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Contents

Vitamin D, Zinc and Iron in Adult Patients with Covid-19 and Their Action in the Immune Response as Biomarkers

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Abstract

COVID-19 in 2020 brought challenges to the Brazilian public health system with an emerging virus with respiratory contagion called SARS-CoV-2. There are few studies in Brazil and in some countries, on the increased incidence of certain viral respiratory infections, including H1N1 and coronavirus and their association with low levels of vitamin D, zinc and iron. The aim of this study was to demonstrate that the deficit of vitamin D, zinc and iron has an impact on the infectious process of patients with COVID-19 and to establish new forms of prevention for the worsening of COVID-19 in the human body. Data were collected from medical records and test results from patients being followed up during the treatment period for COVID-19. Patients with low blood levels of vitamin D, zinc and iron during the treatment period of COVID-19 had a higher percentage of worsening and complications requiring hospitalization in intensive care beds. The ingestion of vitamin D, zinc and iron in the treatment period of patients with COVID-19 in addition to being an immunological protector against SARS-CoV-2 and alleviating the process of worsening the disease can also act as a biomarker in cases of this disease.

Keywords: Zinc, vitamin D, iron, gripes, COVID-19, anemia

1. Introduction

In April 2020, Brazil began to mobilize to combat COVID-19 in order to establish risk factors and prognostic markers, such as the deficit of Vitamin D, zinc and iron (OPAS, OMS. 2020; Ramos, Mendes dos Reis, de Souza, de Freitas, de Lima, & de Abreu, 2020). COVID-19 reached Brazilian states such as São Paulo, Rio de Janeiro, Fortaleza and Amazonas, and in adult infected patients the result was the development of severe pneumonia through Beta Coronavirus (SARS-COV-2) (OPAS, OMS, 2020; Ramos, E. M., Mendes dos Reis, Ramos, M. V., de Souza, & Bochenek, 2020). However, cases of death in Brazil have characteristics related to viral pathogenicity without worsening the patient according to a deficit of macro and micro elements (Ramos, Mendes dos Reis, de Souza et al., 2020; Ramos, E. M., Mendes dos Reis, Ramos M. V. et al., 2020; Razzaque, 2020).

COVID-19 patients in Brazil are adults with one or more comorbidities (Xu et al., 2020; Zhou et al., 2020). Most

patients are over 50 years old and have pre-existing diseases mainly in the heart and respiratory system; some patients are smokers, which cause complications (Ramos, de Abreu, et al., 2020; Ramos, Mendes dos Reis et al., 2020). On the other hand, there are patients who have severe kidney diseases that hinder clinical improvement during the treatment period (OPAS, OMS, 2020; Ramos, Mendes dos Reis, de Souza, et al., 2020). In addition, hypertension or chronic and neurodegenerative diseases brings aggravations such as death during the treatment period (Zhou et al., 2020).

In Italy, COVID-19 manifests itself in patients through high fever ($\geq$ 38.0 ºC), fatigue, non-productive cough, dyspnea and diarrhea. In this case, laboratory tests of patients with confirmed diagnosis show normal or reduced white blood cell count, as well as reduced lymphocyte count, especially in severe cases, thrombocytopenia, high transaminase, high lactate dehydrogenase (LDH), high creatine kinase (CK) and myoglobin elevated (Ramos, de Abreu, de Freitas et al., 2020; Prasad, Bao, Beck, & Sarkar, 2011; Ramos, Mendes dos Reis, de Souza et al., 2020). The death of patients occurs in severe cases, because the disease progresses quickly to septic shock with great difficulty in treatment due to the presence of metabolic acidosis and coagulation dysfunction (Razzaque, 2020; Prasad et al., 2011).

Studies in Brazil, China, Italy and the United Kingdom involving Covid-19 have brought direct primary outcomes of this disease with comorbidities, mainly responses to direct primary immune deficiency such as the body's immune deficiency, coagulation, coagulative activation, myocardial injury, liver damage, kidney damage and secondary bacterial infectious correlations (Malek Mahdavi, 2020; Mohammad, Mishra, & Ashraf, 2019; Xu et al., 2020). The virus reaches the innate immune system through non-specific responses whereas in the adaptive system the responses are specific to the antigen by the innate immune response (Huang et al., 2020). However, in Brazilian patients it is possible to verify that severe cases with evolution to death tend to occur in patients who have developed lymphopenia and secondary inflammation (Cen et al. 2020; Giacomelli et al., 2020).

In addition to the text quoted above, there are cases of patients who are able to recover from Covid-19 with little or no medical and hospital intervention, in this case, patients who do not have deficits in elements such as zinc, iron and Vitamin D (Chan et al., 2020; Grant et al., 2020; Read et al., 2020). Thus, this discrepancy as an immunological outcome of patients with COVID-19 has challenged the Brazilian public health system to find an adequate response (D'Avolio et al., 2020; Huang et al., 2020). Some Brazilian regions have limited data, which makes it difficult to make statements about populations that may be susceptible to COVID-19 (Ampawong et al., 2015; Gruber-Bzura, 2018). However, it is possible to state that the severity of the disease is associated with some underlying conditions of the host, such as age, biological sex, immunological health, deficits of macro- and microelements, vitamin D, zinc and iron and the existence of diseases pre-existing such as diabetes (Cen et al., 2020).

Given the above, the objective of this study was to describe through a case report that the deficit of vitamin D, zinc and iron has an impact on the infectious process of patients with COVID-19 and on the worsening process, as well as on the development of complications in COVID-19 during the treatment period.

2. Materials and Methods

2.1 Study Population

In this case report, patients aged $\geq$ 40 years and with laboratory diagnosis of COVID-19 through real-time reverse transcriptase "polymerase chain reaction assay (RT-qPCR)" for specific severe acute respiratory tracts were included in the positive control groups (Treatment).

In addition, patients with blood tests with dosages of elements such as zinc, iron and levels of vitamin D (25-hydroxyvitamin D (25 (OH) D) who presented deficits in the results were included, and those patients who presented consistent symptoms for COVID-19 such as cough, dyspnoea, fever, fatigue and loss of smell and taste in the period from June to October 2020.

All patients were observed by public health professionals and private hospitals during the period of preventive treatment to control worsening by chest X-ray or chest and D-dimer tomography. Patients who did not show any deficits in the results were included in the negative control group for COVID-19.

The positive control group for COVID-19 was divided into patients with vitamin D, zinc and iron deficiency. In the positive control group (Treatment) with Vitamin D deficit, patients were included according to national and international guidelines with local laboratory standards (Vitamin D $\leq$20 ng/dL), zinc (Zn $\leq$ 70 ug/dL).

The positive control group or treatment group for COVID-19 was divided into patients with vitamin D, zinc and iron deficiency. In the positive control group (Treatment) with Vitamin D deficit, patients were included according

to national and international guidelines with local laboratory standards (Vitamin D $\leq$20 ng/dL), zinc (Zn $\leq$ 70 ug/dL).

In addition, an evaluation of the blood iron level was performed in the laboratories of the Brazilian public health system or private health system with the purpose of verifying the presence of anemine, verifying the deficit of serum ferritinin and serum iron to be used as a determinant of health or worsening of the patient's health with COVID-19. The treatment group included adult participants who had Hb levels $\leq$ 11 ng/dL and serum iron levels <50 ug/dL according to the standard used by the Ministry of Health in Brazil. The treatment of patients with CO-VID-19 in public or private hospitals was carried out in accordance with the national guidelines and care instituted by the Ministry of Health of Brazil. Some patients were treated with subcutaneous low molecular weight heparin as a prophylaxis of venous thromboembolism according to guidelines from the Ministry of Health of Brazil.

2.2 Data Collection Methods

In this experimental and observational study, data were collected through the extraction of medical records and results of follow-up exams in hospitals and laboratories with a database of patients included in the study. Also, age, weight, BMI, smoking and hyperglycemia were included. COVID-19 related hospital mortality was considered as the primary outcome.

  Results that included patients with alterations in radiological images and with the presence of important cellular laboratory alterations were considered as results. In order to maintain the quality of clinical care, Vitamin D, zinc and iron were quantified as requested during the treatment period at the care institution. The data were stored in an Excel spreadsheet which contains biochemical and hematological information. The entire procedure was carried out according to the Brazilian guidelines for the diagnosis and prognosis of COVID-19 through the measurement of C-reactive protein (CRP), D-dimer, ferritinin, hemoglobin, high sensitivity of troponin T, lactate dehydrogenase (LDH) and count of lymphocytes and other cells of the defense system in the human body. The data related to the cause of death was obtained by verifying the death certificates issued by hospital institutions held by family members.

2.3 Ethical Principles

This research was authorized by the Department of Continuing Education of the city of Campo Grande/MS and the Federal University of Mato Grosso do Sul for data collection. Clinical data were collected and were not identifiable.

All data were collected in situ and treated according to the regulations of the Ethics Committee of the Federal University of Mato Grosso do Sul considering local standards on data protection (CAAE: 42969320.0.0000.0021). All practices carried out in the study were carried out in accordance with regulations and clinical practice protocols. Serum levels of Vitamin D, zinc and iron were performed at the health institution to which the patient attended for the treatment of COVID-19 and did not require researchers to perform phlebotomy and supplementation of zinc, iron and vitamin was not performed. D. All patients were monitored and received care according to standard practice for the treatment of COVID-19 over the period of the study offered by the Ministry of Health in Brazil.

3. Results

A total of 20 patients aged 40 to 80 years were selected in this study. Only 8 men and 5 women totaling 13 patients (65%) with a positive result for COVID-19 were allocated to the "positive control or treatment" group, on the other hand, 7 patients (35%) without a diagnosis of COVID-19 were allocated to the "negative control" (Table 1).

In the positive control group, 9 patients (45%) had a level of 25 (OH) D $\leq$ 20 ng/dL and 02 patients (10%) had a level greater than 20 ng/dL (Table 3). In addition, 8 patients (61.5%) had a level of Zinc (Zn) $\leq$ 70 ug/dL and 1 patient (7.6%) had a level greater than 120 ug/dL (Table 3).

When assessing the blood level of iron concentration in the positive control group that underwent treatment, it was found that 9 patients (69.2%) had a serum iron level equivalent to < 50 ug/dL. On the other hand, 5 female patients (38.4%) also had a ferritinin blood level < 23.6 ng/mL. However, 4 patients (30.7%) were male and had ferritinin < 11.0 ng/ml, of all patients included in the treatment group, a total of 8 patients (61.5%) had hemoglobin < 11 (g/L) (Table 3). In addition, 8 patients (61.5%) were included in the treatment group are diabetics with glucose > 99 mg/dL (Table 3) in blood level.

Based on the results of the 13 patients belonging to the treatment group (Positive control group) with COVID-19, it is possible to verify that about 9 patients (69.2%) had a hemoglobin level lower than that standardized in Brazil (Reference value of 11 - 15 ng/dL). It was found that these lower hemoglobin levels occurred in patients over the

median age (60 years) and with a greater proportion in female (n=8) and diabetic (61.5%) patients. In addition, these diabetic patients with low hemoglobin levels worsened during the COVID-19 treatment period and needed to be admitted to intensive care unit beds (Table 3 and Table 2).

A total of 9 patients in the treatment control group (69.2%) had D-dimer with elevation levels above 1 mcg/ml. On the other hand, 5 patients (38.4%) progressed to mortality during the hospitalization period with a hospital stay of more than 20 days, which mainly evolved to radiological worsening (Table 2 and Graph 2).

The clinical data of positive control patients with COVID-19 and with vitamin D, zinc and iron deficiency (Temperature, SaO2, hospitalization, Use of intensive therapy with use of mechanical ventilation and death) were compared with the negative control groups (Table 2). From the comparisons between groups, it was possible to verify that 2 patients in the positive control group (15.3%) used intensive care and had the need to use mechanical ventilation, however, in the negative control group 6 patients (46,1%) experienced the need to use intensive therapy with the use of mechanical ventilation (Table 2 and Graph 1). Thus, it is possible to verify that there was a difference in the mean length of stay of patients in the positive control group (treatment) with COVID-19 during the hospitalization period compared to the negative control without COVID-19 (Table 2).

Blood levels of vitamin D in the positive control group (treatment) with COVID-19 were significantly lower than the reference values used in Brazil, which totaled 9 patients (69.2%) (Table 3). The zinc concentration was lower in the positive control group (treatment) with COVID-19 compared to the standardized reference value in Brazil, and totaled 8 patients (61.5%). Serum iron, ferritin and hemoglobin were lower than the values standardized by Brazil, totaling 9 patients in the positive control group with COVID-19 (69.2%) (Table 3).

According to the results, 7 patients had a vitamin D deficit (53.8%), as well as 7 patients had a zinc deficit (53.8%). On the other hand, 9 patients had an iron deficit (45%). An interesting fact is that such patients with vitamin D, zinc and serum iron deficits evolved with worsening in COVID-19 and had a high average in the level of D-dimer. Such patients required hospitalization with the use of the bed in intensive care and mechanical ventilation during the treatment period. In addition, 5 patients progressed to death, mainly those with pulmonary worsening (Table 3, Graph 1 and Graph 2).

In the positive control group with COVID-19, patients with Vitamin D, zinc and iron deficiency had higher peak levels of lymphocytes, leukocytes, Natural Killers cells, IL-6, IL-4, IL-10, IL-2 and IL-8 due to the increase in the hospitalization period and the need to use intensive care (Table 2, Table 3 and Graph 1). In this case, it was observed that these patients showed an increase in the percentage of peak levels in CD3 (7,35%). It is possible to verify a significant difference in mortality in the positive control group with COVID-19 when compared with the negative control group COVID-19 (Table 2).

Table 1. Demographic characterization of patients with COVID-19 according to the case report

DEMOGRAPHIC DATA

Age	Male	Female	Tobacco Use	IMC ≥ 30.0 a 39.9	Patients with Covid-19 Positive Control Group or treatment	Patients without COVID-19 Negative Control Group
(40 – 50)	1	1	1	2	2	2
(50 – 60)	2	1	1	2	3	2
(60 – 70)	3	1	3	4	4	1
(70 – 80)	2	2	1	1	4	2
TOTAL					13	07

Table 2. Clinical characterization of patients with COVID-19 according to a case report

CLINICAL DATA

Clinical Data	Male	Female	Patients with Covid-19 Positive - Control Group(n = 13)	Patients without COVID-19 - Negative Control Group(n = 7)
Temperature (°C)				
(36.0 – 37.9)	2	1	2	2
(38.0 – 38.5)	2	2	8	2
(38.5 – 39.5)	4	1	3	3
SpO2				
(91% - 100%)	1	1	2	2
(81% - 90%)	4	2	6	2
(71% - 80%)	1	0	1	1
(61% - 70%)	0	1	1	0
(50% - 60%)	2	1	3	2
Hospitalization (Days hospitalized)				
(01 – 10)	1	1	2	7
(11 – 20)	1	1	2	0
(21 – 30)	3	2	5	0
Use of intensive therapy using mechanical ventilation (Days)				
(01 – 10)	1	1	2	1
(11 – 20)	1	1	2	0
(21 – 30)	1	1	2	0
Death during the patient's follow-up period in the case report				
Death during the patient's follow-up period in the case report	3	2	5	1

Table 3. Characterization of the laboratory results of patients with COVID-19 according to the case report

RESULTS OF LABORATORY EXAMINATIONS

Clinical Data	Male N (%)	Female N (%)	Patients with Covid-19 - Positive Control Group - N (%) (n = 13)	Patients without COVID-19 - Negative Control Group – N (%) (n = 7)
Serum Vitamin D (ng/dL)				
< 20	5	4	9	2
(20 - 60)	1	1	2	2
≥ 100	1	1	2	3
Serum Zinc (ug/dL)				
<70	5	3	8	3
(70.0 – 120)	3	1	4	2
> 120	0	1	1	2
Serum Iron (ug/dL)				
< 50	4	5	9	1
50 - 175	0	1	1	3
> 175	2	1	3	3
Ferritin (ng/mL)				
> 23.9 (Male reference value)	4	0	4	5
<23.9(Female reference Value)	0	5	5	2
Hemoglobin (g/L)				
< 11	1	8	9	2
(11 – 15)	2	1	3	2
> 15	0	1	1	3
Protein C (%)				
1.0 - 3.0 mg/L	3	6	9	7
Proteín S (%)				
67.5 – 139.0 % (Male reference value)	5	0	5	7
60.1 – 113.6 % (Female reference Value)	0	4	4	7
Glycated Hemoglobin (Hb A1c)				
5.7% - 6.4%	2	03	5	5
≥ 6.4%	3	05	8	2
D-Dimer (mcg/mL)				
< 0.5	2	2	4	5
> 1	5	4	9	2
Glucose (mg/dL)				
70 – 99	2	3	5	4
> 99	3	5	8	3
Auxiliary T lymphocytes CD4+ (%)				
< 30.7	1	1	2	4
30.7 – 49.0	8	1	9	2
> 49.0	1	1	2	1

Total Leukocytes (cells / μL)				
< 3.8000	3	1	4	4
3.800 – 11.000	1	1	2	1
> 11.000	3	4	7	2
CD4 T lymphocytes (CD3 + CD4 +) (cells /μl)				
< 477	4	5	9	4
477 - 1140	1	1	2	1
> 1140	1	1	2	2
Total Lymphocytes (cells / μl)				
< 1000	1	1	2	4
1000 - 4000	1	8	9	1
> 4000	1	1	2	2
Cytotoxic T lymphocyte CD8 + (CD8 (CD3 + CD8 + / CD3 +)%				
< 13.8	0	1	1	4
13.8 – 27.4	5	5	10	1
>27.4	1	1	2	2
CD8 T lymphocytes (CD3 + CD8 +) (cells / μL)				
< 211	1	1	2	4
211 - 724	3	5	8	1
> 724	2	1	3	2
CD3 %				
< 55.5	2	5	7	4
55.5 – 75.2	1	2	3	1
> 75.2	1	2	3	2
Natural Killer cells (CD56 + CD16) (cells /μ)				
< 137	1	2	3	4
137 - 567	2	5	7	1
> 567	1	2	3	2
Interleukin 6 (IL-6) (pg/mL)				
> 5.9	5	5	10	3
Interleukin 10 (IL-10) (pg/mL)				
< 9.1	7	4	11	3
Interleukin 2 (IL-2) (UI/mL)				
< 0.10	6	4	10	3
Interleukin 4 (IL-4) (pg/mL)				
< 38.7	6	5	11	3
Interleukin 8 (IL-8) (pg/mL)				
< 50.0	7	2	9	3
Neutrophils (μL)				
< 1600	1	1	2	4
1600 - 8000	1		2	1
> 8000	4	5	9	2
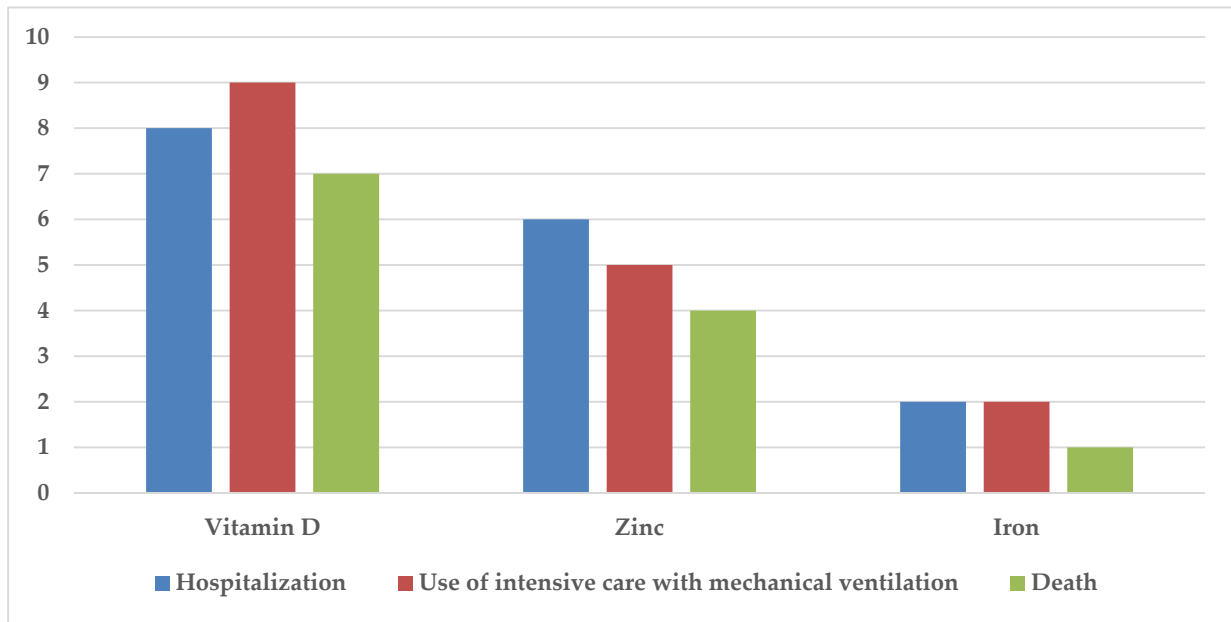
Graph 1. Deficit of Vitamin D, Zinc and Iron as biomarkers in the clinical worsening in patients with COVID-19
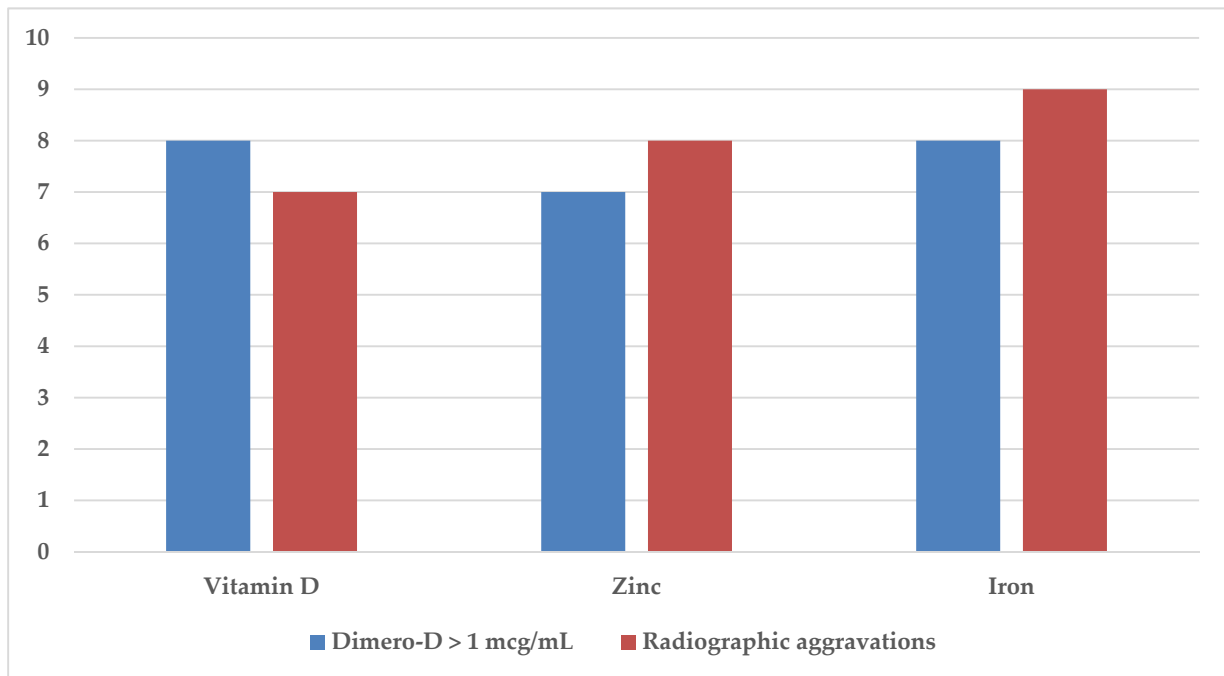
Graph 2. Characterization of Vitamin D, Zinc and Iron deficiency as biomarkers in radiographic deterioration
and D-dimer > 1 mcg/mL in patients with COVID-19

4. Discussion

In this case report study, it is possible to verify that when adjusting the data in a linear regressive manner, a significant trend is observed for mean hemoglobin and serum iron at levels that were below the standard and that are related to the average age of 60 years of the participants in the study (Table 1 and Table 2) (International Artemisinin Study Group, 2004; Anstey et al., 2002; Ramos, de Abreu et al., 2020). Compared to other studies with patients who presented moderate symptoms in COVID-19, it is possible to observe that there is a similarity

between both, because the patients with severe symptoms in this study also had the lowest hemoglobin levels when used as a standard (Alves et al., 2007; Ampawong et al., 2015; Ramos et al., 2020). In addition, hemoglobin and iron levels decreased with a higher percentage in diabetics, which was similar to other studies already developed (Brenner, Holleczek, & Schöttker, 2020; Bishop et al., 2021; Ramos, de Abreu et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., et al., 2020).

Huang et al. (2020) in their descriptive study obtained similar data in which hemoglobin levels in 45% of patients with COVID-19 were hospitalized and required an intensive care bed (Anstey et al., 2002; Ramos, E. M., Mendes dos Reis, Ramos, M. V., 2020). The results presented in our study corroborate the study carried out by Wang et al (2020), which demonstrated a worsening in the symptoms of patients such as COVID-19 with serum levels below 11.0 Hb g/L (Ampawong et al., 2015; Ramos, E. M., de Abreu, 2020).

According to Cen et al (2020), hemoglobin levels below 11 g/dL are directly related to the worsening of the disease in patients with COVID-19 (Cen et al., 2020; Ramos, E. M., Mendes dos Reis, Ramos, M. V., et al., 2020). In addition, Giacomelli et al. (2020) highlighted in their observational study a high prevalence of patients with COVID-19 and anemia, which totaled 24,262 patients, with the ferritinin level being below the highest standard in populations over the age of 60 years and these patients evolved to death, such evidence confirms the data found in the present study, which is the case report type (International Artemisinin Study Group, 2004; Brenner, Holleczek, & Schöttker, 2020; Ramos, de Abreu et al., 2020).

Corroborating our findings, Zhou et al. (2020) found in their analysis that the chances of death of patients hospitalized in an intensive care bed are higher among patients with ferritin levels above 23.9 ng/mL (Adjuik et al., 2004; Andrade et al., 2010). In fact, this occurs because serum ferritin is high in patients who progress to death compared to patients recovered over the course of the clinic, and this increase is due to the deterioration of the disease (Ramos, E. M., Mendes dos Reis, Ramos, M. V., et al., 2020). For example, patients with severe hypoxemia had significantly lower serum iron levels than the standard used (Read et al., 2019).

According to Tables 2 and 3, from the assessment of iron quantification in patients with COVID-19 and progression of worsening signs, it was possible to observe that hemoglobin levels decrease with advancing age (Ramos, E. M., de Abreu et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., et al., 2020). In addition, the increase in deaths and morbidities was seen with a greater increase in women, the elderly, diabetics with levels of ferritinin and serum iron below the standard level (Ramos, E. M., de Abreu et al., 2020; Castro et al., 2011).

The serum iron concentration is a determinant of the body's ability to transport oxygen from the blood, thus, in this study it is possible to verify that the serum hemoglobin levels that are lower than the standard established in Brazil, develops the worsening of the patient with COVID-19 mainly in the at-risk population such as the diabetic patients in this study (International Artemisinin Study Group, 2004; Anstey et al., 2002; Ramos, E. M., de Abreu et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., et al., 2020).

Given the above, serum iron can be considered as a biochemical indicator for the worsening of the patient with COVID-19, since the patient with COVID-19 suffers a decrease in the ability of hemoglobin to support the increase in peripheral tissue in the distribution of oxygen in the body, which in turn is linked to the hypermetabolic state during the virus infectious process (Graph 2) (Ampawong et al., 2015; Andrade et al., 2010).

Studies demonstrated that patients with serum iron deficit may develop a change in hemoglobin concentration and develop a decrease in oxygen saturation in the body (Table 2) (International Artemisinin Study Group, 2004; Ampawong et al., 2015). Thus, these patients may worsen the treatment process of COVID-19 and evolve to the need for hospitalization in an intensive care bed due to a decrease in the ability of hemoglobin to develop sepsis in the body with dysfunction of the multiple organ syndrome, usually during the diagnosis period and treatment of the patient with COVID-19 (Ramos, E. M., de Abreu et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., et al., 2020). Viral sepsis is ignored in clinical diagnosis (Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., et al., 2020). Therefore, the current evidence in the patient with COVID-19 demonstrates that they develop acute breathing difficulty or acute respiratory distress syndrome, and the prognosis depends on the body's ability to use the demands of peripheral oxygen in the tissues, and when not able to using develops hypoxia and ischemia (Castro et al., 2011; Cooper et al., 2020; Read et al., 2019; Cen et al., 2020).

In view of the above, it can be said that these dysfunctions are related to the serum biochemical marker due to changes in the hemoglobin profile (Gladwin & Kato, 2008; Ramos, E. M., de Abreu, et al., 2020). Furthermore, it is possible to identify that the worsening of patients with COVID-19 can be compared to the macrophage activation syndrome and that it may be associated with high levels of ferritin or due to the occurrence of a

cytokine storm (Ampawong et al., 2015).

Serum iron influences the activation of macrophages in order to increase the secretion of inflammatory cytokines found mainly in patients with COVID-19 (Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V. et al., 2020). In addition, serum iron can increase ferritin in support of the immune system as an intuition to defend the body against the invading virus (Castro et al., 2011).

The ideal serum iron levels in the host cells are necessary for the defense of the organism by the innate system to occur in an orchestrated way in response to the viral infectious process (Anstey et al., 2002). In fact, the innate system decreases the bioavailability of serum iron in order to decrease the replication of the virus in the acute phase of the infectious process (Ampawong et al., 2015). The increase and storage of serum iron carried out by ferritinin in macrophage cells will help in the fall of serum iron through the increase in serum ferritinin and this process was observed in the results obtained in our study as an acute response (Table 3), which will result in worsening of anemia (Anstey et al., 2002; International Artemisinin Study Group, 2004).

In addition, the worsening of anemia demonstrated a worsening of the main defense cells of patients in the positive control group (Treatment) with COVID-19 (Ampawong et al., 2015; Andrade et al., 2010). Therefore, serum iron and elevated ferritin in patients with COVID-19 can be used as a screening biomarkers for the severity of inflammation in patients with COVID-19 (Anstey et al., 2002; International Artemisinin Study Group, 2004; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V. et al., 2020).

Regarding serum zinc (Table 2 and Graph 2), the data presented in this study highlight the importance of further research in relation to the main role of zinc (Zn) in the immune system (Fawzi et al., 2005). Zinc is an essential microelement for nutrition and plays a role in the physiology of the immune system through activity as a signaling molecule (Ramos, E. M., Mendes dos Reis, et al., 2020; Ramos, E. M., de Abreu, A. C., de Freitas, et al., 2020)[29,3]. In addition, this element has specific anti-inflammatory functions in the human body, however, it has antioxidant stabilizing activities on the cell membrane (Fawzi et al., 2005; Prasad et al., 2011; Ramos, E. M., Mendes dos Reis et al., 2020). On the other hand, the deficit of zinc in the human body alters the survival of cells of the immune system by adversely affecting its specific cellular actions, such as phagocytosis, the production of cytokines and the death of target cells (Table 3) (Ramos, E. M., Mendes dos Reis et al., 2020). The zinc deficit causes changes in the mechanism of activation of the response of helper T cells and CD8+ (cytotoxic) T cells (Prasad, 2007; Prasad et al., 2011). Zinc deficiency causes immunodeficiency with the presence of severe lymphopenia which is characterized by a gradual decrease in the development of B cells in the bone marrow (Ramos, E. M., Mendes dos Reis, et al., 2020; Ramos, E. M., de Abreu, A. C., de Freitas, et al., 2020; Prasad, 2007). Thus, such highlighted evidence is in agreement with the results obtained in the present study (Table 2) (Prasad, 2007; Razzaque, 2020).

In fact, it is due to the zinc deficit that the human body presents a depression in the immune system, and thus, the symptoms of patients with the zinc deficit will worsen and evolve into one of the main differentiating signs in COVID-19 which is the impaired taste and smell (Table 2 and Graph 2) (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C., de Freitas, et al., 2020).

Zinc can protect cells from apoptosis and this action has a protective importance mainly in individuals with diabetes, and in this way zinc potentiates the effect of IFN-αgradually in order to neutralize the antagonistic function of IFN by SARS-CoV-2 protein (Ramos, E. M., de Abreu, A. C., de Freitas, et al., 2020; Giacomelli et al., 2020). Thus, it was possible to observe in this study the presence of neutrophilia in patients who evolved with the worsening through the hospitalization process until death (Table 3 and Graph 2) (Giacomelli et al., 2020; Prasad, 2007; D'Avolio et al., 2020). Deficit of zinc causes oxidative damage to phagocytosis in natural killer cells, macrophages and neutrophils (Prasad, 2007). This zinc deficit causes the neutrophil to have difficulty recruiting cells to the site of inflammation and, therefore, undergoes changes in the chemotactic response, which is why we have neutrophilia in the patient diagnosed with COVID-19 (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020). Therefore, when analyzing the results obtained in this study involving COVID-19, it can be considered that elements such as Zinc are supplemented in patients with COVID-19 being treated, however the serum dosage must be monitored by health professionals such as doctors, nurses and nutritionist on a regular basis during the treatment period (Razzaque, 2020; Read et al., 2019).

In the present study (Table 3 and Graph 2), as seen in the infectious period by COVID-19, zinc levels decreased significantly in patients causing worsening and death (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Fawzi et al., 2005). In view of the results obtained, this study emphasizes that zinc is effective in immunological protection and useful in zinc deficit known as hypozincemia (serum zinc <70 µg/dL) and may decrease the innate

and adaptive antiviral response (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C. et al., 2020; Fawzi et al., 2005).

Vitamin D is able to reduce the risk of infectious viral disease as it activates the main physiological actions grouped in forms of physical barrier, as well as cellular in the immune process and adaptive immunity (D'Avolio et al., 2020; Gruber-Bzura, 2018). For example, the respiratory system is considered as the primary site for viral invasion, the deposition of pathogenic microorganisms in the human body, which occurs through inspired air (Ramos, E. M., de Abreu, A. C. et al., 2020; Gruber-Bzura, 2018; Xu et al., 2020). Thus, the respiratory tract brings defenses that involve several factors such as the mucociliary escalator, receptor and effector molecules of the innate immune system (Grant et al., 2020). In this way, this sophisticated defense system is weakened by negative cellular factors capable of aggravating the symptoms of COVID-19, such as age over 60, presence of pre-existing diseases such as diabetes (Table 3) and the deficit of Vitamin D in serum blood (Table 3 and Graph 2) (Grant et al., 2020; Mohammad, Mishra, & Ashraf, 2019). The actions of vitamin D strengthen immunity through the induction of antimicrobial peptides, such as human catelicidin LL-37 and 1,25-dihydrixivitamin D, which will keep the junction clusters adhering to the gaps in the process of inducing antimicrobial peptide. Deficit of Vitamin D alters the effects of catelicidins, which will exhibit a direct antimicrobial action and decrease the amount of invading microorganisms such as COVID-19 (Prasad, 2007; Razzaque, 2020; Zhou et al., 2020).

