularly vulnerable. An intersectional approach also helps us tailor responses to specific needs or concerns which would mean more effective solutions and more efficient use of limited resources.

3. A Federal NCD Patient Participation Group that is supported through capacity building and training should be formed

- This will enable policymakers to easily consult with people living with NCDs when developing policies that may directly or indirectly affect those living with NCDs. By having an existing consultation group, people living with NCDs can easily be engaged and included in the disaster management process when a disaster is imminent.

4. Employers must meet their duty of care to people living with NCDs especially during disasters.

- In this regard, employers must be accountable to the Department of Labour and metrics should be developed to ensure that employers adequately meet the needs of their employees who are living with an NCD. Employers should provide employees with access to medical and

psychological support and adapt the roles of people living with NCDs to minimise stress during disasters.

5. Employers should include their staff in the decision-making process when developing their response to disasters. This should include:

- More meaningful staff consultations
- Greater transparency with regards to the decisions made and policies being introduced
- Sufficient notice being provided to employees to enable them to emotionally and practically prepare for any decisions and policies being implemented
- Better and more frequent communication before, during and after a disaster
- Having a specific focus on and strategy for people with chronic illnesses during disasters

6. The government should ensure that any policies developed during a disaster are assessed to determine their NCD and gender impact.

- This would involve determining the impact any new policies have on NCD self-management, whether these policies may exacerbate challenges associated with the physical health, mental health, relationships, social connection, work and finances of those living with an NCD, and whether these policies address the gender-based needs of people living with NCDs.

7. The government should introduce special support and relief for people living with NCDs during disasters as their financial, medical, mental health and personal needs are significantly different to the general population.

8. The Ministry of Health and the government should improve monitoring and data collection related to people living with NCDs and their experience and outcomes during disasters to measure the success and impact of the disaster management response for people living with NCDs.

- This would enable gaps to be identified and facilitate continuous improvement of the NCD response during disasters and thus allow more effective evidence-based NCD policies and strategies to be developed for future disasters.

9. Front line workers and essential workers living with NCDs must be adequately supported during disasters so as not to create unmanageable stressors that could exacerbate their NCDs.

10. NGOs and faith-based organisations must be adequately supported both in terms of capacity building and finances to support people living with NCDs during disasters.

- A grant programme should be established to enable NGOs and FBOs to access funding to support the disaster response, fill the gaps that Governments cannot fill and provide an effective support service for their target groups.

11. The entire disaster management process including the policy development process must be rooted in empathy, sympathy and kindness towards vulnerable members of society including people living with NCDs. Additionally, a human rights-based approach to disaster management must be considered to protect those who are most vulnerable.

12. An NCD Disaster Wellness Programme should be developed that focuses on protecting the mental health of NCD patients and should include stress management, coping and resilience and mindfulness. This should take into account people's different emotional needs as well as the different social expectations and pressures and the differences in the nature of support men and women tend to have access to.



6. References

1. Chan, E., Kim, J., Lo, E., Huang, Z., Hung, H., Hung, K., Wong, E., Lee, E., Wong, M. and Wong, S., 2020. What Happened to People with Non-Communicable Diseases during COVID-19: Implications of H-EDRM Policies. *International Journal of Environmental Research and Public Health*, 17(15), p.5588.
2. Chang, A., Cullen, M., Harrington, R. and Barry, M., 2021. The Impact of Novel Coronavirus COVID-19 on Noncommunicable Disease Patients and Health Systems: A Review. *Journal of Internal Medicine*, 284 (4), 450-462.
3. European Institute for Gender Equality, 2016. *Gender Impact Assessment: Gender Mainstreaming Toolkit*. Luxembourg: European Institute for Gender Equality.
4. Gutierrez, J. and Bertozzi, S., 2020. Non-communicable diseases and inequalities increase risk of death among COVID-19 patients in Mexico. *PLOS ONE*, 15(10), p.e0240394.
5. Hoecklin, M., 2020. The COVID-19 and NCD Syndemic: Experiences From Rwanda, the UK, and India. [Blog] *Health Policy Watch*, Available at <https://healthpolicy-watch.news/79399-2/> [Accessed 16 February 2021].
6. Loh, S., 2018. Self-care or self-management in palliative survivorship care in Asia: A call for more research. *Nurs Palliat Care* 3: doi: 10.15761/NPC.1000195.
7. NCD Alliance, 2020. *Briefing Note: The Impacts of COVID-19 on People Living with NCDs*. Geneva: NCD Alliance.
8. NCD Alliance, 2020. *COVID-19 and Non-Communicable Diseases Media Q&A*. Geneva: NCD Alliance.
9. Pan American Health Organisation, 2020. *Rapid Assessment of service delivery for NCDs during the COVID-19 pandemic in the Americas*. PAHO.
10. Pan American Health Organisation, 2012. *Health in the Americas 2012: St. Kitts and Nevis* [Online]. Available at: https://www.paho.org/salud-en-las-americas-2012/index.php?option=com_docman&view=download&category_slug=hia-2012-country-chapters-22&alias=145-saint-kitts-nevis-145&Itemid=231&lang=en [Accessed on 18th February 2021]