The catelicidin has in the human body the function of including and inducing a specific type of pro-inflammatory cytokines that will stimulate the chemotaxis of neutrophils, monocytes, macrophages and T lymphocytes at the site of infection (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C. et al., 2020). Thus, they have the ability to eliminate the virus that causes COVID-19, which is a respiratory pathogen, since it induces apoptosis and autophagy of epithelial cells infected by the COVID-19 virus (Cooper et al., 2020; Gruber-Bzura, 2018). Such processes occur since the 1,25 (OH) D-Vitamin D receptor acts to promote the catelicidin gene, and according to the literature, Vitamin D through this receptor is capable of potentiating the catelicidin transcription. COVID-19 patients activate the innate immune system as a response to the virus and generate pro-inflammation with anti-inflammatory cytokines (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C. et al., 2020). Thus, Vitamin D assists in the treatment of patients with COVID-19, as it reduces the production of pro-inflammatory drugs, mainly auxiliary Cytokines T (Th1), TNF-α and IFN-γ with the increase in the expression of anti-inflammatory cytokines by macrophages (Table 3) (Ramos, E. M., de Abreu, A. C. et al., 2020).

Vitamin D also promotes the production of cytokines (Th2) mainly by suppressing the production of Th1 cells and this suppression is a complement of immune defense with actions mediated by specific cell types that will induce the production of regulatory T cells (Treg) by inhibition of the inflammatory process (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Huang et al., 2020).

From the results obtained in the presente study it was possible to verify that the serum concentrations of Vitamin D decrease with increasing age, that is, patients over the age of 60 had a high Vitamin D deficit and this is due to lower sun exposure and levels lower levels develop in patients with less sun exposure time (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C. et al., 2020). In addition, it should be taken into account that the ideal levels of Vitamin D in the blood serum decrease with the use of antiepileptic, antibiotics, anti-inflammatories, antihypertensive, antiretroviral, as well as the use of endocrine and some herbal medicines, and this occurs by activating the pregnane X receptor (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Ramos, E. M., de Abreu, A. C. et al., 2020). Therefore, the present study (Table 3) is consistent with the results obtained by Gruber-Bzura et al. (2018) in demonstrating that the deficit of Vitamin D reduces the risk of flu-like illnesses such as COVID-19 (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Mohammad, Mishra, & Ashraf, 2010).

In terms of the impact on Vitamin D deficit in patients with COVID-19, the present research demonstrated that Vitamin D has a direct relationship in the worsening of complications in COVID-19, because patients with normal blood levels had a slight percentage of worsening (Table 3, Graph 1 and Graph 2) (Mohammad, Mishra, & Ashraf, 2010; Ramos, E. M., Mendes dos Reis et al., 2020).

Such results prove that the deficit of Vitamin D contributes to the development of the Acute Respiratory Discomfort Syndrome and thus the lethality rates increase with age, comorbidity of chronic disease, being directly associated with a concentration of 1.25 (OH) lower 2D (Malek Mahdavi, 2020). The normal measurement in blood serum of Vitamin D increases the host's immune response against COVID-19 and its aggressive effects on all organs of the human system. The increase in serum vitamin D levels above 30 ng/mL has beneficial effects in reducing the incidence and severity of various viral diseases such as COVID-19 (Malek Mahdavi, 2020; Ramos, E.

M., Mendes dos Reis, Ramos, M. V. et al., 2020).

Patients with a BMI greater than 30 had a high rate of hospital admission due to COVID-19 (Table 1 and Graph 2) [31]. According to results published in the literature. And the COVID-19 enters the human body through the cells of the intestine and alveoli by the dysregulation of the renin-angiotensin system which will contribute to the activation of cytokines and this is deadly in patients who progress to Acute Respiratory Syndrome (Malek Mahdavi, 2020). The increase in obesity (BMI > 30) facilitates the increase in adiposity and affects the internal lung level, such as the alveolar, in which the distribution of immune defense cells can contribute to a maladaptive inflammatory cycle and secondary to the injury process in the body and generally is aggravated by the high presence of hypertension and diabetes mellitus (Malek Mahdavi, 2020). In addition, deficit of Vitamin D contributes to the increase of infections in the respiratory and gastrointestinal tracts (Jin et al., 2013).

The Italian population that died from COVID-19 had a very high prevalence of hypovitaminosis D due to the long winter [31]. Vitamin D has activity in the negative endocrine modulating renin-angiotensin system (RAS) and is able to inhibit renin expression and generation (Grant et al., 2020; Malek Mahdavi, 2020). In addition, Vitamin D is able to reduce the activity of the ACE2/Ang- (1-7)/MasR axis by inhibiting renin on the ACE/Ang II/AT1R axis and thus an increase in the expression and concentration of ACE2 occurs, MasR and Ang- (1-7) that will play a protective role in the potential against acute lung injury in Acute Respiratory Syndrome (Mohammad, Mishra, & Ashraf, 2010; Grant et al., 2020; Malek Mahdavi, 2020).

According to previous studies (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Mohammad, Mishra, & Ashraf, 2010; Jin et al., 2013) and the results observed in this case manuscript, it is possible to identify that Vitamin D can be used as a potential in the therapeutic approach to combat COVID-19.

In addition, the effect of vitamin D against COVID-19 is related to the suppression of the cytokine response and can be used as a biomarker capable of characterizing probabilities of aggravation caused by COVID-19 in populations such as the one investigated in this study and who present with hypovitaminosis D (Table 3 and Graph 2) (Ramos, E. M., Mendes dos Reis, Ramos, M. V. et al., 2020; Mohammad, Mishra, & Ashraf, 2010; Grant et al., 2020; Malek Mahdavi, 2020).

In addition, Ramos et al. (2020) suggests that hypovitaminosis D may explain geographical variations according to the lethality rates reported in COVID-19, indicating that the deficit in Vitamin D is related to the increase in mortality due to the pandemic. In fact, Vitamin D deficit decreases the TCD4+ lymphocyte count in viral infectious processes like COVID-19 and similarly occurs in HIV infections (Ramos, E. M., Mendes dos Reis, et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V. et al., 2020).

In addition, Vitamin D deficiency causes the risk of thrombosis, however, Vitamin D is able to control the expression of several genes relevant to cell proliferation, differentiation, apoptosis and angiogenesis (Mohammad, Mishra, & Ashraf, 2010).

According to the results obtained in this study, the deficit of Vitamin D increases the risk of death of patients (Graph 1 and Graph 2) and corroborate that the deficit of Vitamin D may be associated with an increase in the worsening of COVID-19, therefore, there is more evidence of the positive role of the use of Vitamin D in the treatment and prevention of aggravations in COVID-19 (Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V. et al., 2020; Mohammad, Mishra, & Ashraf, 2010; Jin et al., 2012).

The results of this study are in line with those published by Jakovac et al. (2020), which emphasizes the importance of assessing the status of vitamin D and the polymorphism of the VDR gene in the patient with COVID-19 in order to explain the disproportionate spreading behavior of COVID-19 mainly related to decreased immune functions in individuals with BMI>30, that is, the presence of overweight and/or obesity and diabetics related to greater pathogenicity (Table 3 and Graph 1) (Ramos, E. M., de Abreu et al., 2020; Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V. et al., 2020).

In fact, type II diabetic patients have hyperinsulinemia that will stimulate the reduction of Vitamin D status through sequestration in adipocytes by decreasing the negative charge of the plasma membrane between red blood cells, platelets and endothelial cells that will increase agglutination and cause example thrombosis (Mohammad, Mishra, & Ashraf, 2010; Cooper et al., 2020; Bishop et al., 2021; Mohammad, Mishra, & Ashraf, 2019).

5. Conclusions

The pandemic caused by COVID-19 in the world and in Brazil has shown a small decrease in cases of death, mainly in Brazil and in the state of Mato Grosso do Sul.

This study brought the possibility of using Zinc, Iron and Vitamin D as elements in order to potentially protect the

citizens of SARS-CoV-2 or alleviate their illness process by worsening the disease and act as biomarkers for the worsening. The deficiency of Zinc decreases the anti-inflammatory, immunomodulatory and antiviral activities, mainly in COVID-19 and results in the worsening of the disease, as well as the increase in the use of intensive care beds and the death of patients.

As noted, the iron deficit increases the death of patients hospitalized in an intensive care bed, especially in patients with a ferritinin level greater than 23.9 ng/mL. In addition, the level of normal serum iron tends to increase this percentage of ferritinin in the body, giving positive support to the innate immune system in the body's defense process against the invading COVID-19 virus.

Vitamin D has immunomodulatory actions in the body and can have favorable effects on the viral infectious process by COVID-19, and vitamin D deficit increases the risk of death for patients with COVID-19.

Author Contributions

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Institutional Review Board Statement

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Research Ethics Committee at the Federal University of Mato Grosso do Sul (Reference: CAAE: 42969320.0.0000.0021).

Informed Consent Statement

Applied to all participants according to Brazilian legislation for conducting research on human beings (Resolution 196/96 of the CNS and improved by Resolution 466/12).

Data Availability Statement

The data used to support the findings of this study are available from the corresponding author upon request.

Sample Availability

Samples of the compounds are available from the authors.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Alves, A., Martins, A., Adolphsson, S., Bockorny, B., Carleti, G., Cabral, G., ... & Vianna, A. (2007). Severe imported malaria: case report. *Revista Brasileira de terapia intensiva*, *19*(2), 231-236. https://doi.org/10.1590/S0103-507X2007000200016

Ampawong, S., Chaisri, U., Viriyavejakul, P., Prapansilp, P., Grau, G. E., Turner, G. D., & Pongponratn, E. (2015). A potential role for interleukin-33 and γ-epithelium sodium channel in the pathogenesis of human malaria associated lung injury. *Malaria journal*, *14*(1), 1-15. https://doi.org/10.1186/s12936-015-0922-x

Andrade, B. B., Reis-Filho, A., Barros, A. M., Souza-Neto, S. M., Nogueira, L. L., Fukutani, K. F., ... & Barral-Netto, M. (2010). Towards a precise test for malaria diagnosis in the Brazilian Amazon: comparison among field microscopy, a rapid diagnostic test, nested PCR, and a computational expert system based on artificial neural networks. *Malaria journal*, *9*(1), 1-11. PMID: 20459613; PMCID: PMC2883547. https://doi.org/10.1186/1475-2875-9-117

Anstey, N. M., Jacups, S. P., Cain, T., Pearson, T., Ziesing, P. J., Fisher, D. A., ... & Maguire, G. P. (2002). Pulmonary manifestations of uncomplicated falciparum and vivax malaria: cough, small airways obstruction, impaired gas transfer, and increased pulmonary phagocytic activity. *The Journal of infectious diseases*, *185*(9), 1326-1334. https://doi.org/10.1086/339885

Bishop, L. E., Ismailova, A., Dimeloe, S., Hewison, M., & White, J. H. (2021). Vitamin D and immune regulation: antibacterial, antiviral, anti-inflammatory. *JBMR plus*, *5*(1), e10405.

https://doi.org/10.1002/jbm4.10405

Brenner, H., Holleczek, B., & Schöttker, B. (2020). Vitamin D insufficiency and deficiency and mortality from respiratory diseases in a cohort of older adults: potential for limiting the death toll during and beyond the COVID-19 pandemic?. *Nutrients*, *12*(8), 2488. https://doi.org/10.3390/nu12082488

Castro, T. G. D., Silva-Nunes, M., Conde, W. L., Muniz, P. T., & Cardoso, M. A. (2011). Anemia and iron deficiency among schoolchildren in the Western Brazilian Amazon: prevalence and associated factors. *Cadernos de saude publica*, *27*(1), 131-142. https://doi.org/10.1590/S0102-311X2011000100014

Cen, Y., Chen, X., Shen, Y., Zhang, X. H., Lei, Y., Xu, C., ... & Liu, Y. H. (2020). Risk factors for disease progression in patients with mild to moderate coronavirus disease 2019—a multi-centre observational study. *Clinical Microbiology and Infection*, *26*(9), 1242-1247. https://doi.org/10.1016/j.cmi.2020.05.041

Chan, J. F. W., Yuan, S., Kok, K. H., To, K. K. W., Chu, H., Yang, J., ... & Yuen, K. Y. (2020). A familial cluster of pneumonia associated with the 2019 novel coronavirus indicating person-to-person transmission: a study of a family cluster. *The lancet*, *395*(10223), 514-523. PubMed PMID: 31986261. Epub 2020/01/28. eng. 2020.

Cooper, I. D., Crofts, C. A., DiNicolantonio, J. J., Malhotra, A., Elliott, B., Kyriakidou, Y., & Brookler, K. H. (2020). Relationships between hyperinsulinaemia, magnesium, vitamin D, thrombosis and COVID-19: rationale for clinical management. *Open Heart*, *7*(2), e001356. https://doi.org/10.1136/openhrt-2020-001356

D'Avolio, A., Avataneo, V., Manca, A., Cusato, J., De Nicolò, A., Lucchini, R., ... & Cantù, M. (2020). 25-Hydroxyvitamin D concentrations are lower in patients with positive PCR for SARS-CoV-2. *Nutrients*, *12*(5), 1359. https://doi.org/10.3390/nu12051359

Fawzi, W. W., Villamor, E., Msamanga, G. I., Antelman, G., Aboud, S., Urassa, W., & Hunter, D. (2005). Trial of zinc supplements in relation to pregnancy outcomes, hematologic indicators, and T cell counts among HIV-1–infected women in Tanzania. *The American journal of clinical nutrition*, *81*(1), 161-167. https://doi.org/10.1093/ajcn/81.1.161

Giacomelli, A., Ridolfo, A. L., Milazzo, L., Oreni, L., Bernacchia, D., Siano, M., ... & Galli, M. (2020). 30-day mortality in patients hospitalized with COVID-19 during the first wave of the Italian epidemic: a prospective cohort study. *Pharmacological research*, *158*, 104931. https://doi.org/10.1016/j.phrs.2020.104931

Gladwin, M. T., & Kato, G. J. (2008). Hemolysis-associated hypercoagulability in sickle cell disease: the plot (and blood) thickens!. *Haematologica*, *93*(1), 1. https://doi.org/10.3324/haematol.12318

Grant, W. B., Lahore, H., McDonnell, S. L., Baggerly, C. A., French, C. B., Aliano, J. L., & Bhattoa, H. P. (2020). Evidence that vitamin D supplementation could reduce risk of influenza and COVID-19 infections and deaths. *Nutrients*, *12*(4), 988. https://doi.org/10.3390/nu12040988

Gruber-Bzura, B. M. (2018). Vitamin D and influenza—prevention or therapy?. *International journal of molecular sciences*, *19*(8), 2419. https://doi.org/10.3390/ijms19082419

Huang, Y., Tu, M., Wang, S., Chen, S., Zhou, W., Chen, D., ... & Guo, L. (2020). Clinical characteristics of laboratory confirmed positive cases of SARS-CoV-2 infection in Wuhan, China: A retrospective single center analysis. *Travel medicine and infectious disease*, *36*, 101606. https://doi.org/10.1016/j.tmaid.2020.101606

International Artemisinin Study Group. (2004). Artesunate combinations for treatment of malaria: meta-analysis. *The Lancet*, *363*(9402), 9-17. https://doi.org/10.1016/S0140-6736(03)15162-8

Jin, H. J., Lee, J. H., & Kim, M. K. (2013). The prevalence of vitamin D deficiency in iron-deficient and normal children under the age of 24 months. *Blood research*, *48*(1), 40-45. https://doi.org/10.5045/br.2013.48.1.40

Malek Mahdavi, A. (2020). A brief review of interplay between vitamin D and angiotensin-converting enzyme 2: Implications for a potential treatment for COVID-19. *Reviews in Medical Virology*, *30*(5), e2119. PMID: 32584474. PMCID: PMC7362103. https://doi.org/10.1002/rmv.2119

Mohammad, S., Mishra, A., & Ashraf, M. Z. (2019). Emerging role of vitamin D and its associated molecules in pathways related to pathogenesis of thrombosis. *Biomolecules*, *9*(11), 649. https://doi.org/10.3390/biom9110649

OPAS, OMS. Folha informativa - COVID-19 (doença causada pelo novo coronavírus). (2020). Retrieved from https://www.paho.org/bra/index.php?option=com_content&view=article&id=6101:covid19&Itemid=875

Prasad, A. S. (2007). Zinc: mechanisms of host defense. *The Journal of nutrition*, *137*(5), 1345-1349. https://doi.org/10.1093/jn/137.5.1345

Prasad, A. S., Bao, B., Beck, F. W., & Sarkar, F. H. (2011). Zinc-suppressed inflammatory cytokines by induction of A20-mediated inhibition of nuclear factor-κB. *Nutrition*, *27*(7-8), 816-823. https://doi.org/10.1016/j.nut.2010.08.010

Ramos, E. M., de Abreu, A. C., de Freitas, S. L. F., de Lima, M. D., dos Reis, F. J. M., Ramos, H. V., ... & do Nascimento, V. A. (2020). COVID-19, rate of case factors and nutritional characteristics of patients dying in Italy and Brazil: a critical analyze. *Global J Health Sci*, *12*(7), 133. https://doi.org/10.5539/gjhs.v12n7p133

Ramos, E. M., Mendes dos Reis, F. J., de Souza, I. D., de Freitas, S. L. F., de Lima, M. D., & de Abreu, A. C. (2020). Does Vitamin D Supplementation have a Positive and Important Response in the Immune System on Covid-19 Pandemic? A Short Critical Analysis. *International Journal*, *8*(1), 33-39. https://doi.org/10.15640/ijmp.v8n1a5

Ramos, E. M., Mendes dos Reis, F. J., Ramos, M. V., de Souza, I. D., & Bochenek, L. D. S. (2020). Vitamin D produce antibodies in pandemic response to gripal viruses? A critical analysis. *Int J Clin Virol*, *4*, 023-026. https://doi.org/10.29328/journal.ijcv.1001010

Razzaque, M. S. (2020). COVID-19 pandemic: can maintaining optimal zinc balance enhance host resistance?. *The Tohoku journal of experimental medicine*, *251*(3), 175-181. PMID: 32641644. https://doi.org/10.1620/tjem.251.175

Read, S. A., Obeid, S., Ahlenstiel, C., & Ahlenstiel, G. (2019). The role of zinc in antiviral immunity. *Advances in nutrition*, *10*(4), 696-710. https://doi.org/10.1093/advances/nmz013

Xu, T., Huang, R., Zhu, L., Wang, J., Cheng, J., Zhang, B., ... & Liu, L. (2020). Epidemiological and clinical features of asymptomatic patients with SARS-CoV-2 infection. *Journal of medical virology*, *92*(10), 1884-1889. https://doi.org/10.1002/jmv.25944

Zhou, F., Yu, T., Du, R., Fan, G., Liu, Y., Liu, Z., ... & Cao, B. (2020). Clinical course and risk factors for mortality of adult inpatients with COVID-19 in Wuhan, China: a retrospective cohort study. *The lancet*, *395*(10229), 1054-1062. https://doi.org/10.1016/S0140-6736(20)30566-3

Midwives' Perceptions Regarding the Use of the Cardiotocograph Machine as an Intrapartum Monitoring Tool in Namibia: A Qualitative Research Study

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Abstract

Although, at the time of this study, the cardiotocograph machine was the acceptable monitoring tool to be used intrapartum, its appropriate use was a matter of concern for midwives globally. This article reports the findings of a qualitative study which investigated the perceptions of midwives, who were working in a labor ward in a public referral hospital in Namibia, regarding the use of the cardiotocograph machine. The objectives of the study included: to explore and describe the perceptions of midwives working in a labor ward in Namibia regarding the use of the cardiotocograph machine as a labor monitoring tool; and to explore and describe how midwives working in a labor ward in Namibia perceived informing women who were in labor about the use of the cardiotocograph machine as a labor monitoring tool.

The study site was a public referral hospital which offered services to the five northern regions of Namibia. The requisite data was collected using semi-structured, one-on-one interviews which were conducted with seventeen (17) purposively selected participants. The interviews were recorded on an audio device. The spiral method of data analysis was adopted. The study findings revealed that the participants had varying perceptions on the use of the cardiotocograph machine intrapartum and, as such, perceived its use as a challenge. It was concluded that midwives need to be empowered via refresher courses with regard to the use of cardiotocograph machine to ensure optimum results.

Keywords: cardiotocograph machine, intrapartum monitoring tool, Namibia

1. Introduction and Background

Labor is stressful for both the mothers and the midwives. The pressure on the midwives arises from their knowledge regarding the birthing physiological stress experienced by both the mother and the fetus while the mother must also meet the expectations of the family. In addition, Sowmya et al. (2013) also highlight that the health of the fetus and of the mother who is in labor are inextricably linked. It is for these reasons that intrapartum monitoring becomes crucial and, hence, the importance of the role played by the cardiotocograph (CTG) machine. Health facilities in Namibia moved from using the fetoscope to the cardiotocograph machine in response to the unexpected complications that may occur during labor.

According to Chudacek et al. (2014), cardiotocograph monitoring is a globally accepted, safe and reliable method of assessment of fetal wellbeing intrapartum and is used mainly for diagnostic purposes, especially in relation to the fetal heartbeat and the nature of the uterine contractions. In addition, health professionals in the USA of the opinion that the use of the cardiotocograph machine is safe and reassuring because it provides a record of the fetal condition in utero (Smith et al., 2012). In the United Kingdom, cardiotocograph monitoring is a commonly used form of fetal assessment in pregnancy because of its reliability although its routine use is not recommended in

order to avoid mismanagement during the intrapartum period (Gyte, 2015). Thus, mastering the principles regarding the use of the cardiotocograph machine would be of assistance to midwives as it would enable them to monitor both the fetal condition and labor (Sowmya et al., 2012). Mastering these principles would provide midwives with reassurance in relation to the required relief in respect of neonatal mortalities and, thus, represent a positive step towards the realization of the 2030 sustainable development goals (SDGs).

The cardiotocograph machine may be used either intermittently or continuously as an intrapartum monitoring tool, depending on the fetal condition (Rhose et al., 2014). However, it has been found that midwives are still using the cardiotocograph machine incorrectly intrapartum despite the frequent in-service training on its use which has been reported and the literature which has been made available to midwives. It is, nevertheless, understood that in-service cardiotocograph training would have positive results in relation to its correct use, thus effecting an improvement in fetal outcomes (Sowmya et al., 2014).

At the time of the study the incidence of neonatal mortality globally was reported to be 2.6 million, while the neonatal death rate for Namibia was 17, 8/1000 live birth (UNICEF Report, 2018). This statistic is significant in view of the fact that it is known that the rate of neonatal mortality and morbidity is alarmingly high in low income countries such as Namibia. On the other hand, neonatal morbidity in high income countries, such as America, is reported to be low with an average of 4 per 1000 live births while Sweden has the lowest neonatal morbidity globally, namely, a rate of 1.6 deaths per 1000 live births (UNICEF Report, 2018). In addition, neonatal mortality is declining in the United Kingdom (UK) which has a rate of 2.5/1000 live births (Drapper et al., 2018). Notwithstanding other measures put in place and the skills of the midwives, these statistics are also attributed to the use of cardiotocograph machines in these countries. Thus, it is recommended that the low income countries learn from these countries how best to use the cardiotocograph machine intrapartum, thereby reducing their rates of neonatal mortalities.

A further benefit of using the cardiotocograph machine correctly is the concomitant reduction in litigation and claims, thus saving governments considerable fiscal reserves. Midwives are, thus, encouraged to embrace the correct use of the cardiotocograph machine in all countries, but especially in the developing countries, to avoid such litigation. Accordingly, the aim of this article is to present the findings that emerged from the study which explored midwives' perceptions regarding the use of the cardiotocograph machine as an intrapartum monitoring tool in Namibia.

2. Design and Methods

The study used a qualitative, explorative, descriptive and contextual research design. The research population comprised midwives working in the labor wards in a public referral hospital in Namibia. Voice-recorded, semi-structured interviews were used to collect the requisite data from seventeen purposively and criterion based sampled participants. The criteria included the participants being registered and enrolled midwives who had been working in labor wards for more than six months prior to the data collection. The interviews were conducted in a private room close to the labor wards to ensure the immediate availability of the participants should an emergency occur in the labor wards. All the participants responded to the main question:

"Can you tell me how you feel about your use of the cardiotocograph on women in labor?"

An interview schedule was also used to facilitate the progress of the interview (Creswell et al, 2014). The interview sessions lasted for an average of 40 minutes each and involved an average of two days until the completion of the data collection process. Data saturation is determined by repetition of themes and no new information obtained (Brink et al., 2012:141). When repetition of themes occurred in this study the researcher concluded that saturation had occurred and that the sample size is now complete. Therefore the seventeen midwives who were interviewed formed the sample size of this study and were representing the whole population of Namibian midwives working at state hospitals who share their perceptions regarding the use of cardiotocograph as an informative labor monitoring tool.

A pilot study preceded the main study during which two participants from the same research site were interviewed. The data collected from these interviews was included in the main study as no methodological errors were identified during the pilot study although minor interview skill related errors did emerge (Creswell et al., 2014).

The demographic profiles of the seventeen participants who were interviewed are presented below:

Table 1. Demographic profiles of participants

Number of Participant	Age	Highest Qualification	Years of Experience	Position/rank	Language
1.	38 years	Diploma in Nursing	8 years	Registered nurse	Oshiwambo
2.	25 years	Degree in Nursing	3 years	Registered nurse	Oshiwambo
3	48 years	Degree in Nursing	4 years	Registered nurse	Oshiwambo
4.	29 years	Certificate in Nursing	1 year	Enrolled nurse	Oshiwambo
5.	27 years	Certificate in Nursing	7 years	Enrolled nurse	Oshiwambo
6.	44 years	Degree in Nursing	15 years	Registered nurse	Oshiwambo
7.	39 years	Diploma in Nursing	13 years	Registered nurse	Oshiwambo
8.	28 years	Certificate in Nursing	2 years	Enrolled nurse	Oshiwambo
9	30 years	Diploma in Nursing	5 years	Registered nurse	English
10.	52 years	Diploma in Nursing	29 years	Registered nurse	Oshiwambo
11.	51 years	Degree in Nursing	4 years	Registered nurse	Oshiwambo
12	28 years	Certificate in Nursing	1 years	Enrolled nurse	Oshiwambo
13.	35 years	Degree in Nursing	10 years	Advanced midwife	English
14.	30 years	Degree in Nursing	10 years	Advanced midwife	English
15.	45 years	Degree in Nursing	25 years	Advanced midwife	English
16.	38 Years	Diploma in Nursing	8 years	Registered nurse	Oshiwambo
17.	34 years	Degree in Nursing	2 years	Registered nurse	Oshiwambo

2.1 Analysis

The interviews were transcribed verbatim by the researcher who then used Creswell's spiral method of data analysis (Creswell, 2009:186). This method entails organizing all the data and reading it several times in order to get a sense of what it contains as a whole, identifying the general themes and summarizing the data in order to answer the research questions (Leedy & Ormrod, 2016). Copies of the original transcripts together with the guide used for the data analysis were forwarded to the independent coder for data analysis (Creswell, 2015). The independent coder was a qualified midwife with an advanced midwifery specialization qualification as well as a master's degree. In addition, the independent coder also had experience in both qualitative research design and in conducting interviews. A meeting was scheduled with the independent coder to finalize the data analysis and to come to a consensus. The researcher, supervisor and independent coder all agreed on the themes which had emerged.

2.2 Ethical Approval

The study was approved by the Faculty Postgraduate Studies Committee (FPGSC) which also accorded ethical clearance for the study to be conducted (**H16-HEA-NUR-006)**. Furthermore, the Department of Health in Namibia as well as the hospital manager of the public referral hospital also approved the study in writing. Written informed consent for the interviews and permission to record the interviews were obtained from all the participants prior to the interviews. The names of the participants selected to participate in the study were not revealed to the nurse managers in an effort to ensure the privacy and confidentiality of the participants. In addition, the participants' names were not used in the report of the study findings. The participants were reminded of their rights in respect of voluntary participation in the study and also that they were free to withdraw from the study at any stage without any repercussions. Lastly, the participants were informed of the compulsory publication of an article by the researcher on the study but were assured that they would not be identified in the article.

3. Findings

The main themes that emerged were as follows:

- The midwives had varying perceptions regarding the use of the cardiotocograph machine.
- The midwives still perceived the interpretation of the cardiotocograph as a challenge and expressed the need for refresher courses.

- The midwives revealed that, in the main, they had limited communication with women in labor regarding the use of the cardiotocograph.

Theme 1. The participants had varying perceptions regarding the use of the cardiotocograph machine.

It was found that, as compared to the fetoscope, the participants perceived the cardiotocograph machine as a useful labor monitoring tool that assisted with the timeous discovery of complications. The participants also appreciated the use of the cardiotocograph machine as it saved them time and allowed them to attend to other patients while the machine was running. One midwife commented:

"*So, I feel that the CTG is really helpful and, sometimes, it is like you do other things while the CTG is monitoring once you have attached the woman to a CTG*" **(P1)**

The other participants also appreciated the use of the cardiotocograph machine based on its ability provide accurate and reliable results, thus assuring them of fetal wellbeing during the intrapartum period. However, it was also mentioned that such accuracy is guaranteed only if the CTG is properly used. They expressed their appreciation as follow:

"*You will be able to ascertain the accurate FHR that is within the normal range as it has a digital screen and you will be able to see the numeration of the heart. It is also reliable and reassures the mother that the baby is ok as you explain the procedure to the mother*" **(P12).**

However, some of participants were clearly irritated by the perceived abuse of the cardiotocograph machine

These participants expressed their dissatisfaction as follows:

"*Besides, I think we are abusing the CTG machine because I think we can use it more in critical cases, for example, if we suspect fetal distress, then you can use it to confirm that but now people are abusing it*" **(P15)**

"*However, the disadvantage is that it confines the women to bed, also if the woman is contracting and there is that tie (pointing at the clip of the CTG belt), it could be irritating and you can see they are not comfortable*" **(P14)**

Thus, although the participants clearly appreciated the use of the CTG tool, the study also found that the majority were experiencing difficulties with interpreting the cardiotocograph. It was also reported that such difficulties had the potential to prevent them from identifying abnormalities and applying measures to address the situation. Accordingly, the participants indicated the need for cardiotocograph refresher courses.

Theme 2. The participants still perceived the interpretation of the CTG as a labor monitoring tool as a challenge and expressed the need for refresher courses.

The majority of the participants reported that they were continuing to experience difficulties with the interpretation of the CTG while such difficulties reportedly had the potential to prevent them from identifying abnormalities and applying measures to address the situation. Accordingly, the participants indicated the need for cardiotocograph updates.

It emerged that most of the participants, especially those who were newly qualified, were still experiencing some difficulties with interpreting the cardiotocograph, although they relied on the doctors for an interpretation, at times they were not in agreement with the findings of the doctors. One participant stated:

"*Yes, the doctors, you can call the doctor when you have a problem and they act if they want to act or they can keep on saying give another hour or so. We are not really in agreement with the doctors*" **(P14)**

"*Yes, because our level of understanding is not the same as that of the doctors and those with years of experience in the labor ward. Sometimes you are new from the university and you are not exposed to such things, thus we rely on doctors to interpret the cardiotocograph for us*" **(P14)**

It is for these reasons that the participants expressed the need of in-service training in order to update their skills in relation to both the CTG and the cardiotocograph interpretation.

Theme 3. The participants revealed that, in the main, they had limited communication with women in labor women regarding the use of the CTG.

Although midwives are expected to provide detailed information to women in labor regarding the use of the cardiotocograph machine, the study found that they were not doing this as expected due to their own limited knowledge and skills. The participants had the following to say in this regard:

"*Yes, briefly and shortly, just to my knowledge, I just tell them that I will put you on this machine to check the FHR of your baby. I cannot explain more because some of the things I also don't know*" **(P3)**

Women in labor are always concerned about the wellbeing of the unborn fetus. A failure either to respond to this concern or to explain to them how they should behave while being attached to the CTG machine may result in unnecessary worries on their part which may, in turn, impact adversely on the progress of their labor.

4. Discussion

The findings of the study revealed that the participants had varying perceptions regarding the use of the cardiotocograph machine. It emerged that the majority of the participants appreciated the availability of the cardiotocograph machine as it could be used to monitor and detect abnormal fetal heart rates. However, this role was limited to their ability both to use the cardiotocograph and to interpret the results obtained from it. Indeed, Sajidah (2015) maintains that 80% of fetal deaths occur during the ante-partum period due to the lack of a proper diagnosis of fetal asphyxia caused by hypertension, diabetes mellitus or fetal congenital malformation. Women who are in labor and who suffer from such conditions require continual monitoring using the CTG (Kavanagh, 2015) as this will ensure both the early identification of complications and that the labor process is under control.

In the past midwives used a fetoscope to detect FHR. However, this has been replaced by the CTG machine (Hasting, 2015). Nevertheless, this transition requires skill in respect of both the use of the CTG and the interpretation of the CTG results in order to obtain the best results and this is creating problems for many of the midwives (Baber et al., 2013). In support of the importance of the correct use of the CTG Thellesen (2016) points out that errors in the management of fetal monitoring are the main cause of hypoxic brain injuries among newborns in cases of substandard care. Regular CTG training improves fetal outcomes as such training enables the users to master the skills involved in its use (Thellesen, 2016). However, according to the findings of this study such training is reportedly not happening in most Namibian hospitals and, thus, the midwives are experiencing difficulties in reading the CTG traces while neonatal mortality remains alarmingly high in Namibia.

Finally, the participants revealed that, in the main, they have limited communication with the women in labor regarding the use of CTG. This finding is supported by Mapute (2018) who indicated that the unlimited communication which was displayed by participants during the study was thought to facilitate participation during labor. However, it has been noted that, where interventions are required, most women would like to receive relevant information from competent health care providers delivered in a way which they are able to understand (WHO, 2018), thus alleviating unnecessary worries on their part which may impact adversely on the progress of their labor. Furthermore, women who are in labor appreciate and value effective communication as one of the key components of respectful maternal care (RMC) (WHO, 2018). Effective communication skills may be developed by training to improve the communication between midwives and women who are in labor.

4.1 Limitations

This qualitative study was conducted in one public hospital and, therefore, it is not possible to generalize the results to other public hospitals. In addition, the study focused on the perceptions of midwives only while their knowledge and experience were not taken account.

5. Conclusion

This study discussed the midwives' perceptions regarding the use of the CTG as a labor monitoring tool. At the time of the study CTG machines were being used in most public and private hospitals globally to monitor fetal and maternal wellbeing during labor. It emerged from this qualitative study on the perceptions of midwives that the participants claimed that the CTG is reliable. In addition, the midwives expressed the view that the CTG machine also saved time, especially when they had to monitor several women who were in labor. However, it was also found that the participants were experiencing challenges when they used the CTG machine, especially in relation to the interpretation of the CTG graph. Some of the midwives revealed that they lacked the skills required to interpret the CTG graph and that this deficiency needed to be addressed via continuous refresher courses. Several studies have highlighted that many of the high income countries, such as Sweden and the United Kingdom, are using the cardiotocograph machine effectively and that the machine has the potential to assist with the avoidance of the neonatal deaths. Consequently, the neonatal death rates are declining in these countries. Thus, low income countries with high neonatal death rates could use these countries as a benchmark. In addition, the CTG has been found to be the safest, fastest and most reliable machine that the midwives trust and on which they depend during the monitoring of labor. Another challenge which the participants highlighted was their inability to adequately explain the purpose of the CTG to women in labor. It is possible that this challenge is due to limited knowledge and skills on their part. However, a failure to explain to them how they must behave when being attached to CTG machine may cause the women unnecessary worry that, in turn, may have an adverse impact on the progress of their labor. It is, therefore, recommended that further research be conducted to ascertain the perceptions of women

in labor regarding the use of the CTG during their labor. Lastly, it was evident that there was a need for midwives to be empowered via refresher courses with regard to the use of the cardiotocography machine in order to ensure the best outcomes possible.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Barber, V., Linsell, L., Locock, L., Powell, L., Shakeshaft, C., Lean, K., ... & Brocklehurst, P. (2013). Electronic fetal monitoring during labour and anxiety levels in women taking part in a RCT. *British Journal of Midwifery*, *21*(6), 394-403.

Chudáček, V., Spilka, J., Burša, M., Janků, P., Hruban, L., Huptych, M., & Lhotská, L. (2014). Open access intrapartum CTG database. *BMC pregnancy and childbirth*, *14*(1), 1-12. https://doi.org/10.1186/1471-2393-14-16

Creswell, J. W. (2015). *Research design: qualitative, quantitative and mixed methods approaches* (3rd ed.). London: Sage.

Creswell, J. W., Ebersohn, L., Eloff, I., & Ferreira, R. (2014). *First steps in research* (14th ed.). Pretoria: Van Schaik.

Drapper, E. S., Gallimore, I. D., Kurinczuk, J. J., Smith, P. W., Boby, T., Simth, L. K., & Manktelow, B. N. (2018). *MBRRACE: UK perinatal mortality surveillance report*. Retrieved April 24, 2019 from http://mbrrace-uk-perinatal mortality surveillance report

Grivell, R. M., Alfirevic, Z., Gyte, G. M., & Devane, D. (2015). Antenatal cardiotocography for fetal assessment. *British Journal of Health Care Management*, (9), 30-40. https://doi.org/10.1002/14651858.CD007863.pub4

Hastings, C. (2015). The role of fetal monitoring in intrapartum care. *British Journal of Healthcare Management*, *21*(4), 166-170. https://doi.org/10.12968/bjhc.2015.21.4.166

Hoad-Robson, R. (2013). *Cardiotocography*. Retrieved March 20, 2021, from http://patient.info/health/cardiotocography

Kavanagh, S. (2015). *Intrapartum fetal monitoring*. Retrieved April 8, 2019, from http://patient.info/doctor/intrapartum-fetal-monitoring

Kruk, M. E., & Lawyn, J. (2018). *UNICEF report: Every child alive, the need to end newborn deaths*. Retrieved April 24, 2019, from https://dataunicef.orga/wp-content/upload/2018/02/every-child-alive-report

Kumar, R. (2014). *Research methodology: a step by step guide for beginners*. Los Angeles: Sage.

Leedy, P. D., & Ormrod, J. E. (2016). *Practical research: planning and design*. New York: Pearson.

Mapute, M. (2018). Support provided by midwives to women during labour in a public hospital, Limpopo Province, South Africa: A participant observation. *BMC Pregnancy & Child Birth Journal,* (8), 1471-23930. https://doi.org/10.1186/s12884-018-1860-8

Rhose, S., Ayesha, M. F., Vandenbussche, F. H., Van Drongelen, J., & Van Dillen, J. (2014). Inter- and intra-observer agreement of non-reassuring cardiotocography analysis and subsequent clinical management. *Acta Obstetrician Etgynecologica Scandinavica, 9*(3), 596-602. https://doi.org/10.1111/aogs.12371

Sajidah, S. O. (2015). Effectiveness of an education program concerning cardiotocography on nurse midwives knowledge in maternity hospitals at Baghdad city. *International Journal of Nursing,* (4), 33-44.

Smith, V., Begley, C., Clarke, M., & Devane, D. (2012). Professional views of fetal monitoring during labour: a systematic review and thematic analysis. *BMC Pregnancy & Childbirth Journal,* (12), 166. https://doi.org/10.1186/1471-2393-12-166

Sowmya, M. N., Gayathri, P., Ramesh, C., & Jothi, K. (2013). Effectiveness of cardiotocography training programme on knowledge and skill among nurses working in maternity units. *Nitte University Journal of Health Science, 3*(4), 87-92.

Thellesen, L. (2016). *A national cardiotocography education programme: development, validation and impact on interpretation skills and birth hypoxia*. University of Copenhagen.

World healeth Organization [WHO]. (2018). Intrapartum care for a positive childbirth experience. Retrieved March 20, 2019 from https://extranet.who.int/...care.../who-recommendation-respectful-maternity-care

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Refractive Errors and Binocular Vision Anomalies among Young University Students

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Abstract

It has been reported that refractive errors (RE) and binocular vision (BV) anomalies are common among university students. In this study we aimed to assess RE and BV status among university students in Saudi Arabia, and its relation to the academic performance. We recruited 109 participants (aged from 18 to 21 years). Visual acuity (VA) and objective refraction were used to assess the refractive status. Cover test, near-point convergence (NPC) and stereopsis tests were used to assess the BV status. Convergence insufficiency symptom survey (CISS) was applied to quantify near-work related symptoms. Mann-Whitney U test (p value was set as $p < 0.05$) was used to compare VA, CISS, NPC and the academic performance between the groups who had heterophoria versus orthophoria. We found that there was only 38% emmetrope, while the percentage of heterophoria was 45.8%. The academic performance was not statistically different among the two groups, but CISS and stereopsis scores were significantly different ($p < 0.03$). We concluded that RE and BV anomalies were common among university students in Saudi Arabia, but did not affect the academic performance. More studies are warranted to understand the low scores of CISS and stereoacuity, and their association with RE and BV anomalies.

Keywords: binocular vision, refractive error, university students

1. Introduction

There has been a worldwide growing concern regarding the prevalence increase for refractive error (RE) and binocular vision (BV) anomalies. According to the World Health Organization (WHO), the rise in the prevalence of RE and BV anomalies is a significant global public health concern (Bourne et al., 2017; French, Morgan, Burlutsky, Mitchell, & Rose, 2013; Wen et al., 2013). Binocular vision anomalies may include, but are not limited to, convergence insufficiency, heterophoria and unparalleled visual axes. These disorders can have an impact on many aspects of life, including academic performance, occupations and near work tasks. The specific mechanism of the presence of refractive error and the degree of binocular vision anomalies remains elusive.

Myopia is the most common RE and is found to be associated with higher levels of education and intensive near work (Wong, Foster, Johnson, & Seah, 2003). It was found that, in children, students with myopia had low academic success and poorer distance visual acuity (Hopkins, Narayanasamy, Vincent, Sampson, & Wood, 2020; Joseph, 2014). Hyperopia, on the other hand, is less common than myopia and has been found to significantly affect near-work tasks in children (Kulp et al., 2016). The amount of hyperopia and myopia could be changed as the eye grows. Consequently, there might be an effect on academic performance in adults. This led to the question of whether or not the presence of RE would influence educational achievement/near-work.

It has been reported that poor academic performance in school children is associated with BV anomalies (Falkenberg, Langaas, & Svarverud, 2019; Wood, Black, Hopkins, & White, 2018). On the other hand, it was found that BV anomalies are common in adult participants over 40(Leat et al., 2013; Pickwell, Viggars, & Jenkins, 1986). However, little is known about the BV status of adults over the age of 20 and under 40. College students are included in this age range, and it is crucial to assess their BV status because they certainly have a considerable number of near-work tasks for their study and work.

BV anomalies were found to be common among university students (García-Muñoz, Carbonell-Bonete,

Cantó-Cerdán, & Cacho-Martínez, 2016; Hokoda, 1985; Lara, Cacho, García, & Megías, 2001). Porcar (Porcar & Martinez-Palomera, 1997) demonstrated that many college students had BV anomalies, which negatively impacted their performance. Garcia-Munoz (García-Muñoz et al., 2016) suggested that university students should be clinically aware of BV anomalies. There is uncertainty regarding the effect of BV on the academic performance of university students since this effect could be considered as a milestone for achieving good academic performance, therefore, a stronger profile for job applications.

The assessment of RE and BV status among university students is unclear in Saudi Arabia. This study therefore aimed to assess the RE and BV status and their relationship with academic performance among university students.

2. Methods

2.1 Study Design

This study was a cross-sectional study conducted among first-year students (preparatory year) at Qassim University, Qassim, Saudi Arabia. The study included 109 participants who were randomly enrolled; their age ranged from 18-21 years old (mean ± standard deviation [SD]: 19.2 ± 0.8). Students were grouped based on their non- strabismic binocular vision (normal group or heterophoria group). This study was approved by local Ethics Committee at ministry of health - Qassim - Qassim office and was conducted according to the Declaration of Helsinki guidelines. Participants attended one visit, and all gave written informed consent after having the procedures of the study explained.

2.2 Study Procedures:

Medical/ocular history was taken for each participant, followed by visual acuity (VA) measurement, which was taken under monocular and binocular conditions. However, only the VA of the right eyes was included in the analysis. Also, data on Grade Point Average (GPA) was collected according to the students' self-report to indicate academic performance for the students.

The CISS Questionnaire

All participants were required to complete the convergence insufficiency symptom survey (CISS) questionnaire (Rouse et al., 2004). The CISS questionnaire is a valid and reliable questionnaire that consists of 15 items meant to quantify near work-related symptoms. A score of 21 or more is considered symptomatic when used with adults (Rouse et al., 2004).

2.3 Clinical Procedures

At first, objective refraction was performed with auto-keratorefractometer Topcon KR8900 (Topcon Co., Tokyo, Japan). The spherical equivalent of ≤ -0.5 diopter was considered myopia in this study, while hyperopia was defined as $+0.5$ diopters or greater. Heterophoria was assessed by unilateral and alternating prism cover tests performed at a distance (6 m) and near (40 cm) with the best possible correction. The magnitude of the deviation was measured using the alternating cover test and prism bar. *Exophoria* was defined as near exophoria more than 6 prism diopter (PD) and/or distance exophoria more than 3 PD, while *Esophoria* was defined as any near esophoria and/or distance esophoria more than 1 PD (Abdi, Lennerstrand, Pansell, & Rydberg, 2008).

Near point of convergence (NPC) was subsequently evaluated with the push-up technique by using Royal Air Force (RAF) ruler, and described as the distance at which the patient first noticed diplopia, or as the distance where convergence was visibly broken (whichever comes first). *Convergence insufficiency* was defined as NPC of 10 cm or greater in this study, accompanied by greater exophoria at near than at distance (Abdi et al., 2008; Leat et al., 2013). Finally, near stereo-acuity was measured using Titmus-fly stereopsis test (Stereo Optical Co., Inc., Chicago, IL, USA) (Garnham & Sloper, 2006), while color vision was screened with Ishihara plates (Birch, 1997).

2.4 Statistical Analysis

Statistical analyses were performed with the SPSS software package (V. 22.0, SPSS Inc., Chicago, IL, USA). Descriptive statistics are presented as (mean ± standard deviation) and frequencies as percentages. As all variables were non-normally distributed, the Mann-Whitney U test was used for the statistical comparison between groups. For categorical variables, cross-tabulation was used to describe the distribution of variable values, while Pearson Chi-Square was used for statistical comparison. Spearman's rho was used to evaluate associations between variables; $P < 0.05$ was considered statistically significant in this study.

3. Results

There were no statistically significant differences between the groups in age (Independent t-test p= 0.39). In this study, 50 out of 109 participants had heterophoria (45.8%), of which 14 participants (12.8%) had convergence

insufficiency (Table 1). Emmetropia was only reported in 39.4% of participants, where myopia was the most common refractive error (44.9%), followed by hyperopia (8.2%), and simple astigmatism was reported only in 7.3%. Color vision tested by Ishihara plats showed only 2 cases affected (out of 109).

Table 1. Prevalence of heterophoria and convergence insufficiency in the study sample (n=109)

Category	Sample (%)
Normal Binocular Vision	59 (54.2%)
Heterophoria	50 (45.8%)
esophoria at near	18 (16.5%)
exophoria at near	32 (29.4%)
Convergence insufficiency	14 (12.8%)

In this study, 54% of students with heterophoria were symptomatic (CISS score mean ± SD 20.5 ± 9.8) compared to 23% of the normal group (CISS score mean ± SD 20.5 ± 9.8), which was significantly different (p= 0.027) (Figure 1 and Table 2). Near stereo-acuity, measured by the Titmus-fly test, was significantly better in the normal group (mean ± SD 75 ± 82) than heterophoria group (136 ± 126, p= 0.01, Figure 2). Other variables, including VA, refractive error, NPC, and GPA, were not significantly different between groups (Table 2).
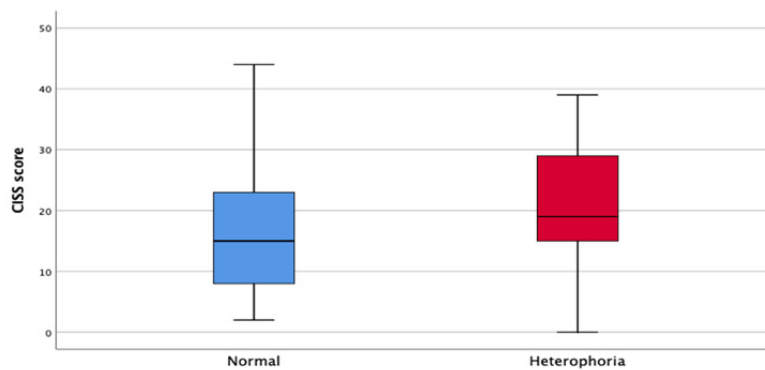
Figure 1. Box plot of CISS score for normal and heterophoria groups
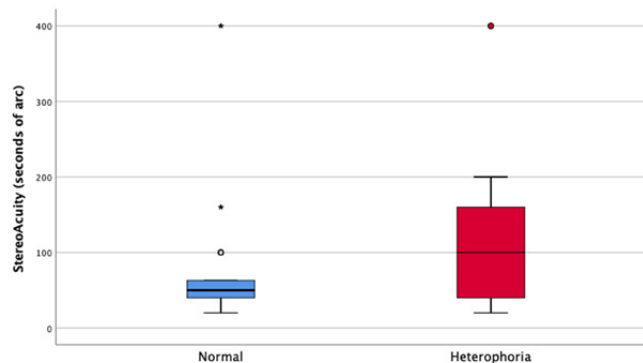
Figure 2. Box plot of stereo-acuity score for normal and heterophoria groups

Table 2. Group means and standard deviations of normal and heterophoria groups for different variables together with the outcomes of Mann-Whitney U analysis

Variable	Normal mean± SD	Heterophoria mean± SD	Mann-Whitney U P value
VA (Right Eye LogMar)	0.1 ± 0.1	0.1 ± 0.1	0.8
CISS score	16.6 ± 10.1	20.5 ± 9.9	**0.027**
NPC (Break) cm	6.97 ± 2.1	8.8 ± 5.2	0.3
NPC (Recovery) cm	9.7 ± 2.4	11.7 ± 5.4	0.2
Stereo-acuity	75 ± 82	136 ± 126	**0.01**
GPA (out of 5)	3.8 ± 0.9	3.9 ± 0.6	0.5

3.1 Correlation Analysis

The associations between different clinical variables are listed in table 3. Heterophoria showed moderate positive correlation CISS score (Spearman's r = 0.31, P-value =0.001) and slight positive correlation with stereo-acuity and NPC (recovery). Refractive error was significantly correlated with VA and stereo-acuity (Table 3). GPA did not correlate with any other parameters.

Table 3. Spearman rho (R) Correlation coefficients (r) analysis of different parameters and their p values

Variable	Correlation analysis	heterophoria	CISS score	Refractive error	VA (right eye)
heterophoria	r	1	**0.31**	0.07	0.04
	p value	.	**<0.01**	0.45	0.67
CISS score	r	**0.31**	1	-0.004	0.15
	p value	**<0.01**	.	0.96	0.11
Refractive error	r	0.07	-0.004	1	**0.53**
	p value	0.45	0.96	.	**<0.01**
Right VA	r	0.04	0.15	**.529**	1
	p value	0.67	0.11	**<0.01**	.
GPA	r	-0.12	0.06	-0.2	-0.15
	p value	0.37	0.61	0.12	0.25
NPC (Break)	r	0.21	0.02	0.01	0.07
	p value	0.04	0.83	0.94	0.45
NPC (Recover)	r	**0.19**	0.05	-0.02	0.05
	p value	**0.047**	0.59	0.82	0.61
Stereo-acuity	r	**0.24**	-0.01	0.18	-0.03
	p value	**0.011**	0.87	0.058	0.74

4. Discussion

The study undertook whether the RE and BV hamper students' abilities to succeed in academic performance at the university level. The results of this study showed that about 54% of the participants had normal binocular vision. Students with abnormal binocular vision had significantly lower scores of stereoacuity and the CISS compared with those who had normal binocular vision. However, a minor impact was found of BV anomalies on the academic performance.

Helveston (Helveston et al., 1985) studied the relationship between visual function and the academic outcome in

school children. There was no concrete relationship found between the academic performance of these children and their visual functions like VA, color vision, eye muscle balance, and refraction. Vaughn (Vaughn, Maples, & Hoenes, 2006) also conducted a study that focused on the vision quality of the individuals and their academic performance. They concluded that there was a relationship between visual impairments and the academic performances of the children.

The results of this study are consistent with the previous studies in terms of the minor impact of RE and BV anomalies on academic performance. Procar and Martinez-Palomera (Porcar & Martinez-Palomera, 1997) found that academic performance would be negatively affected by the non-strabismic anomalies. We found this negative effect in the stereoacuity and CISS, which showed lower scores for those who had abnormal BV than participants with normal BV. However, RE and general BV status did not affect the academic performance as measured by the GPA. Although Pickwell (Pickwell et al., 1986) reported that convergence insufficiency increases with age and may affect adults' visual functions, we did not find a significant difference in NPC between normal BV and abnormal BV groups.

One of the interesting results we found was that heterophoria was present in 46 % among participants; these participants were symptomatic according to the CISS questionnaire. In addition, participants affected with heterophoria had worse stereopsis and CISS score than normal ones. However, there was no significant relationship between the participants' visual functions and their GPA, which reflects their academic performances (p-value > 0.05).

Although there was no direct relationship between the general status of RE and BV, there were interesting observations regarding the BV and RE values in this study. The RE surprisingly had a high percentage (60.4%) of the total participants enrolled. As reported, uncorrected RE is one of the causes of visual impairment in Saudi Arabia. Therefore, extra caution should be taken to assess the refractive status of the students; and prescribe the appropriate refractive corrections.

In conclusion, we demonstrated how the visual functions of the participants did not affect the students' academic performance. However, heterophoria participants approximately represented half of the study sample; and were symptomatic. Stereoacuity and the CISS score warrant more research to understand the underlying causes of significant low scores in this study, and to evaluate their association with RE and BV anomalies. Careful clinical assessment of BV and RE status is essential, especially among university students, to maintain good academic performance and quality of life.

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Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Abdi, S., Lennerstrand, G., Pansell, T., & Rydberg, A. (2008). Orthoptic findings and asthenopia in a population of Swedish schoolchildren aged 6 to 16 years. *Strabismus, 16*(2), 47-55. https://doi.org/10.1080/09273970802020243

Birch, J. (1997). Efficiency of the Ishihara test for idenxtifying red-green colour deficiency. *Ophthalmic Physiol Opt, 17*(5), 403-408. https://doi.org/10.1111/j.1475-1313.1997.tb00072.x

Bourne, R. R. A., Flaxman, S. R., Braithwaite, T., Cicinelli, M. V., Das, A., Jonas, J. B., . . . Taylor, H. R. (2017). Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. *Lancet Glob Health, 5*(9), e888-e897. https://doi.org/10.1016/S2214-109X(17)30293-0

Falkenberg, H. K., Langaas, T., & Svarverud, E. (2019). Vision status of children aged 7-15 years referred from school vision screening in Norway during 2003-2013: a retrospective study. *BMC Ophthalmol, 19*(1), 180. https://doi.org/10.1186/s12886-019-1178-y

French, A. N., Morgan, I. G., Burlutsky, G., Mitchell, P., & Rose, K. A. (2013). Prevalence and 5- to 6-year incidence and progression of myopia and hyperopia in Australian schoolchildren. *Ophthalmology, 120*(7), 1482-1491. https://doi.org/10.1016/j.ophtha.2012.12.018

García-Muñoz, Á., Carbonell-Bonete, S., Cantó-Cerdán, M., & Cacho-Martínez, P. (2016). Accommodative and binocular dysfunctions: prevalence in a randomised sample of university students. *Clin Exp Optom, 99*(4),

313-321. https://doi.org/10.1111/cxo.12376

Garnham, L., & Sloper, J. J. (2006). Effect of age on adult stereoacuity as measured by different types of stereotest. *Br J Ophthalmol, 90*(1), 91-95. https://doi.org/10.1136/bjo.2005.077719

Helveston, E. M., Weber, J. C., Miller, K., Robertson, K., Hohberger, G., Estes, R., . . . Helveston, B. H. (1985). Visual function and academic performance. *Am J Ophthalmol, 99*(3), 346-355. https://doi.org/10.1016/0002-9394(85)90368-X

Hokoda, S. C. (1985). General binocular dysfunctions in an urban optometry clinic. *J Am Optom Assoc, 56*(7), 560-562.

Hopkins, S., Narayanasamy, S., Vincent, S. J., Sampson, G. P., & Wood, J. M. (2020). Do reduced visual acuity and refractive error affect classroom performance? *Clin Exp Optom, 103*(3), 278-289. https://doi.org/10.1111/cxo.12953

Joseph, L. (2014). Refractive Errors and Academic Achievements of Primary School Children. *Nurs J India, 105*(6), 269-271.

Kulp, M. T., Ciner, E., Maguire, M., Moore, B., Pentimonti, J., Pistilli, M., . . . Ying, G. S. (2016). Uncorrected Hyperopia and Preschool Early Literacy: Results of the Vision in Preschoolers-Hyperopia in Preschoolers (VIP-HIP) Study. *Ophthalmology, 123*(4), 681-689. https://doi.org/10.1016/j.ophtha.2015.11.023

Lara, F., Cacho, P., García, A., & Megías, R. (2001). General binocular disorders: prevalence in a clinic population. *Ophthalmic Physiol Opt, 21*(1), 70-74. https://doi.org/10.1046/j.1475-1313.2001.00540.x

Leat, S. J., Chan, L. L., Maharaj, P. D., Hrynchak, P. K., Mittelstaedt, A., Machan, C. M., & Irving, E. L. (2013). Binocular vision and eye movement disorders in older adults. *Invest Ophthalmol Vis Sci, 54*(5), 3798-3805. https://doi.org/10.1167/iovs.12-11582

Pickwell, L. D., Viggars, M. A., & Jenkins, T. C. (1986). Convergence insufficiency in a rural population. *Ophthalmic Physiol Opt, 6*(3), 339-341. https://doi.org/10.1016/0275-5408(86)90096-7

Porcar, E., & Martinez-Palomera, A. (1997). Prevalence of general binocular dysfunctions in a population of university students. *Optom Vis Sci, 74*(2), 111-113. https://doi.org/10.1097/00006324-199702000-00023

Rouse, M. W., Borsting, E. J., Mitchell, G. L., Scheiman, M., Cotter, S. A., Cooper, J., . . . Wensveen, J. (2004). Validity and reliability of the revised convergence insufficiency symptom survey in adults. *Ophthalmic Physiol Opt, 24*(5), 384-390. https://doi.org/10.1111/j.1475-1313.2004.00202.x

Vaughn, W., Maples, W. C., & Hoenes, R. (2006). The association between vision quality of life and academics as measured by the College of Optometrists in Vision Development Quality of Life questionnaire. *Optometry, 77*(3), 116-123. https://doi.org/10.1016/j.optm.2006.01.004

Wen, G., Tarczy-Hornoch, K., McKean-Cowdin, R., Cotter, S. A., Borchert, M., Lin, J., . . . Varma, R. (2013). Prevalence of myopia, hyperopia, and astigmatism in non-Hispanic white and Asian children: multi-ethnic pediatric eye disease study. *Ophthalmology, 120*(10), 2109-2116. https://doi.org/10.1016/j.ophtha.2013.06.039

Wong, T. Y., Foster, P. J., Johnson, G. J., & Seah, S. K. (2003). Refractive errors, axial ocular dimensions, and age-related cataracts: the Tanjong Pagar survey. *Invest Ophthalmol Vis Sci, 44*(4), 1479-1485. https://doi.org/10.1167/iovs.02-0526

Wood, J. M., Black, A. A., Hopkins, S., & White, S. L. J. (2018). Vision and academic performance in primary school children. *Ophthalmic Physiol Opt, 38*(5), 516-524. https://doi.org/10.1111/opo.12582

Psychotherapy via Telehealth during the COVID-19 Pandemic in Australia–Experience of Clients with a Diagnosis of Borderline Personality Disorder

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Abstract

Objective: To investigate the transition to, and experience of, telehealth in people with a diagnosis of borderline personality disorder (BPD).

Method: A cross-sectional study using an online survey was conducted in a specialist clinic for personality disorders in March-May 2020.

Results: Thirty-seven clients (48% response rate) completed the survey. Two participants (5.4%) were decided not to receive treatment via telehealth. Transitioning from in-person to telehealth, the majority of participants had few or no technical issues (51.4%). Telephone, video-conferencing and a mix of telephone and video-conferencing were used. Positive and negative experiences were endorsed asking about the effectiveness of telehealth. While some participants were whether unsure (32%) or not (19%) interested in telehealth following pandemic, half acknowledged the presence of telehealth (54.8%) and wanted to have the option of telehealth following pandemic (48.6%).

Conclusions: Despite some shortcomings associated with telehealth, almost every client continued to attend appointments and half of the study participants wanted to have the option of telehealth in the future. Healthcare policymakers and mental health managers should consider the challenges described in this study while developing telehealth guidelines to best support people experiencing problems living with the psychiatric diagnoses of BPD.

Keywords: Borderline personality disorder, telehealth, telemental health, COVID-19

1. Introduction

On 30 January 2020, the coronavirus disease 2019 (COVID-19) was declared a global public health emergency (World Health Organization, 2020). Its contagious nature and potentially severe outcomes necessitated rapid adaptations across economies, societies, and healthcare systems. Many countries, including Australia, adopted national workplace and community restrictions to limit the spread of the virus. In Australia, in-person clinical appointments were replaced wherever possible with telehealth services (Mikakos, 2020). Telehealth is defined as the provision of healthcare remotely by means of telecommunications technology (World Health Organization, 2010). Although there is evidence for the efficiency, cost-effectiveness, and utility of mental health services delivered via telehealth (Langarizadeh et al., 2017), when it comes to borderline personality disorder (BPD), very few studies were available to provide guidance prior to the pandemic (Ben-Zeev, 2014; Kocsis & Yellowlees, 2018). BPD is the highest prevalence personality disorder, experienced by 1-2% of the population at some time during their lives (Grant et al., 2008). According to the Diagnostic and Statistical Manual (DSM 5), people with this diagnosis may experience intense, uncontrollable emotions, have trouble with their relationships, find it hard to feel comfortable in themselves, be very impulsive and appear to lead chaotic lives, or intentionally harm themselves as a way of coping.

Prior to 2020, telehealth in Australia was utilized primarily for people residing in rural and remote areas (Bradford et al., 2016). During the COVID-19 restrictions, telehealth medical services were introduced throughout Australia,

enabling people to access healthcare services from their homes while decreasing the risk of exposure and spread of COVID-19 (Kidd & Hunt, 2020). The process and funding arrangements for the expansion of tele-mental health services were quickly developed with widespread adoption across the community (Australian Government, 2020).

A meta-analysis that included 2,648 veterans previously reported similar effectiveness in treatment outcomes using both telehealth (video-conferencing and telephone) and in-person psychotherapies. Participants in the meta-analysis had a variety of mental health conditions, mostly trauma, depression, and anxiety (McClellan et al., 2021). Another meta-analysis examined the effectiveness of video-conferencing in the delivery of mental health services. The study concluded that while more rigorous studies are needed to reach a definitive answer, current literature suggests that video-conferencing does not impede clinical outcomes (Batastini et al., 2020). In terms of the acceptability of telehealth, a retrospective study evaluating health record data from two outpatient mental health clinics in the United States (US) that transitioned to telehealth within two days, reported a decrease in scheduled appointments of 10.6% immediately post transition, increasing by 17.8% six months post transition (Mishkind et al., 2021).

For many clients and providers, the transition to telehealth services took place over such a short space of time that opportunities for planning and training were minimal. Although some pilot studies investigating the utility of telehealth for the provision of mental health services have been published (Inchausti et al., 2020; Tullio et al., 2020), the efficacy and utility of psychotherapy via telehealth delivery for people diagnosed with BPD are currently unknown. This study aimed to investigate the transition to and experience of telehealth in clients previously receiving in-person psychotherapy for the treatment of BPD.

2. Method

A cross-sectional study utilizing an online survey was conducted within a public outpatient specialist personality disorder clinic which treats clients diagnosed with severe and complex personality disorder presentations. The clinic offers a range of evidence-based psychotherapy programs, including dialectical behavioral therapy, mentalization-based therapy, and a 'common factors' treatment program. Clients who were receiving treatment services were invited to participate (n=77) during the first wave of social isolation restrictions (March-May 2020). All clients of the service were aged 18 years or older and diagnosed with BPD according to the Diagnostic and Statistical Manual of Mental Disorders (5th Edition, American Psychiatric Association, 2013). Clients were invited to participate via an email message explaining the purpose of the study with a link to the online survey. The survey contained three sections: 1. Demographic information; 2. Experience of transition to and use of telehealth with questions regarding how telehealth affected their relationship with their clinician and their own mental health, and 3. Pros and cons of telehealth treatment and future use of telehealth. The data were analyzed using descriptive statistics in Microsoft Excel 2010.

Ethics approval was obtained from the institutional ethics committee (LR20/037).

3. Results

Thirty-seven clients (48.1% response rate) completed the survey. Most participants were female (86.5%), aged less than 38 years (64.8%), living with family members (56.8%), and in the first year of their treatment in the clinic (78.3%) (see supplementary material). A minority of participants (n=13, 35.1%) had used telehealth previously for health-related services. Two participants (5.4%) had decided not to continue their treatment via telehealth.

Transitioning from in-person to telehealth treatment, the majority of participants had few or no technical issues (n=18 of 35, 51.4%), or only experienced issues initially; however, they either solved the technical issues enabling them to use the videoconference platform or received telehealth by telephone (n= 14, 40.0%). A few had ongoing technical problems (n=3, 8.5%). Difficulties were related to the internet (i.e., quality of connection, cost, and equipment).

Telephone (n=8, 25.8%), video-conferencing (n=9, 29.0%), and mix of telephone and video-conferencing (n=14, 45.1%) were used (out of 31 respondents). The most commonly stated reasons for only using the telephone were participants' ongoing unresolved technical issues with video-conference, feeling self-conscious, anxious, or distracted by their own appearance during the video-conference. Participants who were using video-conferencing (n=24) also reported the occasional feeling of insecurity (n=14, 58.3%) self-consciousness, anxiety (n=16, 66.6%), or distraction (n=17, 70.8%).

When asked about the effectiveness of telehealth as a platform for receiving mental health services, positive and negative experiences were endorsed (Tables 1 and 2). While more than half of the participants appreciated not having to travel to their appointments, two noted the importance of travel for treatment effectiveness. Table 1 illustrates how some participants felt more relaxed, able to speak more freely, and felt that they made similar

progress as when they met with their clinician in person. Some found it a bit harder to make progress and more challenging to stay engaged, experiencing lower mood, a worsening of mood fluctuations, or feelings of abandonment. Of clients who reported worsening feelings of abandonment, four reported reliable access to telehealth, two had technical issues, and three only had access to telehealth treatment by phone.

Out of 30 respondents, many participants endorsed that difficult conversations with their clinicians were easier (n=9, 30%) or no different (n=11, 36.7%) to manage via telehealth than when meeting in person. It was also acknowledged that misunderstandings were more likely when using telehealth (n= 7, 23.3%), more challenging to resolve (n=4, 13.3%), and it was easier to exit the conversation (n=6, 20.0%). Avoiding difficult conversations due to privacy concerns was also endorsed (n=4, 13.3%).

Table 1. Experience of receiving psychological treatment via telehealth for people with BPD during COVID-19 restrictions (N=35)

	N (%)
I like not having the stress of travelling	20 (57.1)
It is a bit harder to make progress compared with face-to-face but it is working OK	14 (40.0)
It is challenging to stay engaged when our main communication is via telehealth; it is not working so well as face-to-face	13 (37.1)
I feel more relaxed and able to talk more freely	10 (28.6)
I find that we accomplish a similar amount in sessions as we did prior to using telehealth	10 (28.6)
I feel a worsening of my feelings of abandonment	7 (20.0)
I feel that my mood fluctuates more easily, making it more difficult to regulate my emotional responses	7 (20.0)
My mood feels lower since my treatment sessions moved to telehealth	7 (20.0)

Table 2. Perceived impact of telehealth on treatment of people with BPD during COVID-19 restrictions

Impact of telehealth	N (%)
Communication with the clinician, n=29	
Caused some instability in my relationship with my clinician.	6 (20.7)
Led to improvement in my relationship with my clinician.	5 (17.2)
Difficult to say whether using telehealth has changed my relationship with my clinician.	18 (62.1)
Expressing thoughts about self-harm or suicide, n=31	
It does not seem to happen more frequently with telehealth	18 (58.0)
It does seem to happen more frequently when using telehealth	4 (12.9)
Unsure – it is hard for me to know	9 (29.0)
More difficult to control impulses for self-harm?, n=31	
Always	1 (3.2)
Usually	2 (6.4)
Sometimes	4 (12.9)
Rarely	12 (38.7)
Never	12 (38.7)
More difficult to control feelings of anger?, n=31	
Always	0 (0.0)
Usually	4 (12.9)
Sometimes	5 (16.1)
Rarely	10 (32.2)
Never	12 (38.7)

Harder to establish and maintain agreed treatment boundaries with their clinician?, n=27	
Always	1 (3.7)
Usually	1 (3.7)
Sometimes	4 (14.8)
Rarely	5 (18.5)
Never	16 (59.2)
More likely to experience fatigue when using telehealth?, n=31	
Always	1 (3.2)
Usually	5 (16.1)
Sometimes	8 (25.8)
Rarely	6 (19.3)
Never	11 (35.5)
Accessibility of individual clinician during the restrictions compared to in-person consultation?, n=31	
More accessible	3 (9.6)
About the same	24 (77.4)
Less accessible	4 (12.9)
Are there aspects of telehealth that work better for you compared with when you received face-to-face psychological treatment?, n=31	
Yes	17 (54.8)
No	9 (29.0)
Unsure	5 (16.1)
Would you like to have the option of receiving psychological treatment via telehealth in the future?, n=37	
Yes	18 (48.6)
No	7 (18.9)
Unsure	12 (32.4)

4. Discussion

This study investigated the transition to and experience of receiving psychotherapy via telehealth from the perspective of clients who have a diagnosis of BPD. Although the transition was rapid, the majority of clients transitioned to telehealth smoothly, with only two clients deciding not to use the telehealth service and three clients having ongoing technical problems using telehealth. Transition difficulties relating to the internet and technology were found in the current and US studies (Mishkind et al., 2021). In the US study, although there was a slight decrease in the number of appointments made immediately after transition - similar to the current study - this number had increased relative to pre-virtualisation six months after transition (Mishkind et al., 2021), suggesting the acceptance of telehealth as a health service tool.