11. Ritchie, J., Spencer, L. and O'Connor, W., 2003. Qualitative Research Practice. London: Sage Publications.
12. The Association for Women's Rights in Development, 2004. Intersectionality: A Tool for Gender and Economic Justice. Facts and Issues. Toronto: The Association for Women's Rights in Development.
13. Trochim, W. 2006. Qualitative Approaches. Research Methods Knowledge Base.[online] Available at <<http://www.socialresearchmethods.net/kb/qualapp.php>> [Accessed 15th February 2021]
14. UAE Gender Balance Council, 2017. Gender Balance Guide: Action for UAE Organisations. OECD.
15. UN-INSTRAW, n.d. Gender Research: A How To Guide. Geneva: UN-INSTRAW.
16. van Witteloostuijn, A., n.d. A critical analysis of how to apply feminist and intersectional methodologies in qualitative research. [Doctoral Thesis]. Utrecht University.
17. World Health Organisation, 2020. The impact of the COVID-19 pandemic on non-communicable disease resources and services: results of a rapid assessment. Geneva: World Health Organisation.
18. World Health Organisation, 2020. COVID-19 significantly impacts health services for non-communicable diseases. [online] Available at: <<https://www.who.int/news/item/01-06-2020-covid-19-significantly-impacts-health-services-for-noncommunicable-diseases>> [Accessed 16 February 2021].



Appendix 1: Interview Guide (People Living With NCDs)

Interview Guide

Introductory questions

1. What is your date of birth?
2. Do you currently live in St. Kitts/Nevis? How long have you lived here?
3. What NCD do you live with?
4. How long have you lived with this NCD?
5. Thinking back to before the pandemic, how would you describe your experience of living with this NCD in 2-3 words?
 - Please explain why you've used these words?
 - Probe on whether they felt they had their NCD under control prior to COVID
 - Explore what a typical day living with that NCD would have been like then
 - Explore how their gender impacted their NCD, its management, the care they receive and the support they need (e.g. 'do you think your gender had any influence on your NCD, the care you received and the support you think you need? How?' 'How do you think your experiences could be different if you were a different gender? Can you explain why you think so?')
6. Since the pandemic started, how would you describe your experience of living with this NCD in 2-3 words?
 - Please can you explain why you've used these words?
 - Explore any differences
 - Probe on whether they felt in control of their NCD
 - Explore any gender issues that may come up (e.g. 'do you think your gender had any influence on your NCD, the

care you received and the support you think you need? How?' 'How do you think your experiences could be different if you were a different gender? Can you explain why you think so?')