Although the widespread introduction of telehealth has occurred due to the pandemic, its continued use is highly likely post-pandemic. While some participants in the current study were unsure (32%) or not (19%) interested in telehealth following the pandemic, half acknowledged the importance of receiving treatment by telehealth during social restrictions and wanted to have the option of telehealth following the pandemic. A survey of mental health clinicians and organizations in the US reported a high likelihood that telehealth use would continue post-pandemic (Molfenter et al., 2021).

Difficult topics and challenging conversations are fundamental to psychotherapy when client presentations include complex trauma, self-harming behavior, suicidality, and interpersonal difficulties (Brodsky & Stanley, 2013). When asked about managing difficult conversations via telehealth, most in this study found such conversations easier or no different from in-person sessions. The majority reported no change in their likelihood of expressing thoughts regarding self-harm or suicidality. Some participants avoided complex topics when interacting with their clinician via telehealth, citing an increased possibility of misunderstandings and greater difficulty achieving resolution, and sometimes leaving a telehealth session if it became too difficult. This could conceivably slow

clinical progress, however, there are early indications that treatment engagement via telehealth of people who have serious mental illness may not differ from other forms of mental health service engagement (Miu et al., 2020). Indeed this service conducting this study noted a substantial rise in client engagement compared with previous levels of attendance at in-person sessions (Broadbear et al., 2021).

With respect to symptom expression, close to a quarter of participants perceived that telehealth made it more difficult to control feelings of anger or impulses to self-harm, highlighting the need for guidance in managing risk when conducting treatment via telehealth (Hames et al., 2020; Inchausti et al., 2020; Jobes et al., 2020). It is notable that the service did not experience an increase in serious adverse events during the months that telehealth was the only treatment option.

4.1 Limitations

This study was conducted within a specialist personality disorder service which therefore limits generalisation of these findings to the wider population of people with a diagnosis of BPD. Data were collected using an online survey with a cross-sectional design during the first national lockdown in Australia. Longer-term utility of telehealth for people with a diagnosis of BPD is yet to be reported. Survey questions did not differentiate between individual and group therapy. However, as almost all participants were receiving individual therapy (transition of group sessions to the virtual format took substantially longer), it is assumed that questions mainly reflected participants' experience of the individual sessions.

5. Conclusion

Results of this study describe the challenges and benefits of telehealth from the perspective of clients of a specialist service for personality disorder. Healthcare policymakers and mental health managers should consider the challenges outlined in this study when developing telehealth guidelines for people with a diagnosis of BPD. Despite some shortcomings associated with telehealth, almost every client continued to attend appointments. Participants did not report harm from the delivery of psychotherapy via telehealth, suggesting that telehealth need not be contraindicated as a treatment option. Participant responses also indicate that using telehealth to deliver psychotherapy may be acceptable in the post-COVID world too. This is particularly important given the 'rolling' nature of the pandemic-related restrictions into the foreseeable future.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (DSM-5®) (5th ed.): Diagnostic and statistical manual of mental disorders. *Am Psychiatric Assoc, 21*. https://doi.org/10.1176/appi.books.9780890425596

Australian Government. (2020). *COVID-19 Temporary Medicare Benefits Schedule Telehealth Services, Mental Health Services*. Australian Government Retrieved from http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/0C514FB8C9FBBEC7CA25852E00223AFE/$File/COVID-19%20Temporary%20MBS%20telehealth%20Services%20-%20Mental%20Health%2008052020.pdf

Batastini, A. B., Paprzycki, P., Jones, A. C., & MacLean, N. (2020). Are video-conferenced mental and behavioral health services just as good as in-person? A meta-analysis of a fast-growing practice. *Clinical Psychology Review*, 101944. https://doi.org/10.1016/j.cpr.2020.101944

Ben-Zeev, D. (2014). Technology-based interventions for psychiatric illnesses: improving care, one patient at a time. *Epidemiology and psychiatric sciences, 23*(4), 317-321. https://doi.org/10.1017/S2045796014000432

Bradford, N. K., Caffery, L. J., & Smith, A. C. (2016). Telehealth services in rural and remote Australia: a systematic review of models of care and factors influencing success and sustainability. *Rural and remote health, 16*(4), 4268. https://doi.org/10.22605/RRH3808

Broadbear, J. H., Heidari, P., Dharwadkar, N. P., Cheney, L., & Rao, S. (2021). Telehealth Psychotherapy for Severe Personality Disorder during COVID-19: Experience of Australian Clinicians. *Global Journal of Health Science, 13*(12). https://doi.org/10.5539/gjhs.v13n12p61

Brodsky, B. S., & Stanley, B. (2013). *The dialectical behavior therapy primer: How DBT can inform clinical practice*. John Wiley & Sons. https://doi.org/10.1111/bjop.12061

Grant, B. F., Chou, S. P., Goldstein, R. B., Huang, B., Stinson, F. S., Saha, T. D., ... & Pickering, R. P. (2008).

Prevalence, correlates, disability, and comorbidity of DSM-IV borderline personality disorder: results from the Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions. *The Journal of Clinical Psychiatry, 69*(4), 533-545.

Hames, J. L., Bell, D. J., Perez-Lima, L. M., Holm-Denoma, J. M., Rooney, T., Charles, N. E., . . . Fondacaro, K. M. (2020). Navigating uncharted waters: Considerations for training clinics in the rapid transition to telepsychology and telesupervision during COVID-19. *Journal of Psychotherapy Integration, 30*(2), 348. https://doi.org/10.1037/int0000224

Inchausti, F., MacBeth, A., Hasson-Ohayon, I., & Dimaggio, G. (2020). *Telepsychotherapy in the age of COVID-19: A commentary*. https://doi.org/10.1037/int0000222

Jobes, D. A., Crumlish, J. A., & Evans, A. D. (2020). The COVID-19 pandemic and treating suicidal risk: The telepsychotherapy use of CAMS. *Journal of Psychotherapy Integration, 30*(2), 226. https://doi.org/10.1037/int0000208

Kidd, M., & Hunt, G. (2020). *COVID-19: Whole of population telehealth for patients, general practice, primary care and other medical services.* Retrieved from https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/covid-19-whole-of-population-telehealth-for-patients-general-practice-primary-care-and-other-medical-services

Kocsis, B. J., & Yellowlees, P. (2018). Telepsychotherapy and the therapeutic relationship: Principles, advantages, and case examples. *Telemedicine and e-Health, 24*(5), 329-334. https://doi.org/10.1089/tmj.2017.0088

Langarizadeh, M., Tabatabaei, M. S., Tavakol, K., Naghipour, M., Rostami, A., & Moghbeli, F. (2017). Telemental health care, an effective alternative to conventional mental care: A systematic review. *Acta Informatica Medica, 25*(4), 240. https://doi.org/10.5455/aim.2017.25.240-246

McClellan, M. J., Osbaldiston, R., Wu, R., Yeager, R., Monroe, A. D., McQueen, T., & Dunlap, M. H. (2021). The effectiveness of telepsychology with veterans: A meta-analysis of services delivered by video-conference and phone. *Psychological Services*. https://doi.org/10.1037/ser0000522

Mikakos, J. (2020). *Pandemic plan for the Victorian Health Sector. Melbourne, Australia: Victorian State Government*. Retrieved from https://www2.health.vic.gov.au/about/publications/researchandreports/covid-19-pandemic-plan-for-vic

Mishkind, M. C., Shore, J. H., Bishop, K., D'Amato, K., Brame, A., Thomas, M., & Schneck, C. D. (2021). Rapid conversion to telemental health services in response to COVID-19: experiences of two outpatient mental health clinics. *Telemedicine and e-Health, 27*(7), 778-784. https://doi.org/10.1089/tmj.2020.0304

Miu, A. S., Vo, H. T., Palka, J. M., Glowacki, C. R., & Robinson, R. J. (2020). Teletherapy with serious mental illness populations during COVID-19: telehealth conversion and engagement. *Counselling Psychology Quarterly*, 1-18. https://doi.org/10.1080/09515070.2020.1791800

Molfenter, T., Heitkamp, T., Murphy, A. A., Tapscott, S., Behlman, S., & Cody, O. J. (2021). Use of Telehealth in Mental Health (MH) Services During and After COVID-19. *Community Mental Health Journal*, 1-8. https://doi.org/10.1007/s10597-021-00861-2

Tullio, V., Perrone, G., Bilotta, C., Lanzarone, A., & Argo, A. (2020). Psychological support and psychotherapy via digital devices in Covid-19 emergency time: Some critical issues. *Medico-Legal Journal*, 0025817220926942. https://doi.org/10.1177/0025817220926942

World Health Organization. (2010). *Telemedicine: opportunities and developments in member states. Report on the second global survey on eHealth*. Geneva: World Health Organization

World Health Organization. (2020). *Rolling updates on coronavirus disease (COVID-19)*. Retrieved from https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen

Supplementary material

Demographic characteristics of people with a diagnosis of BPD who received treatment via telehealth during COVID-19 restrictions

Characteristics	N (%)
Gender, n=37	
Female	32 (86.5)
Male	4 (10.8)
Not stated	1 (2.7)
Age, years, n=37	
18-27	9 (24.3)
28-37	15 (40.5)
38-47	8 (21.6)
48-57	4 (10.8)
58+	1 (2.7)
Living arrangements, n=37	
I live alone	8 (21.6)
I have family members living with me	21 (56.8)
I live with my partner	4 (10.8)
I live with one or more friends	2 (5.4)
I share my house with housemates	2 (5.4)
Having pets, n=37	31 (83.8)
Mental health service received via telehealth, n=36	
Assessment	8 (21.6)
Pre-treatment	6 (16.2)
Individual treatment	34 (91.9)
Group treatment	19 (51.4)
On-request treatment	2 (5.4)
Treatment duration at the start of restrictions, n=37	
More than 12 months	6 (16.2)
Six to 12 Months	11 (29.7)
Between one and six months	18 (48.6)
In assessment	2 (5.4)

Malnutrition and the Risk of Catastrophic Health Expenditure in Nigeria

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Abstract

Background: Malnutrition among children not only affects their health consequences but also does it burden their households' finance especially in developing countries. This study evaluates the household risk of catastrophic health expenditure (CHE) due to malnutrition treatments among malnourished children in Nigeria, according to zones and wealth quintiles. We simulate the CHE risk among households with malnourished children who seek treatment.

Methods: The CHE risk due to malnutrition among treated was computed based on 1) the out-of-pocket (OOP) expenditure and indirect costs associated with malnutrition treatment, and 2) household consumption expenditures. I derived the CHE risk associated with malnutrition across zones and wealth quintiles in Nigeria, using secondary data sources for healthcare utilization, OOP expenditures, and consumption expenditures.

Results: There was a large variation of CHE risk according to zones and wealth quintiles. Among the poorest households, those in northeast and northwest would have the highest risk of CHE, up to 59 and 47%, while those in southwest would have the lowest risk of 14%. For all zones, as the wealth increases, the CHE risk would decrease. There would be zero or very little CHE risk among the richest households in any zones.

Interpretation: Nutrition interventions will help malnourished children improve their health status. However, we should also be wary about the financial consequences of the treatment that households should bear.

Keywords: catastrophic health expenditure, malnutrition, Nigeria

1. Introduction

Malnutrition is the leading cause of deaths in developing countries: up to 45% of deaths among children under 5 years old are attributed to factors related to nutrition (WHO, 2020). Malnutrition also affects people in the long term (for example, see Mwene-Batu et al., 2020). In Nigeria, it is estimated that about 2 million children have severe acute malnutrition but only 20% of them receive treatment (UNICEF, 2021).

Furthermore, malnutrition can have a substantial negative impact not only on population's health, but also on people's finance due to the financial burden of malnutrition treatment and diminished productivity (Njuguna et al., 2020). Thus, treatment of malnutrition at earlier stage is crucial to minimize the long-term health and financial burdens among children and their households.

This paper evaluates the financial consequence of malnutrition treatment in Nigeria. In particular, I focus on the incidence of catastrophic health expenditures (CHE) as an indicator of financial burden as a consequence of malnutrition treatment in this paper. CHE is defined as out-of-pocket (OOP) medical expenditures surpassing a certain threshold of income or consumption expenditures. I investigate differences in CHE risks according to zones and wealth quintiles.

2. Methodology

In this section, I present the main approach to estimate the risk of facing CHE as a consequence of children's malnutrition treatment, among malnourished children, in Nigeria. In this study, I assumed that malnutrition was treated through Community-based Management of Acute Malnutrition (CMAM) (Frankel et al., 2015). Thus, the cost estimates for the malnutrition treatment were based on CMAM intervention. Although many malnourished children have no access to treatment for malnourishment in reality, this paper examined the financial consequence

of malnutrition treatment, assuming children had access to one.

2.1 Modeling Risk of CHE Due to Malnutrition

Generally, for a household, the risk of facing CHE, conditional on being malnourished, would depend on: (i) the likelihood of healthcare utilization to treat malnutrition; (ii) the amount of OOP health expenditures and indirect costs associated with malnutrition treatment; and (iii) the level of household total consumption expenditures. This study focused on the best scenario where all the households with malnourished children received the treatment. Thus, CHE risk among treated was independent on the factor (i).

Illness-related costs associated with treatment of malnutrition included several components: OOP direct medical costs, OOP transportation costs to health facilities, and indirect costs (Table 1). I closely followed the study from Frankel et al. (2015) to refer to the costs related to the malnutrition treatment. According to their study based on Community-based Management of Acute Malnutrition (CMAM), it cost $40.0 for inpatient treatment while it cost $6.3 for outpatient treatment. Transportation costs for both inpatient and outpatient visit were assumed to be $6.3. Indirect costs had two components: an estimated "wage rate" and the number of workdays lost due to inpatient stays. For the wage rate, I used mean annual consumption expenditures per adult equivalent according to zone and wealth quintile. The average bed day for inpatient treatment was assumed to be 8 days from malnutrition treatment study (Daures et al., 2020). We also referred to Daures et al. (2020) for the ratio of inpatient and outpatient visits: 13.7% for inpatient visits and the remaining 86.3% were outpatient visits.

Table 1. Cost information

	USD $
Inpatient costs (total)	39.956
Outpatient costs (total)	6.343
Transportation costs to clinic	6.343
Average bed days (days)	8
% hospitalization	13.7
% outpatient	86.3

Sources of data: inpatient costs, inpatient costs, transportation costs to clinic (Frankel et al., 2015); average bed days, % hospitalization, % outpatient (Daures et al., 2020)

The annual consumption expenditure was drawn from Nigeria Living Standards Survey (NLSS), which was the national representative survey conducted in 2018 to 2019 (Nigeria National Bureau of Statistics, 2019). I calculated the average annual consumption per capita according to zone and wealth quintile (Figure 1).
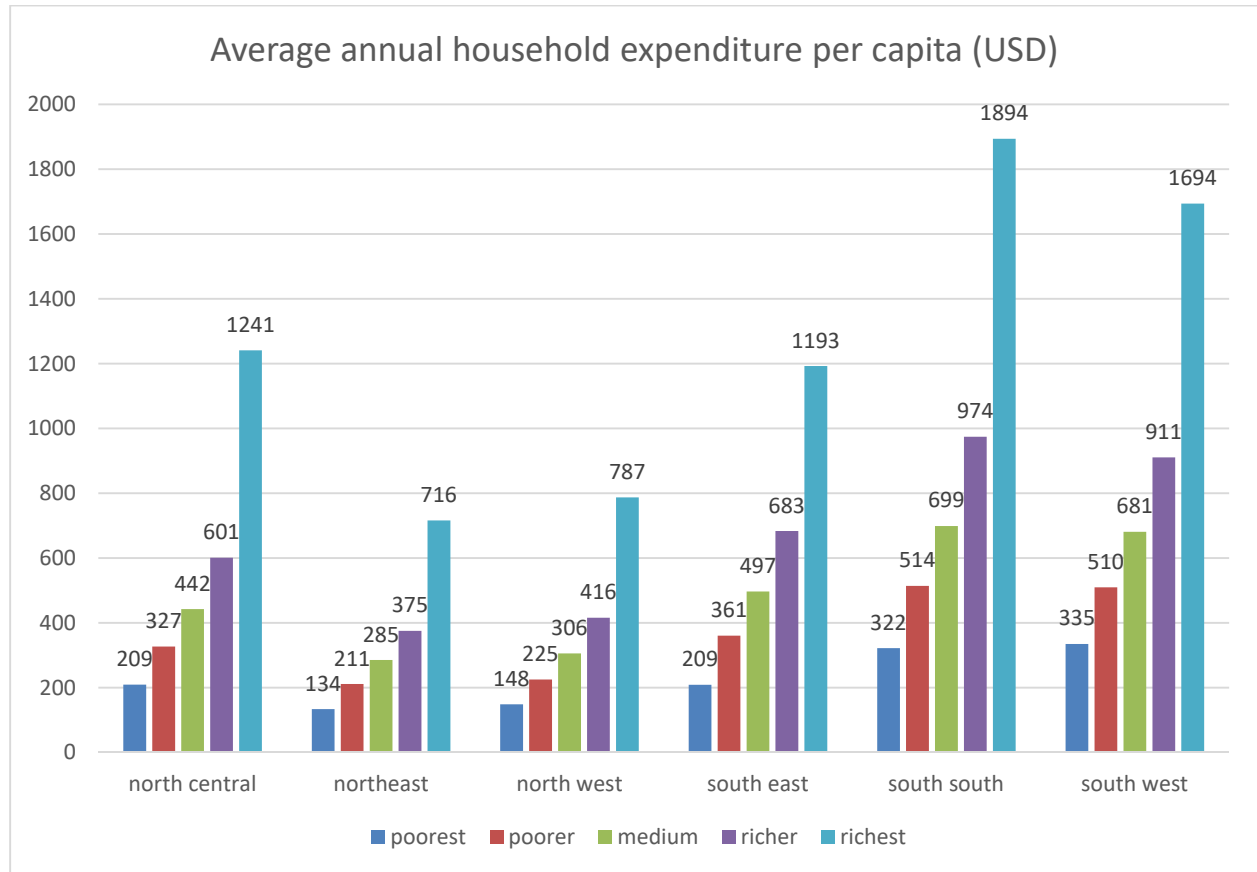
Figure 1. Distribution of household expenditure per capita in each zone across wealth quintiles

With the information above, I could derive a risk to facing a CHE case as a result of malnutrition treatment among households with malnourished children. Employing the methods from Riumallo-Herl et al. (2018), I estimated the number of cases of CHE associated with malnutrition treatment in each zone at each wealth quintile in Nigeria. A case of CHE for malnutrition was counted when total patient-incurred expenditures, which is the total OOP costs of medical, transportation, and indirect costs, surpassed 10% of total annual consumption expenditures.

I reported, per wealth quintile in each zone of Nigeria, on the risk of facing CHE in treating malnutrition. Wealth quintiles were poorest, poorer, medium, richer, and richest. There are six zones in Nigeria: north central, northeast, northwest, southeast, south south, and southwest.

As indicators of malnutrition using the existing data for nationally representative data, the prevalence of severe wasting and severe stunting were evaluated across wealth quintiles in each zone. Although many nutritional interventions, including CMAM, used the indicator of wasting and Mid-Upper Arm Circumference (MUAC), I present the prevalence of wasting and stunting due to the data unavailability of MUAC measurement in Nigeria dataset.

All simulations were conducted using R statistical software (version 3.6.0) and STATA (version 15.1).

3. Results

The estimation of CHE risks depended on the amount of OOP expenditure and time losses for disease treatment, and the consumption expenditures of households. Figure 1 presents the distribution of consumption expenditure according to zone and wealth quintile. There were variations in the distribution of consumption expenditure according to zones.

Northeast zone had the lowest consumption expenditure for all the wealth quintiles. The poorest households in the northeast on average spent $134 annually for consumption, while the richest households spent $716. Northwest also had the low level of consumption expenditure. On the other hand, south south and south west zones were the richest zones in Nigeria: the poorest households in these zones spent about $330 for consumption and this was much higher than the expenditure level among the medium households in north east, $285. The richest households

in south south zone spent the most, $1,894.

Figure 2 presents the distribution of children with malnutrition using severe wasting and severe stunting measurement, in each zone and wealth quintile. Across Nigeria, the prevalence of severe wasting did not exceed 4% in all wealth quintile in all zones. The poorest in northeast and northwest had the highest proportion of children with severe wasting: 3.58% and 3.6% respectively. The clear pattern of the gradients of the prevalence in the severe wasting from the poorest to the richest was not observed. On the other hand, the prevalence of severe stunting was high, especially in northeast and northwest; 20.5% and 26.6% respectively. For the severe stunting, its prevalence became lower as the wealth level got higher for almost all the zones.
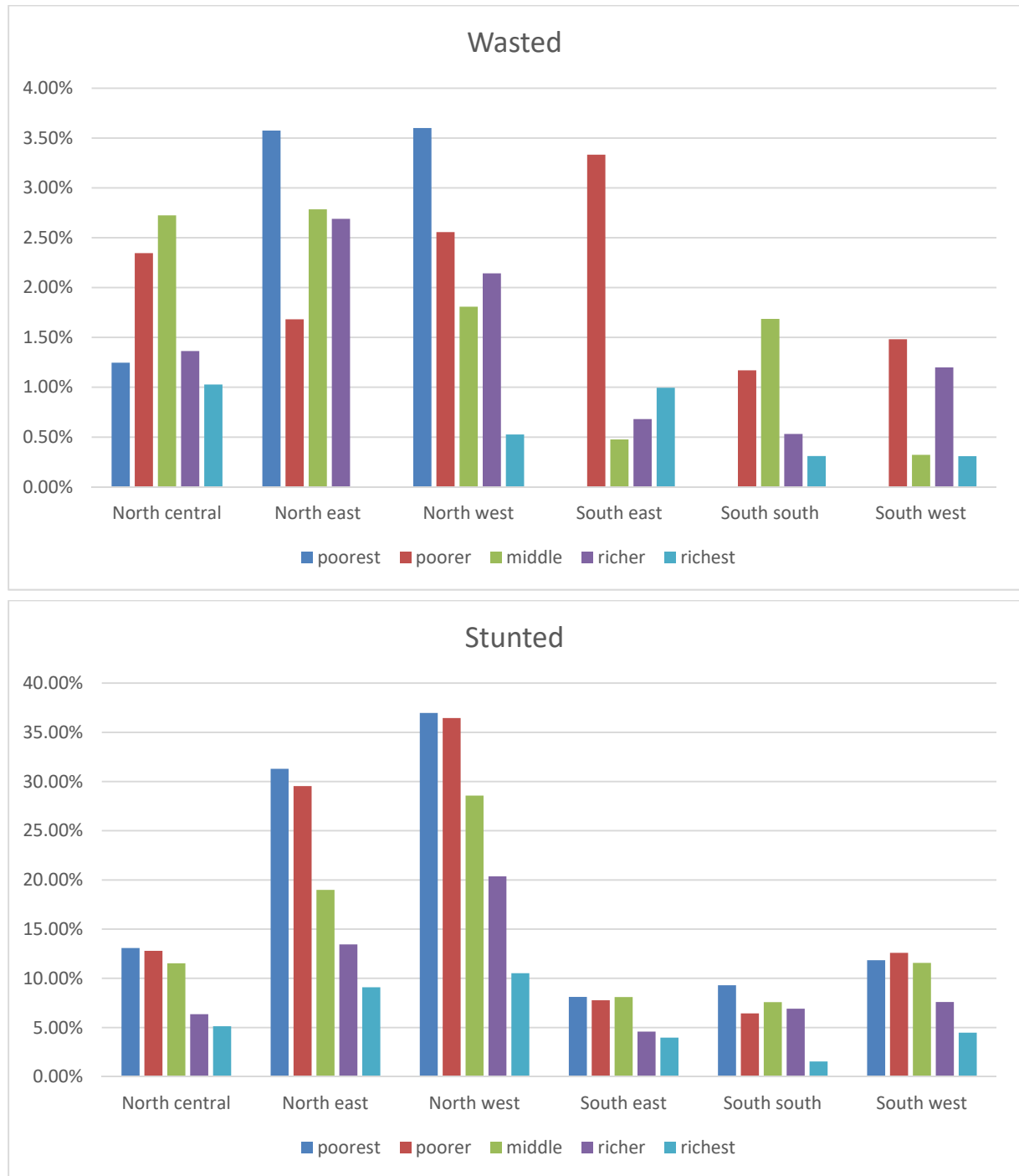
Figure 2. Prevalence of malnutrition in each zone across wealth quintiles

Notes. Wasted: weight for height z-score <-3; Stunted: height for age<-3

Figure 3 and Table 2 present the variations of the CHE risk due to malnutrition treatment across zone and wealth quintiles. On average, households in the northeast would have the highest CHE risk of 21.8%, while households in south south and southwest would have the lowest CHE risk of 6.9 to 7.0%.

Among the poorest households, those in northeast and northwest would have the highest risk, 58.6% and 47.0% respectively, while those in south south and southwest would have the lowest risk; 14.9% and 14.4%. The CHE risk was almost non-existent (0 or less than 1%) among the richest in all zones except northeast and northwest. Richest households in northeast and northwest still had 7 to 9% of CHE risk.

For all zones, as the wealth increases, the CHE risk would decrease. However, the reduction gradient from the poorest to poorer and to medium differed by zone. The CHE risk decreased drastically from the poorest to the poorer wealth category in northeast and northwest zones. For example, the CHE risk was 58.6% in northeast among the poorest but it decreased to 14.5% among the poorer. This CHE risk among the poorer in northeast was not much different from CHE risks among the poorer in other zones. We observed this catch-up among the poorer in northwest zone as well.

Table 2. CHE risk of malnutrition treatment in each zone across wealth quintiles

	North central	North east	North west	South east	South south	South west
poorest	22.5%	58.6%	47.0%	24.6%	14.9%	14.4%
poorer	13.7%	14.5%	13.8%	13.6%	12.5%	12.6%
middle	13.4%	13.7%	13.7%	12.8%	6.5%	7.2%
richer	10.2%	13.6%	13.5%	7.1%	0.5%	0.9%
richest	0.9%	8.6%	7.0%	0.3%	0.0%	0.0%
average	12.1%	21.8%	19.0%	11.7%	6.9%	7.0%
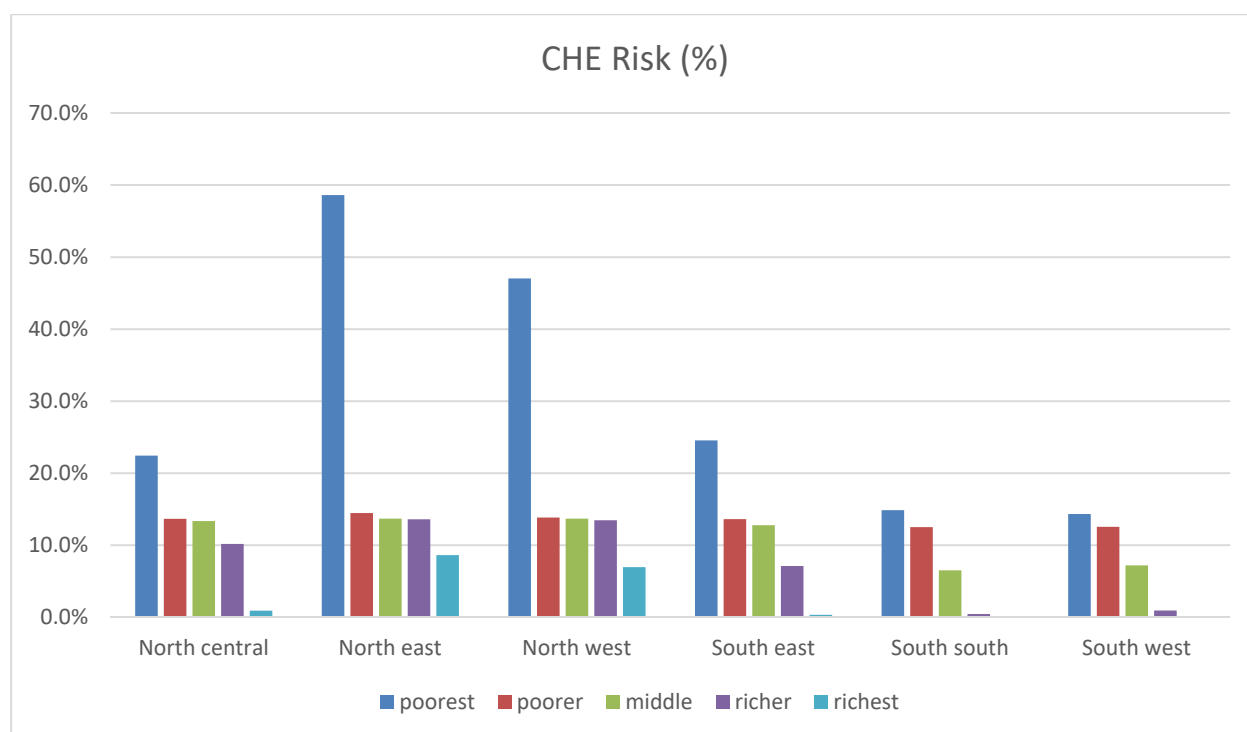
Figure 3. CHE risk of malnutrition treatment in each zone across wealth quintiles

4. Discussion

This paper evaluated the risk of CHE for malnutrition treatment according to the wealth quintile in each zone in Nigeria. The analysis was based on secondary data sources on OOP expenditure, time and wage losses for disease

treatment, as well as on the consumption expenditure.

This modelling study found that the risk to CHE due to malnutrition treatment would vary greatly according to wealth quintiles and zones. The variation of CHE risk across six zones mostly coincided with the variation of consumption expenditure across these zones: if the average consumption expenditure in a zone was higher, then the CHE risk in the zone was lower. The average consumption expenditure was the lowest in northeast and northwest zones, and the CHE risk in these 2 zones was the highest: about 20%. On the other hand, the average consumption was the highest in south south and south west, and the CHE risk in these zones was the lowest: about 7%. This finding was based on that richer households had less chance of experiencing the catastrophic expenditure from malnutrition treatment as compared to poorer households who had tighter budget constraints. Overall, the CHE risk among the richest was almost non-existent across all zones except northeast and northwest. This finding was also consistent with the distribution of the total consumption among the richest across zones.

The gradient of the reduction of CHE risk from the poorest to the poorer households differed by zones. Northeast and northwest zones observed the great CHE risk among the poorest but the risk reduced greatly for the poorer to the level that was similar to CHE risks for other zones.

The findings of the paper are consistent with the literature: it has been found that the majority of OOP expenditure is for outpatient visits and medicines including the ones for malnutrition treatment (Yerramilli et al., 2018). However, the study to evaluate the CHE due to malnutrition is extremely scarce. This paper is the first to evaluate the extent of CHE due to malnutrition.

This study has some limitations. There was no data available to measure the prevalence of malnutrition using MUAC, which was increasingly common, using nationally representative samples in Nigeria. There was also limited data availability on the costing information for malnutrition programs as well as the access to the nutrition programs in Nigeria. It is important to evaluate the percentage of households that have access to such programs across zones and wealth quintiles in Nigeria. This would be useful for policy implications in planning for health budget.

5. Conclusion

The CHE risk of malnutrition treatment in Nigeria varied across zones and wealth quintiles but highly correlated with the average consumption level for each wealth quintile in each zone. While the richest wealth quintile had almost no risk of CHE, the poorest wealth quintile, especially in northwest and northeast zones, faced higher risk of CHE, 47 to 59%.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Daures, M., Phelan, K., Issoufou, M., Kouanda, S., Sawadogo, O., Issaley, K., ... & Becquet, R. (2020). New approach to simplifying and optimising acute malnutrition treatment in children aged 6–59 months: the OptiMA single-arm proof-of-concept trial in Burkina Faso. *British Journal of Nutrition*, *123*(7), 756-767. https://doi.org/10.1017/S0007114519003258

Frankel, S., Roland, M., & Makinen, M. (2015). Costs, cost-effectiveness, and financial sustainability of CMAM in Northern Nigeria. *Field Exchange 50*, 51. Retrieved from https://ciff.org/wp-content/uploads/2019/09/R4D_CMAM_CostEffectiveness_FinancialSustainability_evaluation.pdf

Mwene-Batu, P., Bisimwa, G., Baguma, M., Chabwine, J., Bapolisi, A., Chimanuka, C., ... & Donnen, P. (2020). Long-term effects of severe acute malnutrition during childhood on adult cognitive, academic and behavioural development in African fragile countries: The Lwiro cohort study in Democratic Republic of the Congo. *PLoS One*, *15*(12), e0244486. https://doi.org/10.1371/journal.pone.0244486

Njuguna, R. G., Berkley, J. A., & Jemutai, J. (2020). Cost and cost-effectiveness analysis of treatment for child undernutrition in low-and middle-income countries: A systematic review. *Wellcome Open Research*, *5*. https://doi.org/10.12688/wellcomeopenres.15781.1

Riumallo-Herl, C., Chang, A. Y., Clark, S., Constenla, D., Clark, A., Brenzel, L., & Verguet, S. (2018). Poverty reduction and equity benefits of introducing or scaling up measles, rotavirus and pneumococcal vaccines in low-income and middle-income countries: a modelling study. *BMJ global health*, *3*(2), e000613. https://doi.org/10.1136/bmjgh-2017-000613

UNICEF. "Nutrition". (2021). *The first 1,000 days of a child's life offer a unique window of opportunity for preventing undernutrition and its consequences. See how UNICEF targets its actions to this critical period to ensure good nutrition for every child in Nigeria*. Retrieved Oct 25, 2021, from https://www.unicef.org/nigeria/nutrition

World Health Organization [WHO]. (2020). *Children: improving survival and well-being*. Retrieved Oct 25, 2021, from https://www.who.int/news-room/fact-sheets/detail/children-reducing-mortality

Yerramilli, P., Fernández, Ó., & Thomson, S. (2018). Financial protection in Europe: a systematic review of the literature and mapping of data availability. *Health Policy*, *122*(5), 493-508. https://doi.org/10.1016/j.healthpol.2018.02.006

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The Level of utilization and Satisfaction of Complete Denture Treatment Provided in Fiji from 2010-2016

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Abstract

Background: Wearing dentures helps rehabilitate the oral health status for the older people. Due to lack of previous data, this objective of this study was to determine the level of utilization and satisfaction of complete denture treatment at dental clinics in Fiji.

Materials and Methods: A cross sectional descriptive study was conducted on 85 edentulous patients and dentures at the Fiji National University (FNU) teaching dental clinic from 2010-2016.Patients who utilized the dentures fabricated at FNU and identified as complete denture patients from 2010-2016 were included in this study. Data was collected using the denture assessment form and Oral Health Impact Profile for Edentulous Patients (OHIP-EDENT) questionnaire. Correlation test was done and p less than 0.05 was considered as level of significance.

Results: Participants were between the age range of 40-79 years with majority being male (54%). Greater level of satisfaction noted among 60-69 years male participants and those wearing the dentures for 3-4 years than other groups. Difficulty in chewing (40%) and food catching underneath the denture (33%) were common denture related complains. One thirds of participants reported of uncomfortable dentures while 24% had sore spots due to their dentures. More than two thirds of them, (71%) were unable to eat and enjoy food and for most patients, the vertical dimension (94%), esthetics assessment (94%), tooth selection (91%), boarder extension (78%), posterior seal (99%) and centric relation (99%) were acceptable. Patients with acceptable vertical dimension (46.1±7.6), acceptable esthetics (45.8±7.9) and boarder extension (48.0±7.2) showed greater satisfaction level compared to those with unacceptable denture characteristics.

Conclusion: This study highlighted that satisfaction among recent denture wearers was low and majority participants portrayed poor understanding regarding denture aftercare and hygiene. It can be recommended for the teaching institutes and dental clinics to evaluate the quality of treatments and help to improve the quality of services being provided to the patients. Further study is needed to determine the in- depth perceptions of denture wearers. It also can be recommended for the patients to take heed of the post operative denture hygiene instructions being given.

Keywords: Complete denture, Denture assessment, Edentulism, Fiji, Patient's satisfaction

1. Introduction

Dental caries, edentulism, periodontal disease and oral cancer are currently amongst some of the major public health issues around the globe (Meier et al., 2017) with significant differences between countries (Emami, de Souza, Kabawat and Feine, 2013). Edentulism has been defined as the loss of all-natural dentition (Ishtiaq Ali et al., 2019; Tyrovolas et al., 2016; Pengpid & Peltzer, 2018). Edentulism remains a major disease burden in older adults' worldwide (Ishtiaq Ali et al., 2019). The World Health Organisation (WHO) states the incidence of edentulism is about 7%-69% internationally (Ishtiaq Ali et al., 2019). Apart from elderly, edentulism also affects young age groups being more prevalent in the socially deprived groups (Tyrovolas et al., 2016). Edentulism diminishes the

quality of life of individuals as it affects an individual's oral and general health (El-Dahdah, 2016; Jain, Kaushik, Dhawan, & Tandan, 2018; Michaud, de Grandmont, Feine, & Emami, 2012; Pengpid & Peltzer, 2018; Deniz & Kulak Ozkan, 2012). tooth loss often limits a person's ability to eat and speak well, even to the extent of limiting a person's ability to participate in social activities thereby affecting an individual's overall quality of life (Khan & Khan, 2015; Deniz & Kulak Ozkan, 2012). Edentulous individuals are also in greater risk for different systemic diseases and an increase in mortality rate (Emami et al., 2013). Although complete dentures (false teeth) cannot be considered as a substitute or natural dentition, they remain to be a staple treatment option for edentulous patients (Emami, de Souza, Kabawat, & Feine, 2013).

The number of patients who need conventional complete denturers is on a rise (Negahdari et al., 2016) and is the most common type of prosthesis used (Reginato et al., 2017; G Ashok & Ganapathy, 2017). The demand for dentures (or other prosthetic rehabilitation) is increasing dramatically due to an increase in the rate of edentulousness (Khan & Khan, 2015; Srisilapananet al., 2016; Deniz & Kulak Ozkan, 2012; Santos et al., 2015). Hence, Esan et al., (2004) stated that the demand for dentures was higher in participants of lower level of education and low socio-economic status. Many edentulous patients benefit from complete denture treatment and have reported satisfactory oral and masticatory function with their use (Carlsson & Omar, 2010). Wearing dentures helps rehabilitate the oral health status for the older people. It improves the chewing ability and makes oral health function better. Hence, this improves the quality of life (Srisilapanan et al., 2016). However, even when the dentures satisfy all the prosthodontic criteria, not all complete denture wearers are able to adapt to their dentures (Carlsson & Omar, 2010). Around 65%- 90% of the individuals are generally satisfied with their dentures (Carlsson & Omar, 2010). Complains with removable dental prosthesis are associated with a lot of factors, such as retention, stability, dimensios, occlusion, esthetics, speech, difficulty in chewing, food accumulation, (G Ashok and Ganapathy, 2017; Negahdari et al., 2016; El-Dahdah, 2016) thick or over extended denture flange, tight or loose dentures, occlusal interference, frenal impingements and so forth. These problems can arise due to alteration of anatomical structures, difficulty in adaptation or some technical faults in denture design and fabrication (G Ashok & Ganapathy, 2017). Unsatisfactory dentures may cause issues such as alteration in taste and smell, masticatory issues, oral discomfort, oral ulcerations, denture stomatitis and so forth (El-Dahdah, 2016).

There have been very few studies published in Fiji with regards to the use of prosthesis. King and Kapadia (2003) reported around 63% of edentulous patients in Fiji had no dentures while the other 37% had full upper and lower dentures. In their study, King and Kapadia (2003) stated about 41% patients required adjustment with their dentures as they had some denture related issues.

Prosthodontic complete denture treatment has been into practice at the School of Dentistry and Oral Health (SDOH), Fiji National University (FNU) from the very beginning of the dental school. However, the outcome of these dentures fabricated by the students in terms of utilization and satisfaction over the years had never been yet evaluated. This understanding greatly helps in improving the quality of treatment provided. Hence, the objective of the study was to understand the level of utilization and satisfaction of complete denture treatment provided at FNU dental clinics from 2010-2016.

2. Materials and Methods

2.1 Study Design and Setting

This was a cross- sectional descriptive study on complete denture patients selected from years 2010-2016 and their level of satisfaction and oral health related quality of life. This study was conducted at FNU dental clinics in Suva, Fiji. FNU dental clinics are the only teaching institute in Fiji that offers dental courses.

2.2 Study Population and Sample

The study population comprised of all the edentulous patients who received removable complete (full upper and lower) dentures at FNU dental clinics. The study participants were selected after analyzing files detailing treatments performed from 2010-2016, which were kept at the FNU dental clinics. Selection was done based on the inclusion and exclusion criteria. The inclusion criteria comprised of; student fabricated dentures made at FNU dental clinics, complete denture patients only from 2010-2016, patients should be utilizing those dentures fabricated at FNU, and male and female patients of any age. The exclusion criteria on the contrary included; those patients with serious systemic conditions who could not avail themselves for the interview.85 patients were interviewed and dentures were examined.

2.3 Data Collection Tools

The tools used for data collection were a modified version of the Oral Health Impact Profile for Edentulous Patients (OHIP-EDENT) questionnaire to gauge the patient satisfaction which were developed after literature

search (Reginato et al., 2017; Michaud et al., 2012) and a self-developed Oral Examination and Denture Assessment (OEDA) form.

2.3.1 OHIP-EDENT Questionnaire

The OHIP-EDENT questionnaire consisted of seven sections. They include Functional *Limitation* which had 3 questions, *Physical Pain* with four related questions, two questions under *Psychological discomfort*, three questions under *Physical disability*, two questions under *Psychological disability*, three questions under *Social disability* and two questions under the sub-heading *Handicap*.

Each question in OHIP-EDENT had options of 'yes', 'no' and 'sometimes'. Scores were given for each for the purpose of analysis; 'yes' denoted a score of 1, 'sometimes' was denoted a score of 2 while 'no' had a score of 3. This helped in determining the patient satisfaction levels.

Both data collection tools were pretested prior to its administration. The content of the tools was checked by 3 experts and they were also shown to 5 participants to make sure they are understandable by the study participants.

In terms of the variables, the independent variables included; age, gender, location, occupation while the dependent variable were patient satisfaction and utilization of their dentures, and the years of denture use.

2.3.2 OEDA Form

The OEDA form had two sections. The first section under oral examination and denture assessment was based on the denture history (patients' perception of his/her dentures) while the second section focused on denture assessment (dentists' perception of the denture).

2.4 Study Procedure

Complete denture patients were selected based on the set inclusion criteria by the principal investigator. Every participant was given a written form of information sheet as well as a verbal explanation on the purpose of this study. The information sheet was provided in three different laguages; English, Hindi and Itaukei. Approval was requested from the participants in the form of a written consent. Moreover, every participant was given an identification code instead of using their actual names; to maintain confidentiality. The patients were examined for initial denture assessment using the OEDA form following which the OHIP-EDENT questionnaire was administered by the principal investigator.

2.5 Data Management and Analysis

Data was collected and descriptive statistical analysis was done inSPSS. Significance was set at p< 0.05.

2.6 Ethical Approvals

Ethical approvalswere obtained from the Department of Oral Health Research Committee (DOHRC) and also form the College Health Research Ethics Committee (CHREC) at FNU.

3. Results

A total of 85 participants with full upper and lower set of dentures were examined. Majority (56%) participant were between the age of 60-69 while only 5% participants were between the age range of 40-49. About half of the participants (46%) were male and 54% were female. Participants had at least 1 to more than 5 years of experience of wearing the dentures (Table 1).

Table 1. Demographic characteristics of participants

Characteristics	Frequency (%)
Age	
40-49	4 (5)
50-59	17 (20)
60-69	48 (56)
70-79	16 (19)
Gender	
Male	46 (54)
Female	39 (46)
Denture wearing experience	
1-2	33 (39)
3-4	27 (32)
5+	25 (29)

Participants between 60-69 years were more satisfied with their denture (46.1±8.3) while participants between 70-79 were least satisfied (43.3±7.5). Male participants showed more satisfaction (46.5±7.6) than female participants (44.2±8.6). Participants wearing the dentures for 3-4 years had greater satisfaction (46.4±6.5) while those who recently received their dentures had least satisfaction (44.2±8.8) (Table 2). There was no statistical significance difference between these variables and level of satisfaction.

Table 2. Correlation between independent variables and satisfaction level

Variables	Satisfaction	p- value
Age		
40-49	45.5±9.3	
50-59	44.6± 8.4	0.671
60-69	46.1±8.3	
70-79	43.3±7.5	
Gender		
Male	46.5±7.6	0.209
Female	44.2±8.6	
Years of denture wearing		
1-2	44.2±8.8	
3-4	46.4±6.5	0.575
5+	45.5±9.0	

Majority of participants (94%) felt their dentures were very important to them, 5%felt it was less important while 1%felt it was not important at all. Moreover, 93% participants reported of receiving adequate information during the denture making process while the rest (7%) were not satisfied with the amount and the type of information they received. Participants who received adequate information showed greater satisfactions levels (45.8±8.1) than the rest (38.2±5.7).

Common denture related complains given by participants related to functional limitations were difficulty in chewing (40%) and food catching underneath the denture (33%). These functional limitations brought about psychological discomfort in participants and caused physical and social disability.34% participants reported of uncomfortable dentures while 24% had sore spots due to their dentures. Participants had become more self-conscious (19%) and only 5% had become embarrassed because of their dentures. More than two thirds of them, (71%) were unable to eat and enjoy food and 33% got interrupted while eating meals. A few participants had social disability whereby only 6% avoided socializing, 1% had become less tolerant of the spouse and only 1%

became more irritable of other people. More than half of them (53%) were unable to enjoy others company and only 1% stated that life had become less satisfyingwhile 93% participants reported their overall quality of life had improved after getting dentures (life was satisfying) (Table 3).

Table 3. Participant satisfaction, utilization and denture related complains (n=85)

Variables	Frequency (%)		
	Yes	No	Sometimes
Functional limitation:			
Difficulty chewing	34 (40)	51 (60)	0(0)
Food catching underneath the denture	28 (33)	31 (36)	26 (31)
Denture not fitting	35 (41)	50 (59)	0(0)
Physical Pain:			
Painful aching	25 (29)	60 (71)	0(0)
Sore spots	20 (24)	65 (76)	0(0)
Uncomfortable dentures	29 (34)	56 (66)	0(0)
Psychological discomfort/ disability:			
Worried because of denture issues	11 (13)	64 (75)	10 (12)
Become more self-conscious	16 (19)	62 (73)	7 (8)
Upset because of denture issues	5 (6)	60 (70)	20 (24)
Embarrassed	4 (5)	61 (71)	20 (24)
Physical disability:			
Avoid eating certain food	46 (54)	36 (42)	3 (4)
Able to eat and enjoy food	60 (71)	25 (29)	0(0)
Get interrupted while eating meals	28 (33)	39 (46)	18 (21)
Social disability:			
Avoid socializing	5 (6)	66 (78)	14 (16)
Have become less tolerant of the spouse	1 (1)	80 (94)	4 (5)
Have become irritable of people	1 (1)	80 (94)	4 (5)
Handicap:			
Unable to enjoy others company	45 (53)	32 (38)	8 (9)
Life has become less satisfying	1 (1)	79 (93)	5 (6)

Patients also had issues with denture retention. One third of them (34%) reported their denture falls when in function with 66% having no retention issues. 28% reported both upper and lower denture had become loose overtime and not fitting well, 11% complained of only lower denture being loose, 2% stated the upper denture was loose only while 59% had no issues as such. Moreover, denture esthetics is an important issue often resulting in patient dissatisfaction. Participants complained about the size and color of teeth selected and comparing current dentures to either their old dentures or natural dentition. Dentist's perception of esthetic assessment stated that 94% had acceptable esthetics while the rest did not. Among those with unacceptable esthetics included patients who had protruded facial profile, unacceptable smile line, greater discrepancies felt between the upper and lower facial profile or teeth being covered with acrylic and not giving a pleasant appearance. 91% of the patients has acceptable mold of teeth selected, while 9% had either very large or very small teeth selected not suiting the facial profile, teeth were either worn out or excessively grinded to get correct occlusion.

The dentist examined the patient dentures using the denture assessment form. For most patients, the vertical dimension (94%), esthetics assessment (94%), tooth selection (91%), boarder extension (78%), posterior seal (99%) and centric relation (99%) were acceptable.

The denture characteristics were correlated to patient satisfaction levels. Patients with acceptable vertical dimension (46.1±7.6), acceptable esthetics (45.8±7.9) and boarder extension (48.0±7.2) showed greater

satisfaction level compared to those with unacceptable denture characteristics (Table 4).

Table 4. Correlation between acceptable characteristics of complete denture andpatient satisfaction

Variables	Patient satisfaction	p- value
Vertical dimension		
Acceptable	46.1±7.6	<0.0001*
Not Acceptable	31.8±2.0	
Esthetic Assessment		
Acceptable	45.8±7.9	0.018*
Not Acceptable	36.6±7.8	
Tooth selection		
Acceptable	45.8±8.0	0.062
Not Acceptable	40.1±8.2	
Border Extension		
Acceptable	48.0±7.2	<0.0001*
Not Acceptable	37.0±4.8	
Posterior Seal		
Acceptable	45.4±8.1	0.400
Not Acceptable	36.0±SD	
Centric Relation		
Acceptable	45.4 ± 8.1	0.188
Not Acceptable	33.0±SD	

Participants generally had poor understanding about denture aftercare and hygiene. Most participants used toothpaste to clean their dentures (81%). A few participants also slept with their dentures (20%) as well while the rest took out their dentures and placed them in water before sleeping (80%). Other aids which the participants used to clean their dentures were; using bleaching agent (5%), 6% used denture cleaning tablets while 12% used soap and water to clean their dentures. Only 2% participants reported of cleaning the denture every time after they ate (Table 5).

Table 5. Participant's behavior related to Denture after-care and hygiene

Participant comments	Frequency (%)	
	Yes	**No**
Uses toothpaste to wash	69 (81)	16 (19)
Takes denture out at night before sleeping	68 (80)	17 (20)
Sleeps with denture	17 (20)	68 (80)
Washes with bleaching agent	4 (5)	81 (95)
Uses tablets to clean	5 (6)	80 (94)
Uses soap and water to wash denture	10 (12)	75 (88)
Cleans denture after eating as well	2 (2)	83 (98)

4. Discussion

The objective was to determine the level of utilization and satisfaction of complete denture treatment at dental clinics in Fiji. This study was conducted among edentulous participants between 40-79 years of age. Majority (56%) participant were between the age of 60–69 while only 5% participants were between the age range of 40-49. About half of the participants (46%) were male and 54% were female.

4.1 Patient Satisfaction with Dentures in Relation to Demographic Characteristics

In this study, participants between 60-69 years were more satisfied with their denture (46.1±8.3) while participants between 70–79 were least satisfied (43.3±7.5). Male participants showed more satisfaction (46.5±7.6) than female participants (44.2±8.6). Participants wearing the dentures for 3-4 years had greater satisfaction (46.4±6.5) while those who recently received their dentures had least satisfaction (44.2±8.8). Patients with two complete dentures have longer prosthetic history and are more experienced in the adaptation process than removable partial denture wearers (Komagamine et al., 2016). Thus, shortening the time necessary for adaptation to complete denture wearers (Komagamine et al., 2016). Komagamine et al., (2016) showed a relationship between sex and adaptability to dentures; men were reported to adapt more rapidly to new dentures than women. Similarly, there are other possible factors that might determine the prognosis of complete denture treatment. For instance; previous denture experience, the period of existing denture use, numbers of previous complete dentures, and duration of edentulousness (Komagamine et al., 2016).

4.2 Denture Related Complains and Functional Limitation

Common denture related complains given by participants related to functional limitations were difficulty in chewing (40%) and food catching underneath the denture (33%). These functional limitations brought about psychological discomfort in participants and caused physical and social disability. 34% participants reported of uncomfortable dentures while 24% had sore spots due to their dentures. Participants had become more self-conscious (19%) and only 5% had become embarrassed because of their dentures. More than two thirds of them, (71%) were unable to eat and enjoy food and 33% got interrupted while eating meals. A few participants had social disability whereby only 6% avoided socializing, 1% had become less tolerant of the spouse and only 1% became more irritable of other people. More than half of them (53%) were unable to enjoy others company and only 1% stated that life had become less satisfying. Participants in this study had issues with mastication which were brought about because of pain along the edentulous ridges due to presence of undercuts and sore spots because of unpolished dentures or overextensions. Patients that reported of problems with speech were majority recent denture wearers or those that had existing dentures thus having problems with adaptations. Such patients had issues with pronunciation of words and complained of difficulty during telephone conversations. Food accumulation underneath dentures was also reported in this study. Khan and Khan (2015) stated common complaints reported by complete denture wearers include; difficulty in speech, mastication, pain and esthetic issues. Pain may often cause insomnia and some negative changes in eating behaviours. These problems are often associated with the elderly. The most common areas of dissatisfaction are as follows: mastication, overall perception, speech, denture cleanliness, fit, natural tooth problems, appearance and odour (Khan & Khan, 2015). Pain was reported as one of the most common dentures related complains (Parvez et al., 2020 apart from loose denture, mastication and speech (Salih et al., 2016). Speech issues was noted higher within the age group of up to 60 years 11 (5.5%) (Salih et al., 2016). Speech was not an issue in a study conducted by Bhat et al., (2014) as majority (58%) participants were satisfied with it. Only 3% participants had issues with mastication while the rest were satisfied (Bhat et al., 2014). Very few participants had issues with denture retention (Bhat et al., 2014). Mastication discomfort and looseness of denture were the most common complaints followed by lack of retention, bad breath, tongue restriction and food accumulation (Sanyal et al., 2013). Torres-Sanchez et al., (2018) reported of better retention stability and less accumulation of particles of the food particles underneath the denture with the use of denture adhesives. Perea et al., (2013) reported that the most affected domains were "functional limitation" and "physical pain", followed by "physical disability". Minor impacts were recorded for the psychological and social subscales ("psychological discomfort", "psychological disability", "social disability" and "handicap") (Perea et al., 2013). Women complained about the appearance of their dentures, while more men had objections regarding mastication (Komagamine et al., 2016; Salih et al., 2016).

One third of them (34%) reported their denture falls when in function with 66% having no retention issues. 28% reported both upper and lower denture had become loose overtime and not fitting well, 11% complained of only lower denture being loose, 2% stated the upper denture was loose only while 59% had no issues as such. Zani et al (2009), reported that patients often express dissatisfaction with their lower arch dentures. Frequent complaints with regards to this include; reduced retention and stability of conventional dentures, difficulties with mastication and verbal communication, which are often due to resorption of alveolar bone.

4.3 Denture Assessment and Satisfaction Levels

The denture characteristics were correlated to patient satisfaction levels. Patients with acceptable vertical dimension (46.1±7.6), acceptable esthetics (45.8±7.9) and boarder extension (48.0±7.2) showed greater satisfaction level compared to those with unacceptable denture characteristics. Majority participants from this

study, who were assessed by the dentist, had acceptable vertical dimension (94%), esthetics assessment (94%), tooth selection (91%), boarder extension (78%), posterior seal (99%) and centric relation (99%). Patients who reported of looseness of lower dentures mostly had resorbed edentulous ridges. 6% patients had unacceptable esthetic (according to the dentist that inspected the participant dentures) which was due to wrong type of tooth selection (color and size). Esthetic issues were mostly seen in female participants than to male counterparts with regards to the size, shape and color of teeth selected. Patients had higher speech and esthetics satisfaction levels, but greater mastication complaints with regards to their existing dentures (Komagamine et al., 2016) with similar results obtained from this study. This suggests that in the mastication, speech, and esthetics recovery from mastication problems is most difficult. In complete denture therapy there is a need to cover the palate and the thickness of the cover might cause a prolonged adaptation period (Komagamine et al., 2016). In a study by Bhat et al., (2014), majority participants were either happy or very happy with the denture esthetics in terms of denture colour (88%), colour of the teeth in the denture (93%), overall facial appearance (93%) and denture smoothness (93%). Khan and Khan (2015) argued that elderly edentulous participants had improved overall oral health related quality of life 16 months post denture insertion, whereby females had reported better quality of life than their male counterparts. A study (Srisilapanan et al., 2016) done in Thai population showed that good quality dentures greatly improve their oral health related quality of life, almost to the level of those with natural dentition which is also reflected in this study. In a study by Bhat et al., (2014), 93% participants portrayed that they were satisfied with their dentures. However, a study by Parvez et al., (2020) showed low quality of life of complete denture wearers as they frequently had problems in eating, social interaction and communication. Edentulous elderly people who are well satisfied with their daily lives are also satisfied with their complete dentures (Yoshida et al., 2001). Quality of dentures had been reported as the most significant factor in determining patient satisfaction (Celebic et al., 2003). Apart from that, level of education, self-perception of affective and economic status, and quality of life are all related to patient satisfaction (Celebic et al., 2003). The use of conventional complete dentures brings negative impacts in the oral health related quality of life of patients as reported by Perea et al., (2013). Panchevska et al., (2018) reported that patients' satisfaction was not directly related with the quality of complete dentures.

4.4 Denture Aftercare and Hygiene

Participants in this study portrayed poor understanding regarding denture aftercare and hygiene. 81% participants reported of using toothpaste to wash their denture and 20% slept with the denture overnight. Hence, dentist patient communication is of utmost importance. 93% participants of this study reported of receiving enough information regarding the denture making process while the rest did not. Most of the individuals used only water to clean their dentures twice per day while others used water and toothbrush for denture cleansing (R, Robin* & Raj, 2015). Those who had been wearing dentures for longer had maintained better frequency of denture cleaning (R, Robin and Raj, 2015). Poor denture hygiene was reported as one factor that obviously contributed to the occurrence of various denture related complaints such as pain and discomfort (Budală et al., 2021). 29.3% participants slept with their prosthesis in mouth (Mushtaq et al., 2019). 57.3% told that they were given only verbal instructions about methods of cleaning while 42.7% were not even told or shown any method of cleaning of denture by dentist (Mushtaq et al., 2019). Developing dentist patient relationship involves providing the patient with sufficient information at the treatment planning stage and throughout the course (Chen et al., 2015). The patient should be well informed about the denture fabrication process, denture wearing episodes and after care concerns, individual follow up schedules and instructions related to nutrition, speech, nocturnal wear and denture hygiene (Chen et al., 2015). An improvement in quality of complete denture can be brought about by development of effective clinical skills and technical procedures to improve denture occlusion, articulation, maxillary and mandibular retention and stability (Chen et al., 2015). Clinicians should be well aware of the patient expectations and understand the importance of providing good quality dentures (Sanchana, 2015).

4.5 Limitation

This study applied a self-reported questionnaire to collect data so the results is this study is heavily depending on participant response. This study also used a small sample size that may affect the power of statistics used. Furthermore, searching for folders to call the patients to the clinic for the research was a bit challenging and time consuming as all the folders were mixed in the archive in the record room.

5. Conclusion

Participants between 60-69 years were more satisfied with their denture while participants between 70-79 were least satisfied. Participants wearing the dentures for 3-4 years had greater satisfaction than those who recently received their dentures. Common denture related complains given by participants related to functional limitations were difficulty in chewing and food catching underneath the denture. Other findings reported were uncomfortable

dentures, sore spots due to their dentures, unable to eat and enjoy food because of uncomfortable dentures and getting interrupted while eating meals. A third of the participants reported issues with denture retention. Patients with acceptable vertical dimension, acceptable esthetics and boarder extension showed greater satisfaction level compared to those with unacceptable denture characteristics. Majority participants portrayed poor understanding regarding denture aftercare and hygiene. Further, it can be recommended for the teaching institutes and dental clinics to evaluate the quality of treatments being provided by the students as this can help improve the quality of services being provided to the patients. A qualitative study can be conducted by future researchers to determine the in- depth perceptions of denture wearers. It can be recommended for the patients to take heed of the post operative denture hygiene instructions being given.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Abdulazeez, J., Salih, H., & Aljamoor, C. (2016). Clinical Evaluation of Post Insertion Problems among Newly Wearers of Complete Denture Patients in Sulaimani City. *Sulaimani Dental Journal, 3*(2), 98-102. https://doi.org/10.17656/sdj.10064

Bhat, V. S., & Malli, P. (2014). A survey to assess patient satisfaction after receiving complete denture prostheses in AB Shetty Memorial Institute of Dental Sciences. *Journal of Health and Allied Sciences NU*, *4*(02), 081-085. https://doi.org/10.1055/s-0040-1703768

Budală, D. G., Baciu, E. R., Virvescu, D. I., Armencia, A., Scutariu, M. M., Surlari, Z., & Balcoș, C. (2021). Quality of Life of Complete Denture Wearers—A Comparative Study between Conventional Dentures and Acrylic Dentures with Vitamin B12 Incorporated. *Medicina*, *57*(8), 820. https://doi.org/10.3390/medicina57080820

Carlsson, G. E., & Omar, R. (2010). The future of complete dentures in oral rehabilitation. A critical review. *Journal of Oral Rehabilitation*, *37*(2), 143-156. https://doi.org/10.1111/j.1365-2842.2009.02039.x

Čelebić, A., Knezović-Zlatarić, D., Papić, M., Carek, V., Baučić, I., & Stipetić, J. (2003). Factors related to patient satisfaction with complete denture therapy. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *58*(10), M948-M953. https://doi.org/10.1093/gerona/58.10.M948

El-Dahdah, B. P. (2016). *Reliability and Validity of Patient's Denture Satisfaction Assessment (PDSA) Questionnaire for Patient-Based OHRQoL Assessment of Complete Dentures* (Doctoral dissertation, The University of Texas School of Dentistry at Houston). Retrieved November 12, 2020, from https://www.semanticscholar.org/paper/Reliability-and-Validity-of-Patient%27s-Denture-for-El-Dahdah/f4f9e4b5ae373d554088e5ceaeab3c0fd6943bf7

Emami, E., de Souza, R. F., Kabawat, M., & Feine, J. S. (2013). The impact of edentulism on oral and general health. *International journal of dentistry*, *2013*. https://doi.org/10.1155/2013/498305

Esan, T. A., Olusile, A. O., Akeredolu, P. A., & Esan, A. O. (2004). Socio-demographic factors and edentulism: the Nigerian experience. *BMC Oral health*, *4*(1), 1-6. https://doi.org/10.1186/1472-6831-4-3

Ashok, N. G., & Ganapathy, D. (2017). Evaluation of post-operative complaints in complete denture and removable partial denture wearers: A questionnaire based study. *Journal of Pharmaceutical Sciences and Research*, *9*(9), 1438.

Ali, H. I., Memon, M. R., Shaikh, A. G., Memon, H., & Samejo, I. (2019). Edentulism in relation to sociodemographic status of patients. *Pakistan Oral & Dental Journal*, *39*(1), 98-101. Retrieved 12 November, 2020, from https://podj.com.pk/index.php/podj/article/view/359

Jabeen, B., Samejo, I., Hasan, S. M. U., Khan, A., & Ilyas, Y. (2018). POST INSERTION COMPLAINTS ASSOCIATED WITH NEW COMPLETE DENTURE. *Pakistan Oral & Dental Journal*, *38*(1), 127-129.

Kaushik, K., Dhawan, P., Tandan, P., & Jain, M. (2018). Oral health-related quality of life among patients after complete denture rehabilitation: a 12-month follow-up study. *International Journal of Applied and Basic Medical Research*, *8*(3), 169. https://doi.org/10.4103/ijabmr.IJABMR_171_18

King, T., & Kapadia, D. (2003). Oral health status and treatment needs of institutionalized elderly and disadvantaged population in Fiji (1997). *Pacific health dialog*, *10*(1), 35-40. Retrieved November 12, 2020, from http://pacifichealthdialog.org.fj/Volume2010/No120Oral20Health20In20The20Pacific/Oral20Health/Origin

al20Papers/ORALH201B.PDF

Meier, T., Deumelandt, P., Christen, O., Stangl, G. I., Riedel, K., & Langer, M. (2017). Global burden of sugar-related dental diseases in 168 countries and corresponding health care costs. *Journal of dental research*, *96*(8), 845-854. https://doi.org/10.1177/0022034517708315

Michaud, P. L., de Grandmont, P., Feine, J. S., & Emami, E. (2012). Measuring patient-based outcomes: is treatment satisfaction associated with oral health-related quality of life?. *Journal of dentistry*, *40*(8), 624-631. https://doi.org/10.1016/j.jdent.2012.04.007

Mushtaq, M., Altaf, J., Sheikh, M., Khan, M., & Shah, A. (2019). Assessment of Knowledge and Practices about Denture Hygiene among Complete Denture Wearers in Lahore City. *Journal of The Pakistan Dental Association, 28*(4), 187-191. https://doi.org/10.25301/jpda.284.187

Parvez, K., Parvez, K., Sultan, R., & Muhammad Aliuddin, A. (2020). Oral Complaints of Complete Denture Wearing Elderly Patients and Their Relation With Age & Gender. *Journal of the Pakistan Dental Association, 29*(3), 140-143. https://doi.org/10.25301/JPDA.293.140

Panchevska, S., Elenchevski, S., Janeva, N., & Mijoska, A. (2018). Satisfaction of complete denture wearers. *Medical Review, 71*(7-8), 247-249. https://doi.org/10.2298/MPNS1808247P

Pengpid, S., & Peltzer, K. (2018). The prevalence of edentulism and their related factors in Indonesia, 2014/15. *BMC Oral Health, 18*(1). https://doi.org/10.1186/s12903-018-0582-7

Perea, C., Suárez-García, M. J., Del Río, J., Torres-Lagares, D., Montero, J., & Castillo-Oyagüe, R. (2013). Oral health-related quality of life in complete denture wearers depending on their socio-demographic background, prosthetic-related factors and clinical condition. *Medicina oral, patologia oral y cirugia bucal*, *18*(3), e371. https://doi.org/10.4317/medoral.18648

Pournasrollah, A., Negahdari, R., Mahdi, S., & Bohluli, S. (2016). Evaluation of Gradual Trend of Patients' Satisfaction with Complete Dentures in the Department of Prosthodontics: A Cross-sectional Study. *Advances in Bioscience And Clinical Medicine, 4*(2). https://doi.org/10.7575/aiac.abcmed.16.04.02.04

Robin, R. P., & Raj, J. (2015). A Survey of Denture Hygiene in Older Patients. *Journal of Medical Science And clinical Research, 7*(10), 897-900. https://doi.org/10.18535/jmscr/v3i9.01

Reginato, V. F., Maroli, A., Caldas, R. A., Sánchez-Ayala, A., Spazzin, A. O., & Bacchi, A. (2017). Relationship between prosthetic factors and oral health-related quality of life in complete denture wearers. *Revista Odonto Ciência*, *32*(2). https://doi.org/10.15448/1980-6523.2017.2.27486

Sanyal, P., Ghanchi, M., Gosavi, S., & Malik, S. (2013). A Survey of Complete Denture Patients Experiencing Difficulties with their Prostheses. *The Journal of Contemporary Dental Practice, 14*(3), 524-527. https://doi.org/10.5005/jp-journals-10024-1355

Srisilapanan, P., Korwanich, N., Jienmaneechotchai, S., Dalodom, S., Veerachai, N., Vejvitee, W., & Roseman, J. (2016). Estimate of impact on the oral health-related quality of life of older Thai people by the provision of dentures through the Royal Project. *International journal of dentistry*, *2016*. https://doi.org/10.1155/2016/1976013

Torres-Sánchez, C., Montoya-Salazar, V., Torres-Lagares, D., Gutierrez-Pérez, J. L., & Jimenez-Castellanos, E. (2018). Satisfaction in complete denture wearers with and without adhesives: A randomized, crossover, double-blind clinical trial. *Journal of clinical and experimental dentistry*, *10*(6), e585. https://doi.org/10.4317/jced.54871

Tyrovolas, S., Koyanagi, A., Panagiotakos, D. B., Haro, J. M., Kassebaum, N. J., Chrepa, V., & Kotsakis, G. A. (2016). Population prevalence of edentulism and its association with depression and self-rated health. *Scientific reports*, *6*(1), 1-9. https://doi.org/10.1038/srep37083

Wearers, E. C. D. (2001). Correlation between quality of life and denture satisfaction in elderly complete denture wearers. *The International journal of prosthodontics*, *14*(1), 77-80.

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Adults on the Autism Spectrum Face Significant Challenges Accessing Health Care Services

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by difficulties with social skills, verbal and non-verbal communication, repetitive behaviours and atypical sensory processing. Individuals on the autism spectrum face a higher prevalence of health conditions and have a higher mortality rate than the general population. There is a critical need to understand adults' experiences on the autism spectrum when accessing health care services to understand how to improve accessibility to health care for these individuals. The purpose of this scoping review was to investigate how adults on the autism spectrum access and experience health care services. Four databases, including Embase, MEDLINE, CINAHL, and PsycInfo, were systematically searched for literature exploring how individuals on the autism spectrum access and experience health care. Results were extracted and categorized into five determinants based on the accessibility framework described by Levesque et al. (2013). Results indicated adults on the autism spectrum experience numerous barriers when accessing health care services. The dimension of access most frequently cited was the appropriateness of care, followed by the acceptability of care. It is essential to explore access as it is often conceptualized as the availability and affordability of services; however, results of this study indicate the broader experience of quality care provision and acceptance of the individual are important in understanding the complex experience individuals on the autism spectrum face. Based on these findings, there is a need to provide comprehensive education and clinical practice guidelines for health care providers to help reduce barriers to providing appropriate care for adults on the autism spectrum. Efforts to destigmatize intrapersonal and extra-personal perceptions of individuals on the autism spectrum will help overcome the barriers that affect care acceptability. Further research must understand how to design and implement strategies to maximize health service access for adults on the autism spectrum.