The early phase of COVID-19

1. When you first heard that **COVID-19 might be a threat** to the Caribbean/St Kitts/Nevis, what did you think and how did you feel with regards to what that might mean for your health as a person living with an NCD?

a. Explore any gender issues that may be raised, if not raised explore whether they think that gender impacted what thoughts, feelings or concerns they had

2. Thinking about the management of your health condition, what action did you take at this point?

- Follow up with participant about whether any of these actions were related to their gender / would have been different if they were a different gender or any other personal factors such as socio-economic status

- follow up with participant about whether they sought out information and support

- who did they get this information support from, was it helpful,

- did they feel well-equipped to manage if COVID came to St Kitts,

- did they understand that if COVID-19 came it might lead to lockdowns and restrictions on their movement, did they understand what implication that might have on their management of their NCD

- did they prepare for that, who helped them prepare,

- Explore whether they received specific NCD guidance from the Government, Ministry of Health or COVID taskforce, did this guidance speak to issues particularly pertinent to their gender

3. When the **first case** of COVID-19 was reported in St Kitts and Nevis, what were your first thoughts and how did you feel? What thoughts/feelings did you have about your health condition and what might COVID-19 being in the country mean for you?

- Explore whether any of these thoughts and feelings were gender-specific

4. At this stage, what action did you take? Were any of these actions related to your gender? How so?/Do you think these actions may have been different if you had a different gender?

5. As the **cases started to increase**, what were you thinking and how were you feeling? What actions did you take? Were any of these actions related to your gender? How so?/Do you think these actions may have been different if you had a different gender?

6. Throughout this process, can you describe the type of information, guidance and support that you received from your doctor, employer, church, the Ministry of Health, the Government, NGOs, etc?

a. Was any of this information specific to persons living with NCDs? How so? Did any of this information address gender-related issues that were important to you? How?

b. Was the information/guidance/support useful? How so?

c. How did you use the information provided?

7. Thinking about your specific NCD what type of information/support/guidance was/would have been most useful? Why?
8. Thinking about the fact that you're a man/woman living with an NCD, what type of information was/would have been most useful? Why?

COVID-19 State of Emergency (lockdown)

9. When the lockdown was announced, what were your first thoughts and feelings as it relates to your NCD?
- a. Explore whether any of these thoughts and feelings were gender-specific
10. How prepared did you feel for the lockdown? Why?
- a. Explore any gender-related issues
11. What guidance was given to people living with NCDs with regards to how to manage during the lockdown? Was this helpful? Who provided this information? Do you have any suggestions for how considerations about gender could have been included in this guidance?
12. Can you describe what a typical day in lockdown was like for you, a person living with an NCD? How does your gender affect how you might have spent your day?
13. How did the lockdown impact you and your ability to manage your NCD?
- a. Explore any gender-related issues
14. How did the lockdown impact you physically and emotionally? Why?
- a. Explore any gender-related issues
15. Thinking about your specific NCD, what challenges did the lockdown create? Did you feel able to address these?
16. Thinking about your identity as a man or a woman living with an NCD, what specific challenges did the lockdown create? Did you feel able to address these? How did your identity as a man/woman living with an NCD shape your experience of the lockdown (probe the household makeup, are they parents, who is responsible for childcare, domestic chores, are they the breadwinner, did they have to work from home)
17. Did you feel like you had enough support during the lockdown to manage your NCD? Who did you turn to for help when you needed it? What type of help did you need?
- a. Explore any gender-related support that may be needed or any sensitivities around gender and reaching out for help?
18. What strategies were you aware of, that the Government/Ministry of Health/COVID Taskforce implemented to support people living with NCDs during the lockdown? Can you describe their effectiveness?
19. Thinking about these strategies, how did they also address any concerns/challenges that you had as a **man/woman** living with an NCD?
20. How did you spend the partial curfew days?
- a. Explore how gender may have affected how they spent the partial curfew days
21. During the lockdown did you ever have a health emergency? Can you explain what happened?

a. Probe whether this emergency was gender-related

22. During the lockdown did you ever run out of medication? Can you explain what you did?

a. Explore any gender issues that may be related to their ability to replenish medication etc

23. During the lockdown did you ever feel lonely? Can you explain what action you took when you felt lonely?

a. Explore whether there was a gender component to loneliness

24. When the lockdown was lifted how did you feel with regards to your NCD? Why?

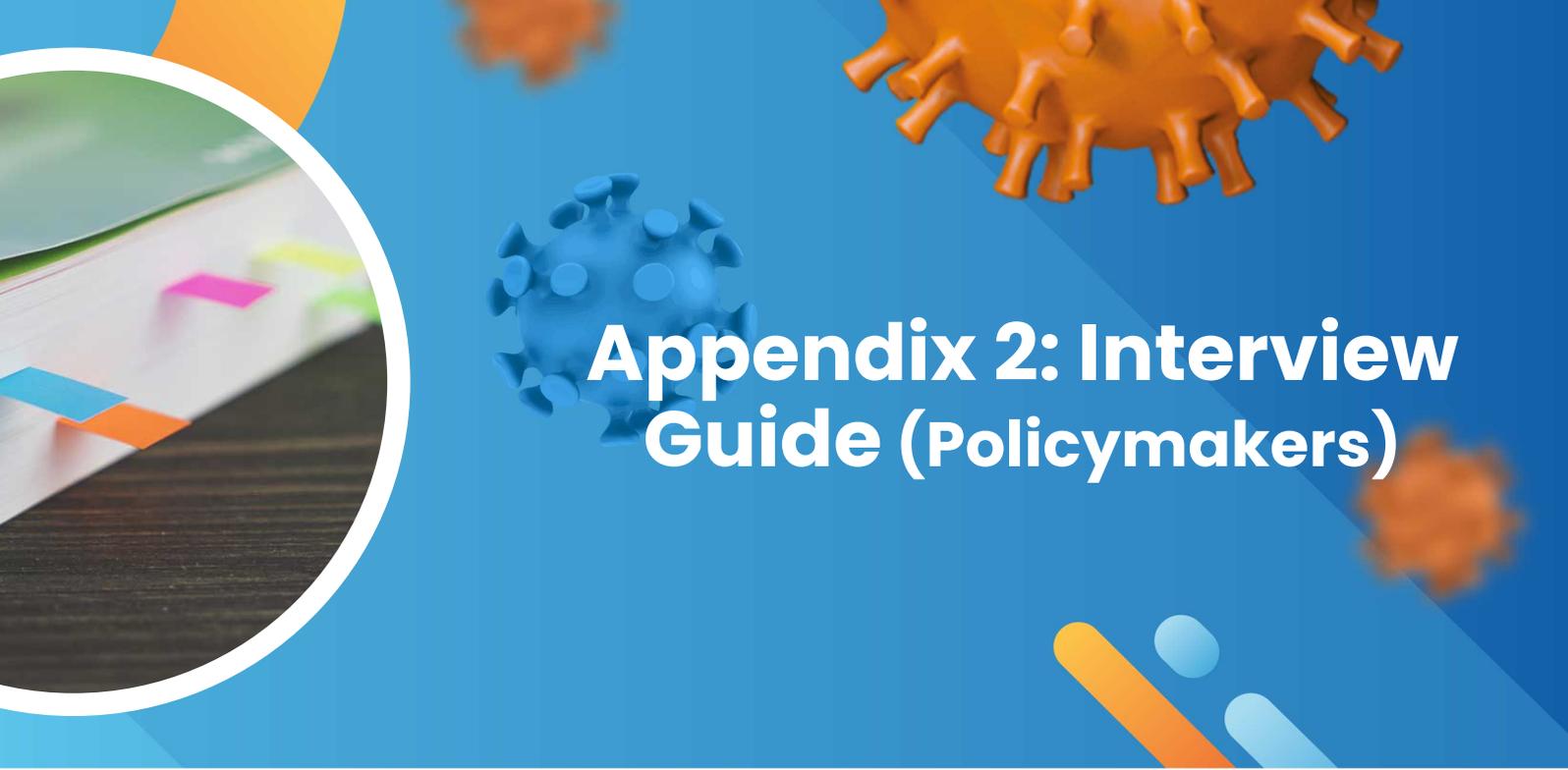
a. Explore any gender-related issues

25. Since the end of the lockdown, how have you felt about living with an NCD in our new normal (face masks, hand sanitising, social distancing)? How have you felt specifically as a man/woman with an NCD in this new normal? What challenges have you faced? What issues/challenges did you encounter that were related to being a man/woman living with an NCD?