Keywords: adult, autism, access, health care, services

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by difficulties with social skills, verbal and nonverbal communication, repetitive behaviors and atypical sensory processing (American Psychiatric Association, 2013). It is estimated that one in 160 children worldwide has an autism diagnosis (World Health Organization, 2018), with the prevalence continuing to increase globally. Historically, individuals were typically diagnosed with ASD as a child. However, data from many countries has shown there is an increasing population of individuals diagnosed with ASD in adulthood (Bachmann et al., 2018; Diallo et al., 2018; Jensen et al., 2014; Schendel & Thorsteinsson, 2018). For example, Jensen et al. (2014) studied the incidence rates of ASD across the lifespan from 1995 to 2010. During this lifespan, the incidence rates for ASD increased from 9.0 to 38.6 per 100,000 persons (Jensen et al., 2014). This increase was very evident in the adult population (Jensen et al., 2014).

Compared to the general population, individuals on the autism spectrum have poorer life outcomes, including reduced education and employment opportunities, fewer social networks and supports, and a lower quality of life (Baldwin et al., 2014; Hewitt et al., 2012; Nord et al., 2016; van Asselt-Goverts et al., 2015; van Hees et al., 2015). Alongside these poor life outcomes, research has consistently shown that individuals on the autism spectrum also have a higher prevalence of health conditions than the general population (Fortuna et al., 2016). Conditions including seizure disorders, hypertension, diabetes, obesity, gastrointestinal issues, immune issues, sleep disorders and genetic disorders, among others, disproportionately affect individuals on the autism spectrum (Croen et al.,

2015; Fortuna et al., 2016). Mental health or psychiatric conditions including depression, anxiety, obsessive-compulsive disorder, schizophrenia, opposition defiance disorder, bipolar disorder are also more frequently observed in individuals on the autism spectrum (Croen et al., 2015; Fortuna et al., 2016; Hirvikoski et al., 2016; Mattila et al., 2010). Of note, this paper will use 'person-first' language when referring to individuals on the autism spectrum, however, the authors acknowledge that there is an ongoing discussion regarding the appropriate use of language amongst the Autism community.

Cumulatively, the presence of co-occurring physical and mental health conditions means that many individuals on the autism spectrum die prematurely. Mortality rates among individuals on the autism spectrum are significantly higher than that of the general population. For example, individuals on the autism spectrum die on average 16.33 years earlier than their typically developing counterparts (Hirvikoski et al., 2016). Furthermore, the risk of mortality is two times higher for the individuals on the autism spectrum than individuals who are not on the autism spectrum (Jokiranta-Olkoniemi et al., 2020).

Ensuring that individuals on the autism spectrum have adequate access to health care services is, therefore, of utmost importance. Indeed, the right to quality, available and accessible health care has been recognized as a human right by the World Health Organization (World Health Organization, 2017). While parents can support their children to access health care, individuals on the autism spectrum must access health care independently as individuals age into adolescence and adulthood. For adults on the autism spectrum, the social-communicative difficulties experienced may pose significant barriers to accessing and navigating the health care system.

Access to health care can be defined as an opportunity to identify health care needs, seek or use healthcare services, and have needs met through services (Levesque et al., 2013). Accessibility can be conceptualized into five dimensions, including approachability, acceptability, availability, affordability, and appropriateness (Levesque et al., 2013). Table 1 presents the definition of the five dimensions of access to health services. Research has consistently shown the importance of accessible health care services, with accessible health care services including factors such as respect towards patients, appointment reminders, sufficient time to meet with health care professionals, consistent health care provider hours, interprofessional care, culturally sensitive health care providers and more (Bogenschutz, 2014; Ross et al., 2015).

Table 1. Levesque et al. (2013) definition of dimensions of access to health services

Appropriateness
The fit between services offered and client needs includes the timeliness of the service, the amount of care spent in assessing and determining the correct treatment for each unique care need, and the technical and interpersonal quality of the services provided.
Acceptability
Cultural and social factors determining the possibility for people to accept the service and the judged appropriateness for the person to seek care.
Availability
The physical places of health services and health care providers and ability to reach both in a physically and in a timely manner.
Affordability
The economic capacity for people to spend resources and time on appropriate services, including the capacity to generate resources to pay for care.
Approachability
Transparency that allows potential clients to identify available services, to identify how to contact the available services, and to understand the impact the available services would have on their health.

There is a vast array of existing literature related to the experience and accessibility of health care services among children on the autism spectrum, their families, and adolescents transitioning from childhood to adulthood. Many existing clinical practice guidelines ensure that families with children on the autism spectrum can navigate through the health care system (Murphy et al., 2016). However, there is a lack of literature regarding individuals' experience on the autism spectrum when accessing health care services when they reach adulthood. A recent systematic review by Mason et al. in 2019 focused on the physical aspect of accessing health services for Autistic adults. They included six papers (two qualitative, two quantitative and two mixed methods studies) in their review.

The main findings from this study were significant challenges in communication between patients and providers, sensory sensitivity that results in anxiety before and during encounters, and barriers resulting from impairments in executive functioning and planning. The findings touch on all areas of access as defined by Levesque et al. (2013) but not on the acceptability and affordability of the services.

Therefore, the purpose of this study was to investigate the barriers adults on the autism spectrum experience when accessing health care services, according to Levesque et al.'s (2013) framework of accessibility. This literature review uses Levesque et al.'s (2013) framework of accessibility which acknowledges the social determinants of health of individuals on the Autism spectrum. This framework includes five corresponding dimensions of abilities (i.e. Ability to perceive; Ability to seek; Ability to reach; Ability to pay; and Ability to engage) (Levesque et al., 2013) that allow for the investigation of barriers as a result of the dimensions of abilities (Corscadden et al., 2017).

2. Methods

2.1 Design

This review adhered to the scoping review approach set out by Arksey and O'Malley (2005). The search strategy was an iterative process to best answer the question: "How do adults on the autism spectrum access and experience health care services?"

2.2 Search Strategy

Search terms included but were not limited to "Autism", "health service", "health care system", "access", "availability", and "health care disparities." These words and phrases were truncated and used with various pertinent connecting terms such as and/or to construct the search strategy. No filters or restrictions were applied to the year of publication.

The search was conducted using Embase, MEDLINE, CINAHL, and PyscINFO, as each database contains a breadth of information concerning health, health services, and health provision. A manual search of relevant studies' references was conducted to ensure the saturation of pertinent articles.

2.3 Study Selection

Publications of interest were peer-reviewed published articles that explored access and health care experiences of individuals on the autism spectrum. Studies were included if 1) all participants were above the age of 18 and had been formally or self-diagnosed with ASD, 2) the article pertained to health care services or 3) explored the perceptions of caregivers and health care professionals connected to adults accessing health care service.

Studies were excluded if the sample population was defined as individuals with an "intellectual or developmental disability" without the provision of ASD-specific data. This decision was made because intellectual and developmental disabilities encompass a broad range of conditions that may not apply to the experience of adults on the autism spectrum. Research related solely to the cost burden on systems such as hospitals, governments, and insurance companies was excluded as they did not address person-level interaction with health care services. Research related to the transition from pediatric to adult service use was also excluded because the period was deemed significantly different and unique from the typical adult experience when accessing health care services.

2.4 Data Extraction

Studies were imported to a reference manager (EndNote) and then into a review manager (Covidence), where duplicates were removed. Three authors worked independently to review and select article titles and abstracts that met the inclusion criteria. The other two authors reviewed articles selected by one author to ensure agreement of selected articles. Three authors conducted a full-text review of the articles independently to ensure the inclusion criteria were met: Information about design, population, purpose, findings related to the experience of access, and implications was extracted from relevant articles (see Table 2). Once data had been extracted from articles, common themes such as "provider knowledge", "communication barriers," or "inadequate service for needs" were generated by the three authors together (see Table 3). Levesque et al.'s (2013) framework of accessibility was then used to categorize the themes into five different dimensions: appropriateness, approachability, availability, affordability, and acceptability (see Table 1 and Table 2). This framework was used as it consists of a cumulative perspective of access, has been referenced and utilized extensively in health literature, and is client-centred based on the obstacles experienced by individuals (Levesque et al., 2013). A secondary database search was performed one year following the initial search. Selected articles were screened against inclusion and exclusion criteria. Findings from the relevant articles were extracted and contributed to the findings detailed in this paper. Three authors worked together to extract themes from papers and sort them into the dimensions of access to ensure the themes' consistency and authenticity.

Table 2. Summary of all papers included in the scoping review

Citation	Study Design	Sample & Sample Size	Age of Sample	Country	Objective	Barriers to Access & Subthemes
Dudley, Klinger, Meyer, Powell, & Klinger, 2019	Quantitative Survey (online, mail)	Caregivers on behalf of individuals on the autism spectrum: n=274	20-58 Mean: 35.4 SD: 6.5	USA	To investigate service use, unmet needs, and obstacles to service access	**Availability**: Lack of or cost of transportation **Affordability**: Living situations lead to less funding **Approachability:** Unsure of where to find or unaware of services
Baldwin & Costley, 2016	Mixed-method Survey (online, mail)	Female individuals on the autism spectrum: n=82	18-64 Mean: 32.7	Australia	To assess the health, education, work, social, and community activities of autistic adult females	**Acceptability**: Extra personal stigma, delayed diagnosis
Bruder, Kerins, Mazzarella, Sims, & Stein, 2012	Mixed-method Survey (online, mail)	Physicians that cared for individuals on the autism spectrum: n=346	Adults on the autism spectrum: 18-51+	USA	To conduct a needs assessment on the prevalence of needs associated with caring for individuals on the autism spectrum	**Appropriateness**: Cognitive ability
Vogan, Lake, Tint, Weiss, & Lunsky, 2017	Quantitative Survey (online, mail telephone,)	Individuals on the autism spectrum: n=40	18-61 Mean: 35.88 SD: 11.70	Canada	To examine the personal health service experiences of access, barriers, and unmet needs for individuals on the autism spectrum	**Appropriateness**: Communication barriers, provider knowledge, past negative experiences with care providers **Acceptability**: Extra personal stigma, intrapersonal stigma **Availability**: Lack of or cost of transportation **Affordability**: Other financial priorities **Approachability**: Health care system complexity

Nicolaidis et al., 2013	Mixed-methods Cross-sectional online survey and Community Based Participatory Research (online data collection)	Adults older than 18-year-old Adults on the autism spectrum: n=209 Adults not on the autism spectrum: n=228	Adults on the autism spectrum: Mean; 37.3 SD: 12.7 Adults not on the autism spectrum: Mean: 39.7 SD: 12.9	USA	To compare the health care experiences of autistic and non-individuals on the autism spectrum	**Appropriateness**: Communication barriers, inadequate services for needs, lack of supportive care **Acceptability**: Extra personal stigma **Approachability**: Health care system complexity
Tint & Weiss, 2018	Qualitative Focus Groups	Female individuals on the autism spectrum: n=20	19-69 Mean: 35.45 SD: 12.26	Canada	To explore questions with female autistic adults: 1) perception of support/care 2) identify unmet needs 3) identify barriers to access	**Appropriateness**: Communication barriers, provider knowledge, inadequate services for needs, lack of supportive care **Acceptability**: Extra personal stigma **Availability**: Lack of or cost of transportation
Saqr, Braun, Porter, Barnette, & Hanks, 2018	Qualitative Focus Group and Retrospective Cross-Sectional study	Individuals on the autism spectrum: n=10	18-30	USA	To explore the clinical experiences and unmet needs for individuals on the autism spectrum	**Appropriateness**: Communication barriers, sensory overload
Lai & Weiss, 2017	Quantitative Online Survey	Caregivers on behalf of individuals on the autism spectrum: n=755	2-61	Canada	To identify priority service needs across age groups	**Affordability**: Could not afford desired services

Nicolaidis et al., 2015	Qualitative Semi-structured open ended Interviews (Telephone, email, in-person or instant messenger)	Caregivers and Health care Providers for individuals on the autism spectrum and individuals on the autism spectrum Adults on the spectrum: n=39 Caregivers: n=16	Adults on the spectrum: 19-64 Mean: 35 Caregivers: 28-74 Mean: 52	USA	To further understanding of the health care experiences for individuals on the autism spectrum and put forth recommendations for improvements	**Appropriateness**: Communication barriers, sensory overload, provider knowledge, inadequate service for needs, the complexity of family involvement **Acceptability**: Extra personal stigma **Approachability**: Health care system complexity
Blomqvist, Bejerot, & Dahllöf, 2015	Quantitative Cross-sectional study: dental examination and questionnaire	Individuals on the autism spectrum Adults on the autism spectrum: n=47 Adults not on the autism spectrum: n=69	Individuals on the autism spectrum: 25-41 Individuals not on the autism spectrum: 27-41	Sweden	To investigate oral health behavior and dental care for individuals on the autism spectrum	**Appropriateness**: Communication barriers
Lum, Garnett, & O'Connor, 2014	Qualitative Pilot study, survey (online, mail)	Adult females Adults on the autism spectrum: n=32 Adults not on the autism spectrum n=16	Adults on the autism spectrum: 18-64 Adults not on the autism spectrum: 18-64	Australia	To investigate the disparity in health care service challenges between high functioning autistic adult females compared to non-autistic adult women	**Appropriateness**: Communication barriers, sensory overload, lack of supportive care, anxiety and fear **Acceptability**: Extra personal stigma

Lewis, 2017	Mixed Methods Exploratory sequential research design, open-ended online survey	Individuals on the autism spectrum Qualitative sample n=144 Quantitative sample n=655	Qualitative sample 18-65 (Mean 36.2) Quantitative sample: 18-68 (Mean 30.9)	International	To determine the barriers to diagnosis for individuals on the autism spectrum and the regularity of such barriers	**Appropriateness**: Inadequate service for needs, past negative experiences with care providers **Acceptability**: Extra personal stigma, intrapersonal stigma Availability: Lack of or cost of transportation, lengthy wait time **Affordability**: Could not afford desired services **Approachability**: Unsure of where to find or unaware of services
Maloret & Scott, 2018	Qualitative Naturalistic research design, semi-structured interviews	Individuals on the autism spectrum: n=20	18-50+ Mean: 35.5	UK	To detail experiences of individuals on the autism spectrum that have been admitted to a mental health unit	**Appropriateness**: Sensory overload, anxiety and fear, lack of routine
Raymaker et al., 2017	Quantitative Survey and Community-Based Participatory Research, online survey	Adults on the autism spectrum: n=209 Adults not on the spectrum, and with 1+ disability n=55 Adults without disabilities: n=173	Adults on the autism spectrum: Mean: 37 SD: 13 Adults not on the spectrum, and with other disabilities: Mean: 45 SD: 14 Adults without disabilities: Mean: 38 SD: 12	USA	To identify and compare barriers to health care experienced by individuals on the autism spectrum and adults with and without other disabilities	**Appropriateness**: Communication barriers, sensory overload, anxiety and fear, cognitive ability **Affordability**: Could not afford desired services

Warfield, Crossman, Delahaye, Der Weerd, & Kuhlthau, 2015	Qualitative Case study, telephone interview	Health care providers that serve individuals on the autism spectrum n=10	Not reported	USA	To explore the training, challenges, ideas for improvement, and interest of health care providers that serve individuals on the autism spectrum	**Appropriateness**: Communication barriers, sensory overload, provider knowledge, inadequate services for needs, the complexity of family involvement **Acceptability**: Extra personal stigma **Affordability**: Financial disincentives for providers
Crane et al., 2018	Qualitative Telephone interviews	Adults on the autism spectrum, parents of adults on the autism spectrum, and health care providers that serve individuals on the autism spectrum n=10	29-59 Mean: 42.89 SD: 11.71	UK	To explore the diagnostic process for individuals on the autism spectrum and seek to determine recommendations for improved services	**Appropriateness**: Sensory overload, provider knowledge, lack of supportive care, past negative experiences with care providers **Acceptability**: Extra personal stigma **Affordability**: Financial disincentives for providers **Approachability**: Unsure of where to find or unaware of services
Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019	Qualitative Online survey (closed and open-ended questions)	Individuals on the autism spectrum: n=200	18-67 Mean: 38.9 SD: 11.5	UK	To explore the experiences of treatment and support for mental health problems, self-injury and suicidality among individuals on the autism spectrum	**Appropriateness**: Provider knowledge, inadequate service for needs, lack of supportive care **Acceptability**: Extra personal stigma **Availability**: Lack of or cost of transportation, lengthy wait time **Affordability**: Could not afford desired services

Lipinski, Blanke, Suenkel, & Dziobek, 2019	Mixed Methods Participatory Research Approach, Online survey	Individuals on the autism spectrum and adults with Major Depressive Disorder (MDD) n=245 individuals on the autism spectrum n=245 adults with MDD	18+ ASD group mean: 37 MDD group mean: 42	Germany	To explore the use of psychotherapy among individuals on the autism spectrum	**Appropriateness**: Communication barriers, sensory overload, provider knowledge **Approachability**: Health care system complexity
Vohra, Madhavan, & Sambamoorthi, 2016	Quantitative Cross-sectional matched case-control design	Individuals on the autism spectrum and individuals not on the autism spectrum n=102,108 ED visits	22-64	USA	To examine trends and types of emergency department visits by autistic and non-individuals on the autism spectrum	**Appropriateness**: Inadequate service for needs
Henry, 2013	Qualitative Interviews	Parent/ caretaker on behalf of an adult on the spectrum: n=8	21-54	USA	To identify perceived barriers to health care access for individuals on the autism spectrum and to determine if social networks influence access to these resources successfully	**Appropriateness**: Provider knowledge, inadequate service for needs **Affordability**: Lack of insurance coverage
Au-Yeung et al., 2019	Mixed-Method online surveys	Adults on the autism spectrum, Adults that may be on the autism spectrum, Adults not on the autism spectrum: n=420	Adults on the spectrum:18-67 Mean: 38.6 SD 11.4 Possible ASD: 20-57 Mean: 40.1 SD: 8.9 Non-ASD: 20-60 Mean: 42.1 SD: 10.6	United Kingdom	Understand the differences in mental health diagnoses for autistic and non-individuals on the autism spectrum	**Appropriateness**: Communication barriers, provider knowledge, inadequate services for needs

Rodgers et al., 2019	Qualitative Focus Groups	Individuals on the autism spectrum: n=23	18-64 Mean: 35 SD: 13	United Kingdom	To explore the nature of the worries individuals on the autism spectrum have about their futures	**Appropriateness**: Communication barriers, providers knowledge **Acceptability**: Extra personal stigma **Approachability:** Health care system complexity, unsure where to find or unaware of services
Stein Duker et al., 2019	Mixed-Method Surveys	Adults on the autism spectrum, caregivers and primary care providers n=78	18+ Adults on the autism spectrum Mean: 31.5 SD: 12 Caregivers Mean: 24.3 SD: 6.6	USA	To explore barriers and strategies to improve primary care encounters amongst adults on the autism spectrum.	**Appropriateness:** Communication barriers, providers knowledge, sensory overload, cognitive ability **Acceptability:** Extra personal stigma **Approachability:** Unsure where to find or unaware of services, health care system complexity **Availability**: Lack of transportation options **Affordability:** Could not afford desired services
Mason et al., 2019	Systematic Review	Not reported	Not reported	United Kingdom	To explore the barriers and facilitators of healthcare access for individuals on the autism spectrum.	**Appropriateness:** Communication barriers, sensory overload

SD: Standard Deviation

Table 3. List of citations categorized into each dimension of access

Dimensions of access	Barriers	Citations
Appropriateness	Communication barriers	Au-Yeung et al., 2019; Blomqvist et al., 2015; Lewis, 2017; Lipinski et al., 2019; Lum et al., 2014; Mason et al., 2019; Nicolaidis et al., 2013, 2015; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015
	Sensory overload	Crane et al., 2018; Lipinski et al., 2019; Lum et al., 2014; Maloret & Scott, 2018; Mason et al., 2019; Nicolaidis et al., 2015; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019; Warfield et al., 2015
	Provider knowledge	Au-Yeung et al., 2019; Camm-Crosbie et al., 2019; Crane et al., 2018; Henry, 2013; Lipinski et al., 2019; Mason et al., 2019; Nicolaidis et al., 2015; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015
	Inadequate service for needs	Au-Yeung et al., 2019; Camm-Crosbie et al., 2019; Henry, 2013; Lewis, 2017; Nicolaidis et al., 2013, 2015; Rodgers et al., 2019; Stein Duker et al., 2019; Tint & Weiss, 2018; Vohra et al., 2016; Warfield et al., 2015
	Lack of supportive care	Camm-Crosbie et al., 2019; Crane et al., 2018; Lum et al., 2014; Nicolaidis et al., 2013; Tint & Weiss, 2018
	Anxiety and fear	Lewis, 2017; Lum et al., 2014; Maloret & Scott, 2018; Raymaker et al., 2017
	Past negative experiences with HCP	Au-Yeung et al., 2019; Crane et al., 2018; Lewis, 2017; Mason et al., 2019; Vogan et al., 2017
	Cognitive ability	Bruder et al., 2012; Mason et al., 2019; Raymaker et al., 2017; Stein Duker et al., 2019
	The complexity of family involvement	Nicolaidis et al., 2015; Warfield et al., 2015
	Lack of routine	Maloret & Scott, 2018

Acceptability	Extra personal stigma	Baldwin & Costley, 2016; Camm-Crosbie et al., 2019; Crane et al., 2018; Lewis, 2017; Lum et al., 2014; Nicolaidis et al., 2013, 2015; Rodgers et al., 2019; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015
	Intrapersonal stigma	Lewis, 2017; Vogan et al., 2017
Availability	Lack of or cost of transportation	Camm-Crosbie et al., 2019; Dudley et al., 2019; Lewis, 2017; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017
	Lengthy wait time	Camm-Crosbie et al., 2019; Lewis, 2017
	Delayed diagnosis	Baldwin & Costley, 2016
Affordability	Could not afford desired services	Camm-Crosbie et al., 2019; Lai & Weiss, 2017; Lewis, 2017; Raymaker et al., 2017; Stein Duker et al., 2019
	Financial disincentive for providers	Crane et al., 2018; Warfield et al., 2015
	Lack of insurance coverage	Henry, 2013
	Other financial priorities	Vogan et al., 2017
	Living situations lead to less funding	Dudley et al., 2019
Approach ability	Health care system complexity	Lipinski et al., 2019; Nicolaidis et al., 2013, 2015; Rodgers et al., 2019; Stein Duker et al., 2019; Vogan et al., 2017
	Unsure of where to find or unaware of services	Crane et al., 2018; Dudley et al., 2019; Lewis, 2017; Rodgers et al., 2019; Stein Duker et al., 2019

3. Results

3.1 Search Results

After the database search yielded 2816 unique articles, a title and abstract screen narrowed the search to 160 articles for full-text review. The full texts of the 160 articles were reviewed, and 24 articles were included in this scoping review to answer the question "How do individuals on the autism spectrum access and experience health care services?" Articles were excluded when the content did not discuss individuals on the autism spectrum accessing care (n=68), the study population was children or transitioning youth (n=55), the sample was not specific to individuals on the autism spectrum (n=12), or the article was not in English (n=1). A PRISMA flow chart of this process can be viewed in Figure 1.
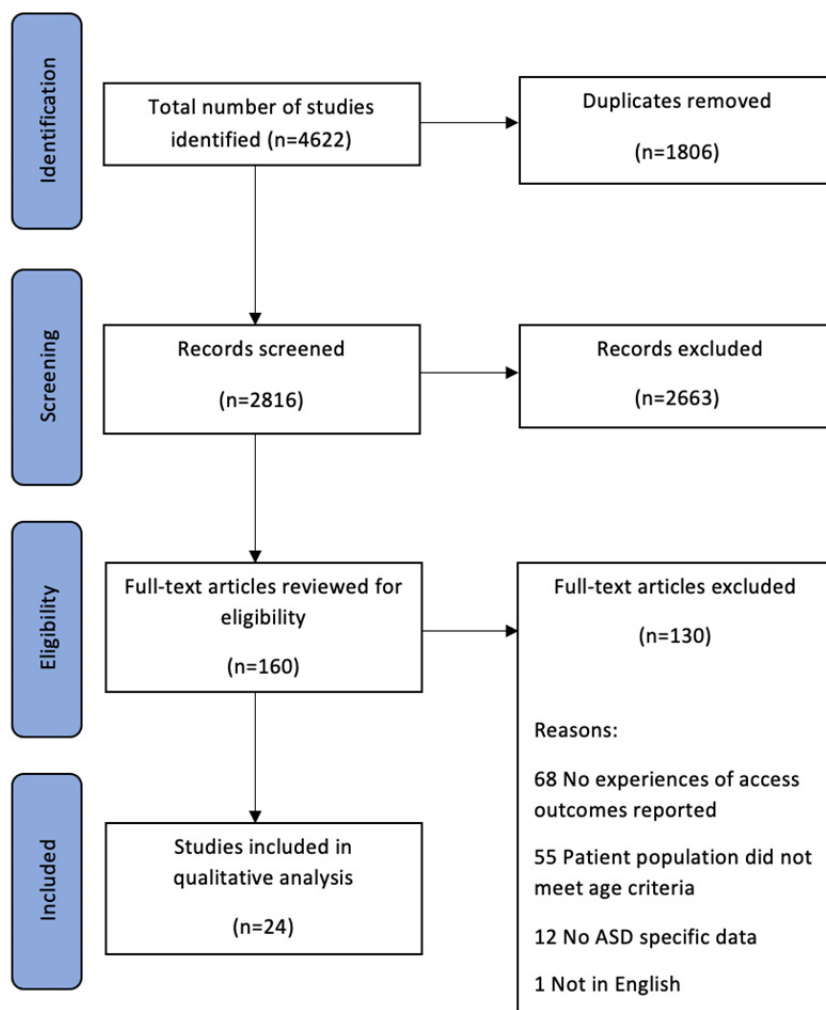
Figure 1. PRISMA chart

3.2 Study Design, Demographics, and Country of Origin

Of the 24 included articles, ten were qualitative, six were quantitative, seven were mixed methods, and one was a review article. Ten of the 24 studies had a majority of female participants, 2 of which included a sample made up of 100% females. Ten more of the studies had most male participants, and in the four remaining studies, gender was not reported. The articles were based on five countries' data: ten studies from the United States of America, three from Canada, six from the United Kingdom, two from Australia, one from Sweden, one from Germany and one included a multinational sample.

3.3 Appropriateness

The dimension of access that was most often cited was the dimension of appropriateness. Within this dimension, one consistent theme reported in 14 of the 24 articles was communication challenges between the provider and adults on the autism spectrum posing as a barrier to care (Au-Yeung et al., 2019; Blomqvist et al., 2015; Lewis, 2017; Lipinski et al., 2019; Lum et al., 2014; Mason et al., 2019; Nicolaidis et al., 2013, 2015; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015). When looking more in-depth at the root of these communication challenges, it was clear that challenges arise from both the provider and the client's perspectives. Communication difficulties that originated from the provider's side encompassed interactions in which a provider spoke in inaccessible ways such as being overly reliant on jargon, speaking too quickly or other such patterns that made it hard for the client on the autism spectrum to follow (Blomqvist et al., 2015; Lewis, 2017; Lipinski et al., 2019; Lum et al., 2014; Mason et al., 2019; Nicolaidis et al., 2013, 2015; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015). One study compared the experience of individuals on the autism spectrum and neurotypical adults through an online survey (Nicolaidis et al., 2013). The individuals on the autism spectrum scored significantly lower in questions related to communication such as: "health professionals gave me the chance to ask all the health-related questions I had", "health professionals understood what I was trying to communicate", and "health professionals communicated in a way I could understand" (Nicolaidis et al., 2013). Another study by the same team reported the experience of providers being unwilling to allow patients on the autism spectrum to communicate in writing when that was their preference (Nicolaidis et al., 2015). Communication challenges were reported by individuals on the autism spectrum in regards to their abilities as well such as feeling unable to express their feelings and explain their symptoms resulting in care that did not meet their needs (Au-Yeung et al., 2019; Blomqvist et al., 2015; Lewis, 2017; Lipinski et al., 2019; Lum et al., 2014; Mason et al., 2019; Nicolaidis et al., 2013, 2015; Raymaker et al., 2017; Saqr et al., 2018; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015). A specific example of this is a study focused on women with "high functioning" ASD and their experience with maternity care. It found that women on the autism spectrum experience a decreased ability to communicate pain and needs during childbirth (Lum et al., 2014). Still, another individual stated that they had significant difficulties with communicating their needs to health providers and, "after obtaining medical notes, it [was] clear that my account of my experiences were… misunderstood and I was not given opportunities to clarify" (Au-Yeung et al., 2019).

Another frequently reported theme among the included articles related to the appropriateness of care was the sensory overload in health care settings that individuals on the autism spectrum experience (Crane et al., 2018; Lipinski et al., 2019; Lum et al., 2014; Maloret & Scott, 2018; Mason et al., 2019; Nicolaidis et al., 2015; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019; Warfield et al., 2015). Adults who took part in a focus group study concluded that the sensory overload in the waiting room and physical examinations are the most stressful parts of a health care visit (Saqr et al., 2018). This was backed by three qualitative studies that reported the presence of other people and stimulation in waiting rooms created anxiety for individuals on the autism spectrum before their appointments began (Lum et al., 2014; Nicolaidis et al., 2015; Warfield et al., 2015). In rare instances, the heightened anxiety led to acts of physical violence towards other patients in the waiting room (Warfield et al., 2015).

Multiple studies reported from the patient's perspective showed that inadequately trained staff and health care professionals lacked knowledge about the needs of individuals on the autism spectrum and how to provide care for the spectrum of adults in this population (Au-Yeung et al., 2019; Camm-Crosbie et al., 2019; Crane et al., 2018; Henry, 2013; Lipinski et al., 2019; Mason et al., 2019; Nicolaidis et al., 2015; Tint & Weiss, 2018; Vogan et al., 2017; Warfield et al., 2015). Individuals on the autism spectrum reported physicians who lack knowledge of the autism spectrum presented the diagnosis to patients in a negative light, focusing on associated deficits rather than adopting a strength-based approach (Crane et al., 2018). Individuals on the autism spectrum have expressed that physicians regularly underestimate their abilities and limit their autonomy in the care process because of their poor understanding of the condition (Nicolaidis et al., 2015). Health care providers also attest to this knowledge gap. One qualitative study specifically looked at the physician perspective of individuals on the autism spectrum accessing health care by collecting data through in-depth case studies with nine doctors and one nurse who provided primary medical care to individuals on the autism spectrum (Warfield et al., 2015). The results of this study reported that health care providers felt unprepared to provide appropriate services for individuals on the autism spectrum (Warfield et al., 2015). Providers pointed to insufficient training and education during their school and the workforce (Warfield et al., 2015). This lack of knowledge and skills leaves providers feeling unable to provide adequate care, which often causes them to shy away from taking on individuals on the autism spectrum as

clients (Warfield et al., 2015).

Individuals on the autism spectrum and their caregivers also reported inadequacy of the services offered, with care not fitting their needs or a lack of appropriate treatment, support, and resources (Au-Yeung et al., 2019; Camm-Crosbie et al., 2019; Henry, 2013; Lewis, 2017; Nicolaidis et al., 2013, 2015; Rodgers et al., 2019; Stein Duker et al., 2019; Tint & Weiss, 2018; Vohra et al., 2016; Warfield et al., 2015). Care for individuals on the autism spectrum is often poorly tailored and is delivered in a "one size fits all" manner that results in many individuals on the autism spectrum receiving inadequate care (Tint & Weiss, 2018). Researchers emphasize that problems adults on the autism spectrum might have can present in many ways, and therefore, generic care can be unhelpful. In addition to inadequate care, many studies reported unsupportive care as an additional barrier (Camm-Crosbie et al., 2019; Crane et al., 2018; Lum et al., 2014; Nicolaidis et al., 2013; Tint & Weiss, 2018). There is evidence that providers do not communicate enough information to help individuals on the autism spectrum understand options and participate in the decision-making process (Lum et al., 2014; Nicolaidis et al., 2013). In a study of women on the autism spectrum, participants reported a feeling of decreased support and overall dissatisfaction with the health care system compared to women not on the autism spectrum (Lum et al., 2014). Similarly, in Canada, women on the autism spectrum also reported serious dissatisfaction with their interactions with the health care system (Tint & Weiss, 2018). These results' convergence highlights the international shortcomings of health systems' ability to appropriately serve adults on the autistic spectrum.

Other barriers related to the appropriateness of care included respondent's anxiety levels and fear (Lewis, 2017; Lum et al., 2014; Maloret & Scott, 2018; Raymaker et al., 2017), which often were related to past negative experiences with the health care system (Au-Yeung et al., 2019; Crane et al., 2018; Lewis, 2017; Mason et al., 2019; Vogan et al., 2017). A mixed-methods study including 799 individuals on the autism spectrum from 18 countries looked explicitly at the diagnostic process and found participants reported anxiety around making appointments (85%), attending appointments (82%), or experienced anxiety during appointments (80%) (Lewis, 2017). One participant elaborated to explain that due to past negative experiences he was nervous about health care interactions because he feared that he would not be believed and ultimately would receive unhelpful care (Lewis, 2017). Individuals on the autism spectrum also expressed frustration because the medical system is structured in a way that can exceed their cognitive abilities including the comprehension and memory required to understand medical recommendations (Bruder et al., 2012; Mason et al., 2019; Raymaker et al., 2017; Stein Duker et al., 2019). In one study, 32% of participants reported not being given enough time to process and understand information during medical appointments (Raymaker et al., 2017). This finding suggests that many adults on the autism spectrum could more fully process and participate in their medical care if they were allowed more time to ask questions and consume information. In a study that aimed to understand the physician's perspective of this issue, 57% of the 346 physicians who completed an online questionnaire reported their patients on the autism spectrum could not understand medical care and therefore required a caregiver to be present (Warfield et al., 2015). Another issue of appropriateness relates to caregiver involvement in health care service provision. An in-depth qualitative study of 10 health care professionals also discussed challenges of providing care when there are two adults in the room and uncertainty in navigating family involvement (Warfield et al., 2015). When caregivers are brought to appointments, the patient's autonomy is diminished. The provider will usually rely on the caregiver rather than taking the time to communicate appropriately with the patient (Nicolaidis et al., 2015). Finally, adults on the autism spectrum living in an inpatient mental health unit experience those above and further barriers of poor unit structure and inconsistent routine patterns that limit their ability to interact with health care providers and receive adequate services (Maloret & Scott, 2018).

3.4 Acceptability

To understand how individuals on the autism spectrum may access health care, we need to understand if they feel comfortable accessing and utilizing the available services. Across the 24 included studies, stigma was discussed in 12, including stigma from health care professionals (Baldwin & Costley, 2016; Camm-Crosbie et al., 2019; Lewis, 2017; Lum et al., 2014; Nicolaidis et al., 2013, 2015; Stein Duker et al., 2019; Vogan et al., 2017; Warfield et al., 2015), cultural stigma (Lewis, 2017; Vogan et al., 2017), stigma from family (Crane et al., 2018; Lewis, 2017), and personal stigma (Lewis, 2017; Vogan et al., 2017). All types of the stigma created barriers to accessing services for this population.

The presence of self-stigma was explored in a large-scale mixed-method study of 799 adults on the autism spectrum, where 38% reported to have self-stigma, often portrayed by the belief that they do not deserve or need to access the services that may be available (Lewis, 2017). To compound this self-stigma, Lewis (2017) also found that 68% of respondents reported stigma from family, friends, or the community as a barrier to seeking a diagnosis.

Family members often refused to accept the adult's diagnosis for those with a diagnosis, which created complications when seeking and accessing services to meet health needs (Crane et al., 2018). Several articles included in this review also reported individuals on the autism spectrum frequently experiencing stigma from HCPs. Consequences of this stigma led to individuals on the autism spectrum fearing disclosing their diagnosis to new HCPs. Their past experiences led them to fear labelling's harmful effects and the difference in the care they might receive (Lewis, 2017; Lum et al., 2014; Nicolaidis et al., 2015). In one study, 81% of respondents identified barriers arising from a general cultural belief that autism is strictly a childhood condition (Lewis, 2017). Misunderstanding is often core to the experience of stigma.

3.5 Availability

The availability of health services is what people may initially think of when considering access, including aspects of the physical space and location and how it can be accessed promptly (Levesque et al., 2013). Eight of the 24 studies discussed availability to care access. Two quantitative questionnaires of community-dwelling individuals on the autism spectrum found that a quarter of individuals on the autism spectrum required services that were not accessible due to their physical location being too far away (Dudley et al., 2019; Vogan et al., 2017). Transportation also acted as a barrier, studies conducted in multiple countries have shown that both a lack of transportation and the potential expense of paid transportation pose challenges to access (Camm-Crosbie et al., 2019; Dudley et al., 2019; Lewis, 2017; Stein Duker et al., 2019; Tint & Weiss, 2018; Vogan et al., 2017). The studies reporting these data were quantitative and did not elaborate on what is considered too far or too expensive for travel. Elements of timely availability also were revealed, with lengthy wait times reported as a barrier in Canada and the UK (Camm-Crosbie et al., 2019; Lewis, 2017).

Further research specific to mental health services identified 73% of the 799 adults on the autism spectrum included in the study report long wait times to access mental health professionals (Lewis, 2017). Similarly, a study of access to mental health services found lengthy waiting lists reported as a barrier to services (Camm-Crosbie et al., 2019). Other availability components included adults experiencing delayed diagnosis, which prevented access to autism-specific services (Baldwin et al., 2014).

3.6 Affordability

Ten of the included articles discussed affordability barriers to access. Among these studies, the burden of the economic capacity to pay for care was the primary discussion. Participants who could not afford the desired services were primarily based out of the United States of America (Dudley et al., 2019; Henry, 2013; Raymaker et al., 2017; Stein Duker et al., 2019; Warfield et al., 2015), Canada (Lai & Weiss, 2017; Vogan et al., 2017), the United Kingdom (Camm-Crosbie et al., 2019; Crane et al., 2018), and one multinational study that focused on the former three countries (Lewis, 2017). Studies from other countries did not address affordability.

Affordability must be understood from both the provider and patient perspectives. From the physicians' perspective, financial disincentives to service provision result in poor care availability for adults on the autism spectrum. International health care providers agree that there are disincentives to take on individuals on the autism spectrum as part of the caseload (Crane et al., 2018; Warfield et al., 2015). Physicians in the US and UK acknowledged a variety of financial burdens that encumbered their care for adults on the autism spectrum. Some of these burdens included the need for additional staff to support the clients, longer appointment times to accommodate diverse needs, complex reimbursement systems, and caseload overflow due to little provider availability (Crane et al., 2018; Warfield et al., 2015).

From the patient perspective, health care will not be accessible if it imposes a financial burden and prevents individuals on the autism spectrum from seeking services. A Canadian study found that 37% of individuals on the autism spectrum reported they had other financial priorities aside from medical expenses. A small American study of eight participants found adults on the autism spectrum lacked insurance plan benefits that would allow them to access appropriate care (Henry, 2013; Vogan et al., 2017). One American quantitative study that focused on how one's living situation would impact service usage found adults on the autism spectrum who live with family receive significantly more government aid than individuals on the autism spectrum living alone (Dudley et al., 2019). However, all adults on the autism spectrum living outside of supported living facilities such as long-term care were less likely to receive government-funded services (Dudley et al., 2019). Another American-based researcher found that most insurance plans do not cover therapy that help clients maintain function or assist in independent living, such as psychotherapy or occupational therapy, hindering the individual's ability to access health care (Henry, 2013). These findings speak to the broader idea that individuals on the autism spectrum are not provided with the financial support they need to prioritize health care and seek out services they need. Most notably, the American health insurance system is not built to promote these adults' financial freedom as they seek

out health services.

3.7 Approachability

Nine of the articles reported approachability barriers to care access for adults on the autism spectrum. The themes found in the approachability dimension of access were related to the health beliefs and health literacy levels of individuals on the autism spectrum. The barriers noted in this dimension were related to system-level complexity and poor awareness of the services available to individuals. To avoid these barriers, services must be transparent, providing all applicable information to potential clients in an approachable manner (Levesque et al., 2013). One of the cited barriers to the approachability of services for individuals on the autism spectrum was the complexity of the health care system (Lipinski et al., 2019; Nicolaidis et al., 2013, 2015; Rodgers et al., 2019; Stein Duker et al., 2019; Vogan et al., 2017). In a longitudinal study, 52.6% of respondents reported feeling overwhelmed by the process of seeking care (Vogan et al., 2017). Some individuals on the autism spectrum reported being unsure where to find the service they require (Crane et al., 2018; Dudley et al., 2019; Lewis, 2017; Rodgers et al., 2019; Stein Duker et al., 2019). Many noted feeling directionless when seeking care; one man detailed an experience when he thought he had found a clinical group for individuals on the autism spectrum but instead found himself in a group for parents of children on the autism spectrum (Crane et al., 2018). ASD services are often broad and aim to address this population's many needs, which can be overwhelming and, therefore, a barrier in itself (Crane et al., 2018). Even after accessing initial services, steps within the health care system such as filling prescriptions are also more difficult for adults on the autism spectrum than a typical adult (Nicolaidis et al., 2013).

Further literature shows that newly diagnosed adults on the autism spectrum also believe there are no services available. Of the newly diagnosed adults from Lewis' study, 61% saw no benefit for their formal diagnosis due to a lack of available services (Lewis, 2017). Adults reported feeling lost following their formal ASD diagnosis and connected with services only once they had reached some type of crisis in their life (Crane et al., 2018). Additionally, adults on the autism spectrum report difficulties identifying available care and navigating the complex process of planning and booking appointments (Lipinski et al., 2019).

4. Discussion

In this scoping review, the most prominent barriers for accessing healthcare services are the broad experience of quality care provision and the presence of stigma. The service appropriateness is also challenging for this population. Service appropriateness encompasses communication barriers, sensory appropriateness of the care environment, and provider knowledge. Of the papers included in this review, 18 of the 24 discussed at least one barrier to the dimension of appropriateness, which highlighted the experienced-based challenges to access that individuals on the autism spectrum face. These barriers reflect a need for a greater understanding of ASD in adulthood by the health care community. The majority of physicians reported a lack of training in caring for adults on the autism spectrum. Still, those physicians who did serve individuals on the autism spectrum indicated a significantly greater need for training (Bruder et al., 2012). At the same time, those without this experience are less likely to acknowledge this gap, contributing to the barriers and creating inappropriate care for adults on the autism spectrum.

Several solutions are suggested to bridge the gap in providing services to individuals on the autism spectrum. First, providing educational programs for HCPs during their school years and later as professional development opportunities is strongly recommended. Service providers need to learn how to provide appropriate service and be equipped with strategies to make the service and its environment appropriate for this client group. Some strategies can be as simple as allowing enough time for the person to understand options and participate in decision-making. Reducing the time in the waiting room and directing the clients to a private room faster than usual can help reduce the risk of sensory overload. HCPs should take a strength-based approach rather than focusing on the person's deficits.

Second, HCPs need to learn skills to communicate more effectively with this client group better. Some articles suggested HCPs should receive education around accommodating alternative forms of communication such as written messa+ges to reduce communication barriers in practice settings (Blomqvist et al., 2015; Lipinski et al., 2019; Lum et al., 2014). Competent HCPs should be attentive to the needs of individuals on the autism spectrum, such as creating environments with low stimulation and allowing clients additional processing time as needed to understand services (Lipinski et al., 2019; Mason et al., 2019; Nicolaidis et al., 2013; Saqr et al., 2018; Stein Duker et al., 2019; Warfield et al., 2015). Furthermore, adults on the autism spectrum, caregivers and HCPs found strategies such as reducing wait times, strategic scheduling, providing HCP with a list of needs before the visit, using social stories and visual schedules will significantly improve the experience of health care visits (Stein Duker et al., 2019).

Third, to reduce the access barriers, further research is needed to develop clinical guidelines focusing on improving service access. Clinical practice guidelines elated to ASD tend to focus solely on the diagnostic element of care, and its focus was primarily on the child population. Resources such as Autism Awareness Australia and Autism Canada focus on diagnosing the pediatric population with limited resources available for health care providers (*Autism Canada*, 2018; *Www.Autismawareness.Com.Au*, 2019). There are currently some helpful resources provided by the English Primary Autism Network (National Autistic Society, 2019) for HCPs to improve the appropriability of services. Further studies are needed to understand how effective these interventions can be to reduce barriers to health care for adults on the autism spectrum.

Fourth, efforts should be made to reduce stigma. Acceptability barriers result from extra personal and intrapersonal stigma experienced (Bachmann et al., 2019). Stigma is a sociocultural phenomenon of disempowering an outgroup through stereotypes and separation, using internal pressure to make decisions that are culturally permissible or superimposed by others (Corrigan, 2000). A typical example is HCPs who prefer to communicate with caregivers or other professionals rather than adults on the autistic spectrum. This act of neglect is due to the underlying presumption that the adult cannot be trusted to govern their care (Lewis, 2017; Rodgers et al., 2019). Health care providers who ask the other adults in the room to make care decisions, reaffirm stigma by marginalizing the client. It is important to recognize, call out, and relinquish this practice in health care by educating care providers about the damage it can cause. Intrapersonal stigma is also a significant barrier to access. This study demonstrated that adults on the autism spectrum often avoid seeking care because they feel they would pose an undue burden on the system. This finding illustrates the importance of validating the care needs of individuals on the autism spectrum to work towards decreasing internalized stigma.

Stigma as a barrier to health care services is not unique to the population of individuals on the autism spectrum. Progress to reduce stigma and improve appropriateness should be built on the lessons from the past. Populations such as the transgender communities, individuals that are HIV positive, individuals that are obese, and beyond have been subjected to the stigma that has affected their ability to access health care services (Drury & Louis, 2002; Kinsler et al., 2007; Poteat et al., 2013). For example, a study in 2007 found that 1 in 4 HIV-positive residents of Los Angeles reported having experienced some type of stigma from care providers that interfered with their ability or willingness to seek necessary health supports (Kinsler et al., 2007). Frameworks have been developed and implemented to address the stigma for these communities and others, which can guide work to address the stigma that individuals on the autism spectrum experience, such as prioritized training of HCPs and empowering the stigmatized to demand respect (Brinsdon et al., 2016; Heijnders & Van Der Meij, 2006; Nyblade et al., 2009).

As demonstrated by this paper's results, barriers to access health services by adults on the autism spectrum exist in all dimensions of Levesque's access framework (Levesque et al., 2013). The dimensions of accessibility, affordability, and approachability are valued pieces of the access puzzle. They should not be dismissed when considering how to improve the experience adults on the autism spectrum have when accessing health services. There is room for vast improvement at the policy level to improve services' accessibility, such as increasing funding for providers that deliver care that accounts for individuals' needs on the autism spectrum (Baldwin & Costley, 2016). Improved availability of formal supports for adults on the autism spectrum can result in better health care self-efficacy and reaffirm their role in the care process (Nicolaidis et al., 2015). It can also improve the continuity of care between providers so that clients' needs can be continually met in different care settings (Henry, 2013). Two studies also suggested that providers should receive incentives to provide services that consider the needs of individuals on the autism spectrum (Tint & Weiss, 2018; Warfield et al., 2015). The findings of this study add to the results of the study by Mason et al. (2019) in that affordability and acceptability of the services are necessary to consider to enhance access to the health care services by this population group. People on the autism spectrum need to be educated about when and how to access the services and the financial barriers such as lack of insurance coverage and incentives for providers hinder individuals on the autism spectrum from receiving services when they need them.

Other specific areas identified for future research include understanding individuals' intersectionality, such as sex and gender, when accessing the healthcare system. There is an overrepresentation of women on the autism spectrum reported in multiple studies included in this review. Additionally, there is an increased societal and academic level of attention to gender. Therefore, more research is required to understand the compounding effects of gender and ASD and how experiences can differ between populations. There is also a need for more specificity in ASD research, as ASD represents a spectrum of conditions but in health care, it is often treated with a one size fits all mentality. There is space to begin to understand how adults with various types of ASD experience access to health care services. For example, an adult with what was traditionally diagnosed as Asperger's Syndrome may access health services differently from someone diagnosed with Fragile X. Their strategies to remove barriers and

improve access may differ. Therefore, it is necessary to understand these differences and how they may affect the implementation of accommodations within the health care setting.

5. Limitations

As per the inclusion criteria of this study, the search was conducted for papers published in English, limiting the generalizability of the study and reducing the diversity of sample populations. While this study sought to take a global perspective, over two-thirds of the studies referenced in this review focus on the experience of individuals on the autism spectrum in three countries: The United States of America, Canada, and the United Kingdom, further limiting the generalizability of findings. The experience of individuals on the autism spectrum in non-English speaking nations and those with fundamentally different health care systems may differ from the results reported in this review and should be investigated in future research. Conference abstracts were also excluded due to insufficient data, and studies that focused on youths transitioning into adulthood were excluded. However, the inclusion of this population may have provided experiential data around access as one begins interacting with adult health services.

Furthermore, there is a limitation around excluding studies with a sample population of individuals with an "intellectual or developmental disability," as this may have omitted pertinent information related to the specific experiences of individuals on the autism spectrum. Finally, many studies relied on gathering information through technology such as online surveys, limiting the sample's demographic to those who can access and utilize this mode of communication. Future research should consider an inclusive data collection strategy to ensure results are widely applicable.

6. Conclusion

This paper investigated the barriers individuals on the autism spectrum experience when accessing health care services. Results revealed that most barriers fell under the dimensions of appropriateness and acceptability of care. These results may be counter-intuitive to the instinctive spontaneous elements of affordability and availability that one may strive to improve when working to improve access. The experiences of adults on the autism spectrum demonstrate the quality of care they are receiving, and acceptance is their primary concern. Therefore, a need for improvement in these areas is evident. Some strategies to remove barriers include educating HCPs and creating an environment that accommodates the individual's needs. Efforts need to be put in place to destigmatize individuals' perceptions on the autism spectrum to counter both internalized and external stigma this population faces when accessing care. More robust research is required to increase the amount of high-quality work to develop strategies to remove barriers and improve access to health care services. Future research should also vary their sample populations to more pointedly consider the intersection of gender and ASD and explore individuals' experiences in various countries.

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Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

Alegria Drury, C. A., & Louis, M. (2002). Exploring the association between body weight, stigma of obesity, and health care avoidance. *Journal of the American Academy of Nurse Practitioners*, *14*(12), 554-561. https://doi.org/10.111/j.1745-7599.2002.tb00089.x

Autism Canada. (2018). *Autism Canada*. Retrieved from https://autismcanada.org/#home-row-3

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, *23*(6), 1508-1518. https://doi.org/10.1177/1362361318818167

Bachmann, C. J., Gerste, B., & Hoffmann, F. (2018). Diagnoses of autism spectrum disorders in Germany: time trends in administrative prevalence and diagnostic stability. *Autism*, *22*(3), 283-290. https://doi.org/10.1177/1362361316673977

Bachmann, C. J., Höfer, J., Kamp-Becker, I., Küpper, C., Poustka, L., Roepke, S., ... & Hoffmann, F. (2019). Internalised stigma in adults with autism: a German multi-center survey. *Psychiatry research*, *276*, 94-99. https://doi.org/10.1016/j.psychres.2019.04.023

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism

spectrum disorder. *Autism*, *20*(4), 483-495. https://doi.org/10.1177/1362361315590805

Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of autism and developmental disorders*, *44*(10), 2440-2449. https://doi.org/10.1007/s10803-014-2112-z

Blomqvist, M., Bejerot, S., & Dahllöf, G. (2015). A cross-sectional study on oral health and dental care in intellectually able adults with autism spectrum disorder. *BMC Oral Health*, *15*(1), 1-8. https://doi.org/10.1186/s12903-015-0065-z

Bogenschutz, M. (2014). " We Find a Way": Challenges and Facilitators for Health Care Access Among Immigrants and Refugees With Intellectual and Developmental Disabilities. *Medical Care*, S64-S70. https://doi.org/10.1097/MLR.0000000000000140

Brinsdon, A., Abel, G., & Desrosiers, J. (2017). "I'm taking control": how people living with HIV/AIDS manage stigma in health interactions. *AIDS care*, *29*(2), 185-188. https://doi.org/10.1080/09540121.2016.1204420

Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of autism and developmental disorders*, *42*(11), 2498-2504. https://doi.org/10.1007/s10803-012-1496-x

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431-1441. https://doi.org/10.1177/1362361318816053

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical psychology: science and practice*, *7*(1), 48. https://doi.org/10.1093/clipsy.7.1.48

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of autism and developmental disorders*, *48*(11), 3761-3772. https://doi.org/10.1007/s10803-018-3639-1

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, *19*(7), 814-823. https://doi.org/10.1177/1362361315577517

Diallo, F. B., Fombonne, É., Kisely, S., Rochette, L., Vasiliadis, H. M., Vanasse, A., ... & Lesage, A. (2018). Prevalence and correlates of autism spectrum disorders in Quebec: Prévalence et corrélats des troubles du spectre de l'autisme au Québec. *The Canadian Journal of Psychiatry*, *63*(4), 231-239. https://doi.org/10.1177/0706743717737031

Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders*, *49*(2), 556-568. https://doi.org/10.1007/s10803-018-3729-0

Fortuna, R. J., Robinson, L., Smith, T. H., Meccarello, J., Bullen, B., Nobis, K., & Davidson, P. W. (2016). Health conditions and functional status in adults with autism: A cross-sectional evaluation. *Journal of General Internal Medicine*, *31*(1), 77-84. https://doi.org/10.1007/s11606-015-3509-x

Heijnders, M., & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, health & medicine*, *11*(3), 353-363. https://doi.org/10.1080/13548500600595327

Henry, A. R. (2013). *Barriers to accessing support services in employment and health care for adults with autism spectrum disorders: A qualitative study*. University of Southern California.

Hewitt, A. S., Stancliffe, R. J., Sirek, A. J., Hall-Lande, J., Taub, S., Engler, J., ... & Moseley, C. R. (2012). Characteristics of adults with autism spectrum disorder who use adult developmental disability services: Results from 25 US states. *Research in Autism Spectrum Disorders*, *6*(2), 741-751. https://doi.org/10.1016/j.rasd.2011.10.007

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, *208*(3), 232-238. https://doi.org/10.1192/bjp.bp.114.160192

Jensen, C. M., Steinhausen, H. C., & Lauritsen, M. B. (2014). Time trends over 16 years in incidence-rates of autism spectrum disorders across the lifespan based on nationwide Danish register data. *Journal of autism and developmental disorders*, *44*(8), 1808-1818. https://doi.org/10.1007/s10803-014-2053-6

Jokiranta-Olkoniemi, E., Gyllenberg, D., Sucksdorff, D., Suominen, A., Kronström, K., Chudal, R., & Sourander,

A. (2021). Risk for premature mortality and intentional self-harm in autism spectrum disorders. *Journal of autism and developmental disorders*, *51*(9), 3098-3108. https://doi.org/10.1007/s10803-020-04768-x

Kinsler, J. J., Wong, M. D., Sayles, J. N., Davis, C., & Cunningham, W. E. (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS patient care and STDs*, *21*(8), 584-592. https://doi.org/10.1089/apc.2006.0202

Lai, J. K., & Weiss, J. A. (2017). Priority service needs and receipt across the lifespan for individuals with autism spectrum disorder. *Autism Research*, *10*(8), 1436-1447. https://doi.org/10.1002/aur.1786

Levesque, J. F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International journal for equity in health*, *12*(1), 1-9. https://doi.org/10.1186/1475-9276-12-18

Lewis, L. F. (2017). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of autism and developmental disorders*, *47*(8), 2410-2424. https://doi.org/10.1007/s10803-017-3168-3

Lipinski, S., Blanke, E. S., Suenkel, U., & Dziobek, I. (2019). Outpatient psychotherapy for adults with high-functioning autism spectrum condition: utilization, treatment satisfaction, and preferred modifications. *Journal of autism and developmental disorders*, *49*(3), 1154-1168. https://doi.org/10.1007/s10803-018-3797-1

Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, *8*(12), 1713-1721. https://doi.org/10.1016/j.rasd.2014.09.009

Maloret, P., & Scott, T. (2018). Don't ask me what's the matter, ask me what matters: Acute mental health facility experiences of people living with autism spectrum conditions. *Journal of psychiatric and mental health nursing*, *25*(1), 49-59. https://doi.org/10.1111/jpm.12438

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., ... & Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of autism and developmental disorders*, *49*(8), 3387-3400. https://doi.org/10.1007/s10803-019-04049-2

Mattila, M. L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., ... & Moilanen, I. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: a community-and clinic-based study. *Journal of autism and developmental disorders*, *40*(9), 1080-1093. https://doi.org/10.1007/s10803-010-0958-2

National Autistic Society. (2019). *Autism and Mental Health*. Retrieved from learn.autism.org.uk

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., ... & Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, *19*(7), 824-831. https://doi.org/10.1177/1362361315576221

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of general internal medicine*, *28*(6), 761-769. https://doi.org/10.1007/s11606-012-2262-7

Nord, D. K., Stancliffe, R. J., Nye-Lengerman, K., & Hewitt, A. S. (2016). Employment in the community for people with and without autism: A comparative analysis. *Research in Autism Spectrum Disorders*, *24*, 11-16. https://doi.org/10.1016/j.rasd.2015.12.013

Nyblade, L., Stangl, A., Weiss, E., & Ashburn, K. (2009). Combating HIV stigma in health care settings: what works?. *Journal of the International AIDS Society*, *12*(1), 1-7. https://doi.org/10.1186/1758-2652-12-15

Poteat, T., German, D., & Kerrigan, D. (2013). Managing uncertainty: a grounded theory of stigma in transgender health care encounters. *Social science & medicine*, *84*, 22-29. https://doi.org/10.1016/j.socscimed.2013.02.019

Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke, C., ... & Nicolaidis, C. (2017). Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*, *21*(8), 972-984. https://doi.org/10.1177/1362361316661261

Rodgers, J., Herrema, R., Garland, D., Osborne, M., Cooper, R., Heslop, P., & Freeston, M. (2019). Uncertain futures: Reporting the experiences and worries of autistic adults and possible implications for social work practice. *The British Journal of Social Work*, *49*(7), 1817-1836. https://doi.org/10.1093/bjsw/bcy117

Ross, L. E., Vigod, S., Wishart, J., Waese, M., Spence, J. D., Oliver, J., ... & Shields, R. (2015). Barriers and facilitators to primary care for people with mental health and/or substance use issues: a qualitative study. *BMC family practice*, *16*(1), 1-13. https://doi.org/10.1186/s12875-015-0353-3

Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism*, *22*(1), 51-61. https://doi.org/10.1177/1362361317709970

Schendel, D. E., & Thorsteinsson, E. (2018). Cumulative incidence of autism into adulthood for birth cohorts in Denmark, 1980-2012. *Jama*, *320*(17), 1811-1813. https://doi.org/10.1001/jama.2018.11328

Stein Duker, L. I., Sadie Kim, H. K., Pomponio, A., Mosqueda, L., & Pfeiffer, B. (2019). Examining primary care health encounters for adults with autism spectrum disorder. *The American Journal of Occupational Therapy*, *73*(5), 7305185030p1-7305185030p11. https://doi.org/10.5014/ajot.2019.037226

Tint, A., & Weiss, J. A. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism*, *22*(8), 928-937. https://doi.org/10.1177/1362361317702561

van Asselt-Goverts, A. E., Embregts, P. J. C. M., Hendriks, A. H. C., Wegman, K. M., & Teunisse, J. P. (2015). Do social networks differ? Comparison of the social networks of people with intellectual disabilities, people with autism spectrum disorders and other people living in the community. *Journal of Autism and Developmental Disorders*, *45*(5), 1191-1203. https://doi.org/10.1007/s10803-014-2279-3

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of autism and developmental disorders*, *45*(6), 1673-1688. https://doi.org/10.1007/s10803-014-2324-2

Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunsky, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal*, *10*(2), 264-270. https://doi.org/10.1016/j.dhjo.2016.11.002

Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, *46*(4), 1441-1454. https://doi.org/10.1007/s10803-015-2692-2

Warfield, M. E., Crossman, M. K., Delahaye, J., Der Weerd, E., & Kuhlthau, K. A. (2015). Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, *45*(7), 2209-2217. https://doi.org/10.1007/s10803-015-2386-9

World Health Organization. (2017). Retrieved from Human rights and health. https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health

World Health Organization. (2018). Retrieved from Autism spectrum disorders. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders?fbclid=IwAR1l3J4HiK1uy65FSMmf8SnDuSBlKcwRVh5PRaWiCCE-4xZ_DpG9Dum80Mw

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Advancing Healthcare for COVID-19 by Strengthening Providers' Capacity for Best Practices in African, Caribbean and Black Community Service Provision in Ontario: A Multisite Mixed-Method Study Protocol

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Abstract

Background: The ongoing COVID-19 pandemic has emerged as an unprecedented challenge for public and private life, and healthcare systems worldwide. African, Caribbean, and Black communities (ACB) represent some of the most vulnerable populations in terms of their susceptibility to health hazards, difficulty receiving adequate health care and relatively lower chances of recovery.

Objectives: The main aim of this study is to improve the health system's response during and after the COVID-19 pandemic by developing evidence-based models to inform policy and collaborative best practices to mitigate its spread and ameliorate related health consequences in vulnerable communities.

Methods: This is a mixed-method, multisite study based in Ottawa and Toronto that will involve in-depth qualitative interviews and surveys using a structured questionnaire. Data will be analyzed using NVivo for qualitative interviews, Stata 16 and IBM SPSS version 26 for statistical analyses.

Discussion: The findings of this study gained from highly professional health practitioners will produce strong evidence on current gaps in knowledge and practice in the healthcare system's capacity to meet the health needs of ACB population. The distinct insights and perspectives will be disseminated with policymakers and researchers at all levels which will facilitate strategic policy making with the goal of addressing the unique challenges for health promotion among the ACB population that are arising within the COVID-19 context.

Keywords: African, Caribbean, and Black communities (ACB), healthcare system, COVID-19, Ontario

1. Background

African, Caribbean and Black (ACB) communities represent some of the most vulnerable populations in Ontario regarding their susceptibility to health risks, difficulty receiving adequate care and lower chances of recovery. For instance, ACB communities account for a quarter of the people living with HIV (PLHIV) in Canada although they constitute merely 5% of the population (African, Caribbean and Black Communities | The Ontario HIV Treatment

Network, n.d.). No race-based data is currently being collected on COVID-19 in Canada, but the Black population is overrepresented among hospitalized patients in the US and mortality rates among Black persons (92.3 deaths per 100,000 population) are substantially higher than those among white (45.2) or Asian (34.5) persons in NYC[i]. Similar statistics have emerged in other US cities and states (Osman, 2020).

Social determinants, including structural inequalities and discrimination, account for the disproportionate health risks and differential health outcomes experienced in ACB populations (Kraemer et al., 2020; Wolf et al., 2020; Garrett, 2020; Nicola et al., 2020; Chung, Dong, & Li, 2020). In the case of COVID-19, excess cases and deaths have been attributed to disproportionately high rates of co-morbid conditions (e.g., diabetes, hypertension) in these communities, as well as structural factors related to income, employment, food insecurity, and the built environment, which necessitate, for example, risky working conditions outside the home and using public transportation. (CBC News, 2020b; Devakumar et al., 2020; Braithwaite & Warren, 2020; Women on the Front Line (2/3): Cashiers Face "warlike" Conditions Working under Covid-19, 2020; Branigin, 2020; Gawley, 2020; Health workers are the frontline soldiers against COVID-19. Let's protect them | Africa Renewal, 2020) Moreover, the same population is over-represented in jails and prisons where social distancing is impossible. (Braithwaite & Warren, 2020) In Canada, data is limited but we know from national surveys that Black Canadians exceed 50% on economic vulnerability arising from the COVID-19 crisis; 61% have seen a decrease in their income, 50% have difficulty meeting their financial obligations and 47% have are unable to pay their mortgage or rent on time (Home, n.d.). The increased burden of COVID-19 morbidity and mortality among ACB populations translates into greater challenges for healthcare systems and for governments through loss of social capital, productive labur force, and erosion of cultural equity. (McKee & Stuckler, 2020; Martínez-Martínez & Rodríguez-Brito, 2020; New study finds higher social capital and trust leads to better COVID-19 response in some U.S. states | Research & Innovation, n.d.)

Evidence from previous public health disasters show that one size does not fit all in terms of the inadequacy of traditional risk communication systems for vulnerable populations such as ACB community. (Vaughan et Tinker, 2009; Rowel et al., 2012) Ability to understand and respond appropriately to risk information is influenced by underlying socio-ecological factors such as poverty, low health literacy, sociocultural issues and lack of political voice. (James, Hawkins, & Rowel, 2007; Bouye et al., 2009) Critical health literacy is becoming a cornerstone in these days of COVID-19 where there is excess information and high expectations to integrate this sea of information into personal behavioral actions to promote health (Abel & McQueen, 2020). It is also well-documented that ACB communities experience multiple and intersecting barriers to accessing appropriate and responsive health services. These include institutional discrimination; poor representation in healthcare leadership, and research and decision-making; lack of awareness of available services; inadequate culturally appropriate services in relevant languages, and lack of culturally competent health professionals.

In response, numerous scholars have identified the need to build capacity, and reduce stigma and paternalism among health providers working with ACB communities.[29–31] Health protection relies not only on a well-functioning health system with universal coverage, but also on social inclusion, justice, and solidarity. In the absence of these factors, inequalities are magnified and scapegoating persists, with discrimination remaining long after (Devakumar et al., 2020). There is also widespread acknowledgment that ACB communities and scholars need to be involved in all aspects of prevention, treatment and outreach. As the COVID-19 pandemic continues unabated, disproportionately affecting the lives and livelihoods of ACB communities, there is an urgent need for research and action to mitigate their health risks and strengthen the capacity of healthcare systems (CBC news, 2020a). Three major research gaps were identified: 1) Information on how factors such as socioeconomic vulnerability, co-morbidity, critical health literacy, and discrimination affect healthcare access and outcomes in ACB communities; 2) Information on the types of knowledge and training needed by frontline health workers (and administrators) in the context of service provision to ACB communities; and 3) Information to inform the development of strategies to ensure health equity and mitigate the impact of COVID-19 in ACB communities. Action towards addressing health inequalities will not only help tackle the pandemic, but also develop better resilience and healthcare capacity building during the post-pandemic era.

Main goals and objectives: The main goal of this study is to improve the health system's response to ACB community during and after the COVID-19 pandemic by developing evidence-based models to inform policy and practice to mitigate its spread and related health consequences in vulnerable communities. The Coordinated Global Research Roadmap (A Coordinated Global Research Roadmap, 2020) recognizes the severe strain placed by COVID-19 on clinical services, including the provision of chronic care services, and the need to focus attention on the current and impending health needs of vulnerable populations. Our specific objectives are to:

1) Engage ACB communities and health provider stakeholders in research and decision-making processes

2) Examine the contextual vulnerability and challenges experienced by ACB communities

3) Identify the adequacy and non-intended consequences of current health care practices on ACB communities

4) Increase individual, community and organizational capacity and leadership and generate strategies to address COVID-19 related-health outcomes, and

5) Share new knowledge and support its translation into policy and practice models to mitigate the impact of COVID-19 on ACB communities.

It is well-documented that ACB communities experience systematic bias(es) within the healthcare system. As described in the WHO Global Research Roadmap, there is a strong need to prioritize vulnerable population subgroups suffering from stigmatization and/or with other co-morbid conditions.