Concluding question

26. What has been the most challenging aspect of living with an NCD during the COVID-19 pandemic? What has been the most challenging aspect of being a man/woman living with an NCD during the COVID-19 pandemic?

27. Is there anything else you'd like to tell me about your experience with the pandemic?



Appendix 2: Interview Guide (Policymakers)

Points to discuss with the participant prior to starting:

- As a reminder, I will be recording the interview (Show participant device). The reason for this is so I can create an accurate account of our discussion. My research advisor, Dr Doyin Atewologun and a research assistant may listen to this recording to confirm the accuracy of my work. Additionally, a transcriber will listen to the recording to create a transcript of the interview. For privacy, I won't be playing the recordings back to anyone else.
- What we talk about today will remain confidential - I won't be sharing any identifying details with anyone else outside of our research team.
- This interview is about me having the opportunity to understand how you developed the COVID-19 strategy for your organisation/the country, what influenced your decisions and if you considered the needs of NCD patients during your policy or strategy development process. If we begin to discuss a subject that you don't want to discuss, please don't hesitate to tell me and we can move to another question.
- If you want to take a break, please don't hesitate to let me know and we can take a short break.
- You will not be named in anything I write about in this research. (Show participant an example of a qualitative research report where the author uses participant quotations and explain how their words might be represented in a similar way).

Interview Guide

Introductory questions

7. What is your role at [add the name of their organisation] and how long have you worked there?
8. Can you provide a brief overview of your role/job, prior to the pandemic?
9. How has your role changed since the pandemic?

Main questions:

9. When you first heard that COVID-19 might be a threat to the Caribbean/St Kitts/Nevis, what did you think and how did you feel with regards to what this might mean for the future of your organisation and your role in planning and preparing for COVID-19

10. How did your organisation as a whole respond to the threat of COVID-19?

11. What steps did you and your organisation begin to take to prepare for COVID-19?

12. Can you describe your thought process and the approach of your organisation as you began to prepare for COVID-19? Who did you reach out to for support in preparing for COVID-19 and what type of support did you feel you needed, at that time, so that you could prepare adequately for COVID-19?

13. As you were preparing guidance/policies/strategies that would protect your organisation/business/the country and the public/your customers/service users what were some of the factors that you considered?

14. Who did you consult as you prepared these policies and strategies?

15. Can you describe any particular groups of people that you considered as you were creating policies/strategies for COVID-19? Why did you feel you needed to consider these groups? (prompt: did you consider people living with NCDs, why? Did you consider gender and NCDs? Why?) What conversations did you have with these groups and how did these conversations inform your policy/strategy development?

NB: NCDs are long-term (chronic) diseases that are not passed from person to person. They include diseases such as cancer, diabetes, heart disease, lung disease and stroke

16. Did you think it was important to consider people living with NCDs? Why?

17. When thinking about people with NCDs, what specific needs did you identify and how did your policy/strategy address these needs? How do you think these needs differ for men and women living with NCDs vs women living with NCDs?

18. When thinking about people with NCDs, what specific NCDs did you develop a strategy/policy for? Why did you focus on these specific NCDs?

19. When thinking about people living with NCDs, what specific needs did you consider when it came to men living with NCDs vs women living with NCDs?

20. Can you provide a specific example of how your policy/strategy helped someone living with NCDs during the pandemic?

21. Can you provide a specific example of where you felt your policy for people living with NCDs needed to be improved once you observed it being implemented and had evaluated it?

22. What have been the most important lessons you have learnt in developing policies/strategies/guidelines for people living with NCDs during this pandemic which you think you could apply to other emergencies? Thinking about any inequalities that may have developed, what could be done during the planning stage to prevent these inequalities that were exacerbated by the pandemic for people living with NCDs? (explore gender inequalities)

Concluding question

34. Is there anything else you'd like to tell me about your experience of policymaking during the pandemic especially as it relates to NCDs and inequalities?