2. Conceptual Framework and Project Management Plan

The underlying theme and analytical approach of the project is based on the Social-Ecological Model (SEM) that was proposed by McLeroy and colleagues in 1988. This model maintains that the determinants of health go far beyond the biological factors and involve many factors functioning as a subsystems that occur at various levels namely individual, interpersonal, institutional, community, and public policy (Table 1). We have chosen the SEM approach to explore the gaps in healthcare system in the context of COVID-19 that is worsening the health situation and access to care among ACB population. This model enables us to identify the gaps, design interventions, and propose implementation strategies by fully acknowledging the complexity of the situation that are causing the challenges for healthcare systems. This model not only allows us to understand how the sociocultural determinants and healthcare system related factors led to health inequities, but also to build policy capacities to address the root-causes at their respective levels.
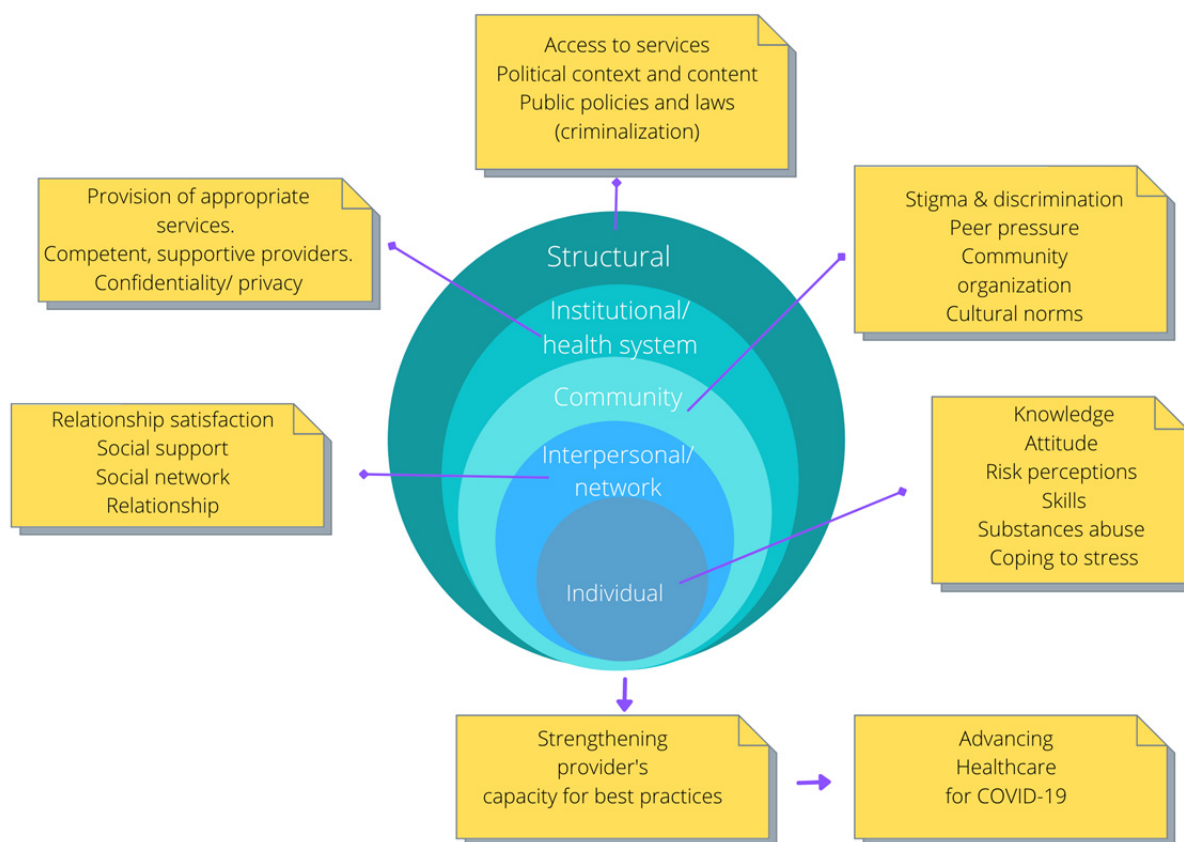

Figure 1. Socioecological Model (SEM) showing the different levels of action to improve COVID-19 related care for racialized communities

Table 1 illustrates the problem statement, major aims, interventions and outcomes specific to the level of analysis including individual, health practitioners and the healthcare system. The outcomes are also classified by their potential impact at their corresponding levels e.g. lowers vulnerability at individual, better quality of care at practitioner, and post-pandemic resilience at healthcare system level.

Table 1. Problem specification and expected intervention and outcomes

		PROBLEM	MAJOR AIMS	INTERVENTION	OUTCOMES		
LEVEL OF VULNERABILITY	Individual	Inadequate preventive knowledge and care	**Aim 1: Engage ACB communities and health provider stakeholders in research and decision-making processes** (e.g. promote health)	Create local advisory group (LAG) in raising awareness e.g. meaningful engagement between communities and healthcare stakeholder	Better coverage of preventive care	Lower vulnerability	LONG-TERM BENEFITS
		Poor living/working conditions and distrust on healthcare providers/ low digital and critical health literacy	**Aim 2: Examine the contextual vulnerability and challenges experienced by ACB communities** (e.g. identifying contextual solutions e.g. occupational hygiene)	Workplace safety (provision of masks, gloves)/ Promoting cultural competence of care-providers	Lower exposure to infection/ Higher uptake of essential health services		
	Practitioners	Changing occupational roles	**Aim 3: Identify the adequacy and non-intended consequences of current health care practices on ACB communities**	Better distribution/sharing of duties	Optimal service quality	Better quality of care	
		Risk of cross-transmission	Identifying contextual risk factors	Better occupational hygiene	Lower exposure to infection		
	Healthcare	Lack of preparedness	**Aim 4: Increase individual, community and organizational capacity and leadership and generate strategies to address COVID-19 related-health outcomes**	Developing effective policy instruments	Better risk management	Post-pandemic resilience	
		COVID-19 pandemic	**Aim 5: Share new knowledge and support its translation into policy and practice models to mitigate the impact of COVID-19 on ACB communities.**	Research & development (e.g. vaccine)	Reduced risk of spread/morbidity/mortality		

3. Methodology

3.1 Research Design and Data Collection

In addition to the SEM described above, this mixed-methods research study will be guided by intersectionality (Collins & Bilge, 2016; Bilge, 2010) and community-based participatory research (CBPR). (Participatory action research (PAR): an approach for improving black women's health in rural and remote communities. - Abstract - Europe PMC) Intersectionality framework will help to explicate the vast array of layered macro, meso and micro level factors – i.e., structural, institutional, community, interpersonal and individual - that must be considered when addressing COVID-19 related inequities among racialized communities. CBPR is an approach of working collaboratively with and through groups of people or communities affected by the issues being investigated with a goal of not only studying the issue, but also to address issues affecting the well-being of the study population (Etowa et al., 2018). The project will take place in four (3 months) phases in two sites in Ontario: Toronto and Ottawa.
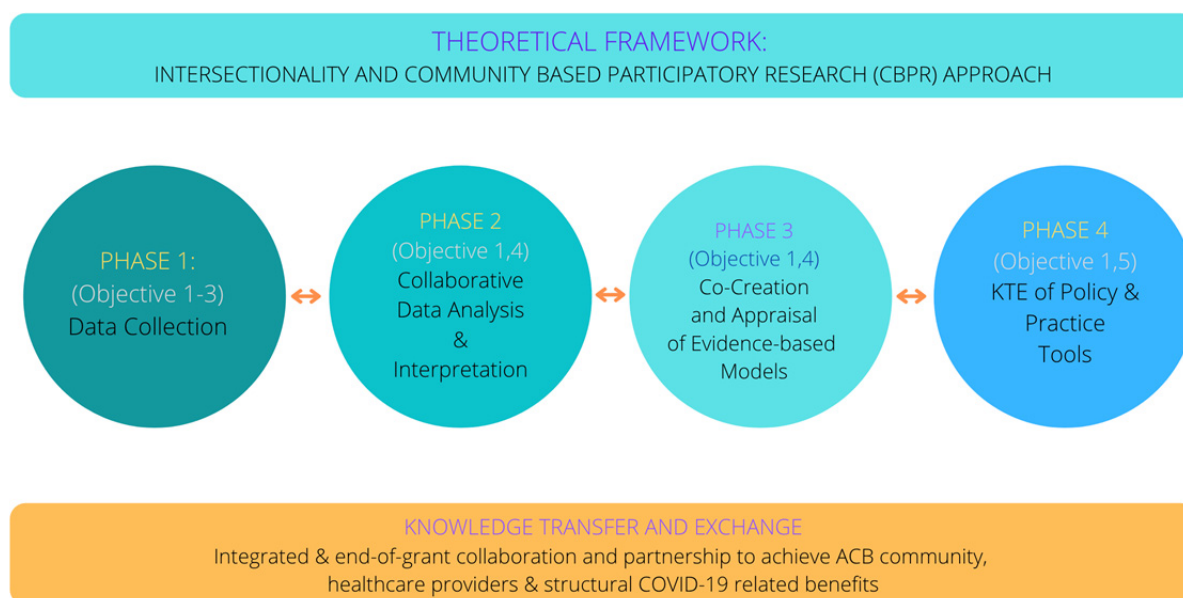

THEORETICAL FRAMEWORK:
INTERSECTIONALITY AND COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR) APPROACH

PHASE 1:
(Objective 1-3)
Data Collection

PHASE 2
(Objective 1,4)
Collaborative
Data Analysis
&
Interpretation

PHASE 3
(Objective 1,4)
Co-Creation
and Appraisal
of Evidence-based
Models

PHASE 4
(Objective 1,5)
KTE of Policy &
Practice
Tools

KNOWLEDGE TRANSFER AND EXCHANGE
Integrated & end-of-grant collaboration and partnership to achieve ACB community,
healthcare providers & structural COVID-19 related benefits

Figure 2. Phases of the project

Phase 1 addresses Aims 1-3 with activities such as creating a local advisory group (LAG), appraising, and synthesizing the growing body of COVID-19 literature, applying for ethical approval, hiring and training research staff, developing research and consent tools, optimizing existing partnerships for collaborative outreach activities, and engaging in recruitment and data collection.

Phase 2 addresses Aims 1,4 and consists of collaborative data analysis and interpretation. Braun and Clarke's six-step framework will inform the thematic analysis of qualitative data (Braun & Clarke, 2006). We will produce a nuanced analysis of the data in respect of the social determinants of health, our chosen socioecological model, and intersectionality theory. Social identities, primarily gender, but also migration status and SES, that affect risk of COVID-19, health outcomes and experiences with health services, will be integrated into all data collection and analysis to ensure adequate representation.

Phase 3: addresses Aims 1,4 and includes knowledge sharing, appraisal and co-creation of best practice framework using concept mapping strategy. This process will engage ACB community leaders, healthcare providers, policy/decision-makers to develop effective and empowering responses that address vulnerabilities (racism, social and economic marginalization) and promote resilience and critical health literacy in the context of COVID-19, health, and healthcare. Concept mapping has been effectively used to develop a best practices model to address migration and health issues in the ACB community.(Schiller et al., 2013; Haque & Rosas, 2010) It promotes critical health literacy, which refers to "the degree to which people can access, understand, appraise and communicate information to engage with the demands of different health contexts to promote and maintain good

health across the life-course. Based on the social distancing orders during this phase, concept mapping may be implemented via face-to-face virtual World café style meetings in both cities with 9-10 focus group discussions (FGDs) in Ottawa and 10-11 in Toronto. FGDs will be transcribed verbatim and thematically analyzed. The scientific rigor of our research qualitative component will be guided by Creswell and Poth (2018) validation strategies. "GroupWisdom" software will be used to perform concept mapping.

The final **phase (4)** addresses Aims 1, 5, and includes end of grant knowledge exchange activities including the sharing of evidence-based policy tools and practices, and the development of plans to scale up the project. Integrated KT will occur throughout the project and will include a local advisory group which will also serve as a mechanism for consistent community engagement and capacity building (Figure 2).

3.2 Qualitative Data Collection and Analysis

The qualitative description approach by Sandelowski will guide the qualitative component of the study. Primary sources of data gathering will be in-depth individual interviews (IDIs) with 100 key stakeholder groups - ACB community (n=60), healthcare providers (n=30) and policymakers (n= 10). Focus group discussions (FGD) will also be conducted for data validation through member-checking. Purposive sampling supported by snowball techniques (Creswell & Poth, 2018) will guide the recruitment of (100) participants comprising of 60 key informants from the ACB community, 30 healthcare providers, and 10 policymakers to participate in this study. Purposeful sampling will allow facilitating the recruitment of participants with rich information, relevant to this study's phenomenon. To ensure participants' representation in both study locations, fifty (50) of these participants will be from the Ottawa area, and fifty (50) will be from the Toronto area. We will use various platforms, including social media, flyers, and referral processes, to recruit participants through our established contacts in the community.

We have developed interview guides for each of the three stakeholder groups; ACB community members, healthcare providers (HCP) and policy makers (PM). group of participants to guide the IDI process. Due to the current COVID-19 restrictions on social distancing, the research assistants will conduct IDIs via Zoom conferencing or any other virtual communication platforms as per the participants' convenience and preference. Each IDI session will last for about 45-60 minutes. Although we have specified the number of participants, past research has indicated that the final sample size often depends on data saturation[41-43]. Data saturation occurs when further data collection does not reveal new information about the phenomena[48]. Therefore, we will collect data until data saturation is reached. As per the principles of community-based participatory research frameworks, project advisory committee (PAC) and focus group discussion (FGD) with the stakeholders will also inform the creation of best practice models.[50] Qualitative data analysis will occur concurrently with the data collection. Professional transcriptionists will transcribe data verbatim. Nvivo software will facilitate data management and storage.

Although the numbers of participants have been specified, qualitative research requires data collection until data saturation is achieved in the analysis; when further data collection does not reveal new information. Past research has indicated that the chosen sample size frequently results in data saturation (Morse, 2016; Guest, Bunce, & Johnson 2006; O'Reilly & Parker 2012), but the final sample size in our study will be dependent on the point at which saturation is achieved.

Data collection will be conducted in both English and French with targeted efforts via key partner organizations at each site; Ottawa (Montfort hospital, Ottawa Public Health and its affiliates- CHCs, and long-term care facilities) and Toronto (St Mike's Hospital, Taibu CHC; Women's Health in Women's Hands, etc). A number of recruitment strategies will be implemented within these sites, such as distribution of a recruitment email to eligible participants, in-person recruitment through short presentations on site when allowed by Public Health guidelines, as well as distribution of a study flyer via Social Media (such as Facebook, Twitter, and Instagram) through key informants. Potential participants interested in participating in the study are invited to communicate their interest via the study email address.

Braun and Clarke's six-step framework will inform the thematic analysis of qualitative data collected through the in-depth individual interviews and data interpretation to explicate data's commonalities or patterns (Braun & Clarke, 2006). Nvivo software will facilitate data management and storage. A theme is a pattern in the information that describes and organizes the possible observations, or interpretations of phenomena identified in the data. This process will begin with the development of a coding framework informed by questions from the interview guides and a systematic approach that involves: (1) familiarizing with the data; (2) generating initial codes; (3) developing a coding tree to guide the coding of transcripts; (4) identifying themes; (5) reviewing, defining and naming themes; 6) interpreting the narratives and stories; and (7) producing the report – a concise, coherent, logical, and

non-repetitive account supported by vivid examples.

Rigour and robustness in qualitative research is to some extent established via a self-conscious and reflexive approach, but it is also accompanied by an explicit methodological framework. To establish the rigour and scientific value of our research, the qualitative component will be assessed with Lincoln & Guba's criteria, namely, credibility, transferability, confirmability, and dependability. Credibility refers to the confidence observers have in the analytical and interpretive processes and findings. In this research, transparent analytical steps have been identified and informed by established qualitative research principles. Transcripts will be carefully verified and checked. In the analysis process, attention will be paid to misrepresentation of the data. We will interrogate the data until data saturation is reached. Furthermore, the research team is trained in the conduct of ethical and sensitive research with racialized and disadvantaged populations.

Table 2. Qualitative Sampling Techniques and Procedures

Study sites	Participant group	Subgroups	Number per site
Ottawa	ACB	Youth	6 (3 Eng[a], 3 Fr[b])
		Adult	14 (8 Eng, 6Fr)
	Provider	Montfort Hospital	5
		Nursing home	5
		OPH & CHCs	5
	Policy Makers	Funder Health organization professional association community leaders	5
Toronto	ACB	Youth	10 (10 Eng)
		Adult	20 (20 Eng)
	Provider	St Michael Hospital St & Taibu CHC	8
		Nursing home	3
		TPH	2
		WHIWH CHC	2
	Policy Makers	Funder S, Health organizations, professional associations, faith-based leaders, community leaders	5

a: Participants whose identified language is English.

b: Participants whose identified language is French.

3.3 Quantitative Data Collection and Analysis

Purposive Sampling Technique will be employed to select 1000 Health care providers who are at the heart of COVID 19 fighting's Toronto and Ottawa towns from Ontario in which high number of ACB peoples resides in both towns (Figure 2 below). Stratified Sampling Technique will be used to highlight a specific stratum (Physicians, Respiratory Therapists, Nurse, Personal Support Workers and others.). Final study participants will then be selected from each stratum using Proportional Allocation Sampling Method from health care providers in each stratum. (https://explorable.com/stratified-sampling).
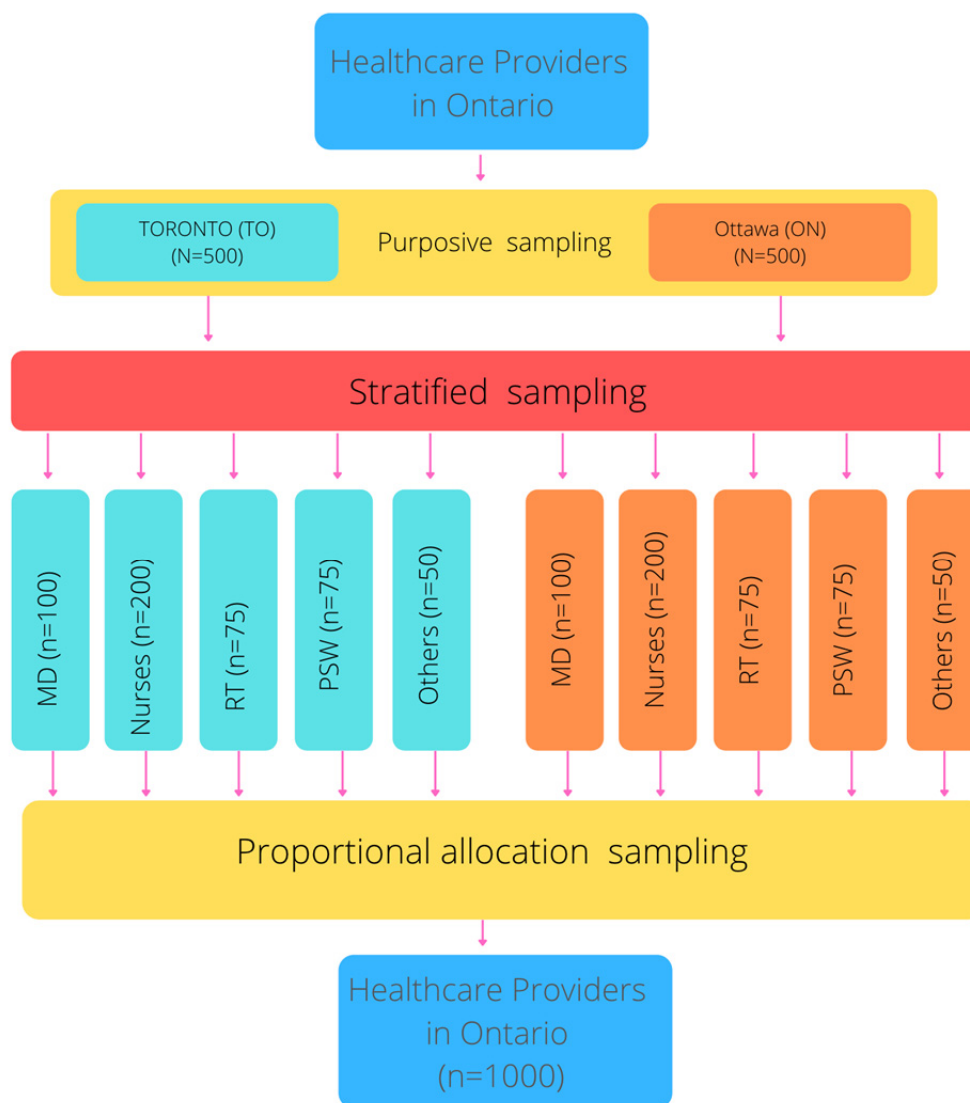
Figure 2. Survey Sampling Techniques and Procedures

Quantitative approaches (1000 online surveys) will be primarily used to collect data from health providers about their knowledge and experience working with ACB communities and their capacity to respond to the needs of ACB patients during and post-COVID-19. Purposive, stratified, and proportional allocation sampling techniques will be employed. Quantitative data collection will be carried out using Survey monkey. Data collection will be conducted in both English and French with targeted efforts via key partner organizations at each site; Ottawa (Montfort hospital, Ottawa Public Health and its affiliates- CHCs, and long-term care facilities) and Toronto (St Mike's Hospital, Taibu CHC; Women's Health in Women's Hands, etc).

4. Expected Results/Impacts of the Project

Both short-term and long-term outcomes and impacts are anticipated. A knowledge translation plan will be developed to ensure that our project findings will be translated into policy and practice. Our main KT goals are to inform health system and facilitate changes in policy and practice to address an immediate response and longer-term consequences of the COVID-19 pandemic. *Integrative knowledge translation (IKT)* will be implemented within the entire research process. First, we will engage a local advisory group consisting of ACB community members, service providers, knowledge users and project team members to serve as a mechanism for consistent community engagement and capacity building. End of project KT will include the following strategies: 1) We will develop a webinar to share our findings with health and community stakeholders throughout the province. 2) We will *host a one-day (virtual) world café style deliberative dialogue/multi-sector think tank with*

6-8 break-out FGDs. This event will engage approximately 100 people, including policy-makers and stakeholders from community and health agencies, ACB service organizations, health professional associations, education, and service users. The goal of this event is to communicate best practices to strengthen the health system's capacity to care for vulnerable populations such as the ACB community. The meeting will begin with a plenary session by presenting the objectives followed by a Q&A period with the attendees regarding current gaps in meeting the healthcare needs of ACB communities. 3) We will communicate findings to the wider scientific community through presentations at professional meetings and conferences (e.g. CIHR, OPHA, ACCHO, CNA, CPHA Annual Conferences, and poster on partner websites. 4) We will prepare linguistically- and culturally appropriate factsheets, webcasts, and, podcasts on the project website, to improve critical health literacy and ensure the equitable access to our findings to the community at large.

The widespread impact of COVID-19 demands that previously considered local concerns are now global concerns. Provincial collaborations, such as this one, bring different research perspectives to the issue of COVID-19 and health service provision from the perspective of ACB people in Ontario. This project will promote and strengthen knowledge exchange and links to providers, knowledge users and researchers in Ottawa and Toronto with the potential for scale-up, facilitate exposure to new ideas and approaches and provide opportunities for redesigning and identifying promising models for post-pandemic care informed by critical and diverse perspectives. While there are no quick fixes, sustained gains in providers' COVID-19-related health equity capacity such as the one that would be provided by this project will successfully harness knowledge for providers who can address critical post-pandemic health priorities.

4. Discussion

The Coordinated Global Research Roadmap recognizes the severe strain placed by COVID-19 on clinical services, including the provision of chronic care services and the need to focus attention on the current and impending health needs of vulnerable populations. Our specific objectives are to: 1). Engage ACB communities and health provider stakeholders in research and decision-making processes 2). Examine the contextual vulnerability and challenges experienced by ACB communities 3). Identify the adequacy and non-intended consequences of current health care practices on ACB communities 4). Increase individual, community and organizational capacity and leadership and generate strategies to address COVID-19 related-health outcomes, and 5). Share new knowledge and support its translation into policy and practice models to mitigate the impact of COVID-19 on ACB communities. It is well-documented that ACB communities experience systematic bias(es) within the healthcare system. As described in WHO Global Research Roadmap, there is a strong need to prioritize vulnerable population subgroups suffering from stigmatization and/or with other co-morbid conditions.

This mixed-methods research study will be guided by intersectionality and community-based participatory research frameworks. The project will take place in four phases in two sites in Ontario: Toronto and Ottawa. Phase 1 consists of data collection using both qualitative and quantitative methodologies. In-depth interviews and focus groups will be used to collect data from ACB community members and leaders on socioeconomic and health vulnerabilities considering COVID-19 and health care experiences. An online survey will be used to collect data from health providers about their knowledge and experience working with ACB communities and their capacity to respond to the needs of ACB patients during and post-COVID-19. Phase 2 consists of collaborative data analysis and interpretation. Phase 3 includes knowledge sharing and co-creation of evidence-based models (i.e., concept mapping) with ACB community and health provider stakeholders that will be used to inform policy and practice. The final phase includes the end of grant knowledge exchange activities and the development of plans to scale up the project. Integrated KT will occur throughout the project and will include a local advisory group which will also serve as a mechanism for consistent community engagement and capacity building.

We have strategically assembled a strong team of influential and committed researchers, community leaders, healthcare providers and knowledge users from diverse backgrounds and disciplines across Ontario. They include people at various stages of their career with a track record of collaboration and extensive networks with frontline healthcare providers at the various levels of the system including long-term care facilities where COVID-19 is most felt.

The widespread impact of COVID-19 demands that previously considered local concerns are now global concerns. Provincial collaborations, such as this one, bring different research perspectives to the issue of COVID-19 and health service provision from the perspective of ACB people in Ontario. This project will promote and strengthen knowledge exchange and links to providers, knowledge users and researchers in Ottawa and Toronto with the potential for scale-up, facilitate exposure to new ideas and approaches and provide opportunities for redesigning and identifying promising models for post-pandemic care informed by critical and diverse perspectives. While

there are no quick fixes, sustained gains in providers' COVID-19-related health equity capacity such as the one that would be provided by this project will successfully harness knowledge for providers who can address critical post-pandemic health priorities.

5. Conclusions

The expected outcomes of the proposed research program include: strengthening multisectoral collaborative partnerships in COVID-19 responses of ACB communities; identifying best evidence based models and interventions to strengthen health system's capacity to care for vulnerable populations such as the ACB community, Improving critical health literacy among ACB people and their responses to COVID-19; and generating new knowledge to reduce COVID-19-related health inequities in ACB communities to address the pandemic in Ontario and beyond.

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Ethical Approval

University of Ottawa (Supplement file) REB: H-07-20-5984.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

References

A Coordinated Global Research Roadmap. (2020). Retrieved from https://www.who.int/who-documents-detail/a-coordinated-global-research-roadmap

Abel, T., & McQueen, D. (2020). Critical health literacy and the COVID-19 crisis. *Health promotion international*, *35*(6), 1612-1613. https://doi.org/10.1093/heapro/daaa040

African, Caribbean and Black Communities | The Ontario HIV Treatment Network. (n.d.). Retrieved from https://www.ohtn.on.ca/research-portals/priority-populations/african-caribbean-and-black-communities/

Baidoobonso, S., Bauer, G. R., Speechley, K. N., & Lawson, E. (2013). HIV risk perception and distribution of HIV risk among African, Caribbean and other Black people in a Canadian city: mixed methods results from the BLACCH study. *BMC public health*, *13*(1), 1-17. https://doi.org/10.1186/1471-2458-13-184

Bilge, S. (2010). Recent feminist outlooks on intersectionality. *Diogenes*, *57*(1), 58-72. https://doi.org/10.1177/0392192110374245

Bouye, K., Truman, B. I., Hutchins, S., Richard, R., Brown, C., Guillory, J. A., & Rashid, J. (2009). Pandemic influenza preparedness and response among public-housing residents, single-parent families, and low-income populations. *American journal of public health*, *99*(S2), S287-S293. https://doi.org/10.2105/AJPH.2009.165134

Braithwaite, R., & Warren, R. (2020). The African American petri dish. *Journal of Health Care for the Poor and Underserved*, *31*(2), 491-502.

Branigin, A. (2020). Black communities are on the "Frontline" of the COVID-19 pandemic: here's why. The Root. Retrieved from https://www.theroot.com/black-communities-are-on-the-frontline-of-the-covid-19-1842404824

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Campbell, K., & Jones, A. (2009). *Prevention Programs in Developed Countries: Lessons Learned: a Report on Prevention Initiatives Used to Address HIV and AIDS Prevention for African, Caribbean and Black Populations in Developed Countries*. Interagency Coalition on AIDS and Development. Retrieved from http://www.icad-cisd.com/publication/prevention-programs-in-developed-countries-lessons-learned-a-report-on-prevention-initiatives-used-to-address-hiv-and-aids-prevention-for-african-caribbean-and-black-populations-in-developed-count/.

CBC News. (2020a). *U.S. Records Deadliest Day yet in Coronavirus Crisis | CBC News*. CBC. Retrieved April 7, 2020, from https://www.cbc.ca/news/world/us-coronavirus-tuesday-ny-increase-1.5524669

CBC News. (2020b). *Money's Not That Important: African Americans in Georgia Wary of Returning to Work as COVID-19 Takes a Toll | CBC News*. CBC. Retrieved May 2, 2020 from

https://www.cbc.ca/news/world/georgia-covid-african-american-1.5552910

Chung, R. Y. N., Dong, D., & Li, M. M. (2020). Socioeconomic gradient in health and the covid-19 outbreak. *Bmj*, *369*. https://doi.org/10.1136/bmj.m1329

Collins, P. H., & Bilge, S. (2020). *Intersectionality*. John Wiley & Sons.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Los Angeles: SAGE Publications.

Devakumar, D., Shannon, G., Bhopal, S. S., & Abubakar, I. (2020). Racism and discrimination in COVID-19 responses. *The Lancet*, *395*(10231), 1194. https://doi.org/10.1016/S0140-6736(20)30792-3

Djiadeu, P., Nguemo, J., Mukandoli, C., Odhiambo, A. J., Lightfoot, D., Mbuagbaw, L., & Nelson, L. E. (2019). Barriers to HIV care among Francophone African, Caribbean and Black immigrant people living with HIV in Canada: a protocol for a scoping systematic review. *BMJ open*, *9*(1), e027440. https://doi.org/10.1136/bmjopen-2018-027440

Etowa, J. B., Bernard, W. T., Oyinsan, B., & Clow, B. (2007). Participatory action research (PAR): An approach for improving black women's health in rural and remote communities. *Journal of Transcultural Nursing*, *18*(4), 349-357. Retrieved from https://europepmc.org/article/med/17911575

Etowa, J., Lisa, P.-D., Adele, V., & Brianna, K. (2015). Mentoring as a Resource for Aboriginal Nurses: Perspectives of Indigenous Knowers. *The International Journal of Organizational Diversity, 14*(4), 11-27. https://doi.org/10.18848/2328-6261/CGP/v14i04/40209

Etowa, J., MacDonald, S., Hannan, J., Phillips, J. C., Boadu, N. Y., & Babatunde, S. (2018). Sociocultural factors influencing infant-feeding choices among African immigrant women living with HIV: a synthesis of the literature. *Journal of the American Association of Nurse Practitioners*, *30*(4), 208-235. https://doi.org/10.1097/JXX.0000000000000014

Garrett, L. (2020). COVID-19: the medium is the message. *The lancet*, *395*(10228), 942-943. https://doi.org/10.1016/S0140-6736(20)30600-0

Gawley, K. (2020). Canada's 'colourblind' coronavirus data could leave officials blind to racial inequities. *City News*. Retrieved from https://www.citynews1130.com/2020/04/07/canadas-colourblind-coronavirus-data-could-leave-officials-blind-to-racial-inequities/

George, C., Adam, B. D., Read, S. E., Husbands, W. C., Remis, R. S., Makoroka, L., & Rourke, S. B. (2012). The MaBwana Black men's study: community and belonging in the lives of African, Caribbean and other Black gay men in Toronto. *Culture, health & sexuality*, *14*(5), 549-562. https://doi.org/10.1080/13691058.2012.674158

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, *18*(1), 59-82. https://doi.org/10.1177/1525822X05279903

Haque, N., & Rosas, S. (2010). Concept mapping of photovoices: Sequencing and integrating methods to understand immigrants' perceptions of neighborhood influences on health. *Family & Community Health*, *33*(3), 193-206. https://doi.org/10.1097/FCH.0b013e3181e4bbf0

Health workers are the frontline soldiers against COVID-19. Let's protect them | Africa Renewal. (2020). Retrieved from https://www.un.org/africarenewal/web-features/coronavirus/health-workers-are-frontline-soldiers-against-covid-19-let%E2%80%99s-protect-them

Home. (n.d.). *Association for Canadian Studies*. Retrevied from https://acs-aec.ca/en/main.

James, X., Hawkins, A., & Rowel, R. (2007). An assessment of the cultural appropriateness of emergency preparedness communication for low income minorities. *Journal of Homeland Security and Emergency Management*, *4*(3).

Kraemer, M. U., Yang, C. H., Gutierrez, B., Wu, C. H., Klein, B., Pigott, D. M., ... & Scarpino, S. V. (2020). The effect of human mobility and control measures on the COVID-19 epidemic in China. *Science*, *368*(6490), 493-497. https://doi.org/10.1126/science.abb4218

Martínez-Martínez, O. A., & Rodríguez-Brito, A. (2020). Vulnerability in health and social capital: a qualitative analysis by levels of marginalization in Mexico. *International journal for equity in health*, *19*(1), 1-10.

https://doi.org/10.1186/s12939-020-1138-4

McKee, M., & Stuckler, D. (2020). If the world fails to protect the economy, COVID-19 will damage health not just now but also in the future. *Nature Medicine*, *26*(5), 640-642. https://doi.org/10.1038/s41591-020-0863-y

Mkandawire, P., Arku, G., Luginaah, I., & Etowa, J. (2019). Informal transit, socio-spatial exclusion, and changing geographies of HIV/AIDS in urban Malawi. *African Journal of AIDS Research*, *18*(1), 81-88. https://doi.org/10.2989/16085906.2019.1575884

Morse, J. M. (2016). *Determining sample size: Qualitative Health Research, juillet*. https://doi.org/10.1177/104973200129118183

New study finds higher social capital and trust leads to better COVID-19 response in some U.S. states | Research & Innovation. (n.d.). Retrieved May 3, 2020, from https://research.info.yorku.ca/2020/04/new-study-finds-higher-social-capital-and-trust-leads-to-better-covid-19-response-in-some-u-s-states/

Nguemo, J. D., Iroanyah, N., Husbands, W., Nelson, L. E., Maina, G., Njoroge, I., ... & Wong, J. (2019). Substance use disorders among African, Caribbean and Black (ACB) people in Canada: a scoping review protocol. *BMJ open*, *9*(7), e028985. https://doi.org/10.1136/bmjopen-2019-028985

Nicole, M., Alsafi, Z., Sohrabi, C., Kerwan, A., Al-Jabir, A., Losifidis, C., ... & Agha, R. (2020). The socio-economic implications of the coronavirus and covid-19 pandemic: A review. *International Journal of Surgery*, *78*, 185-193. https://doi.org/10.1016/j.ijsu.2020.04.018

O'reilly, M., & Parker, N. (2013). 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative research*, *13*(2), 190-197. https://doi.org/10.1177/1468794112446106

Osman, L. (2020). *Demographic Data "essential" to Track Spread of COVID-19: Researchers*. Rettrieved from https://www.ctvnews.ca/health/coronavirus/demographic-data-essential-to-track-spread-of-covid-19-researchers-1.4888879

Rowel, R., Sheikhattari, P., Barber, T. M., & Evans-Holland, M. (2012). Introduction of a guide to enhance risk communication among low-income and minority populations: a grassroots community engagement approach. *Health promotion practice*, *13*(1), 124-132. https://doi.org/10.1177/1524839910390312

Schiller, C., Winters, M., Hanson, H. M., & Ashe, M. C. (2013). A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. *BMC public health*, *13*(1), 1-9. https://doi.org/10.1186/1471-2458-13-428

Shimeles, H., Husbands, W., Tharao, W., Adrien, A., & Pierre-Pierre, V. (2011). African, Caribbean and Black Communities in Canada. *For the Canadian Institute of Health Research*, 1-10.

Social-Ecological Model for Understanding Differential Impact of COVID-19. (n.d.). Retrieved November 18, 2020, from https://curriculum.covidstudentresponse.org/module-3-disparities-policy-socioeconomic-effects/social-ecological-model-for-understanding-differential-impact-of-covid-19

Transformation Through Collective Action: Best Practices in Migration, HIV and Mental Health. (n.d.) ResearchGate. Retrieved May 2, 2020, from https://www.researchgate.net/publication/320665883_Transformation_Through_Collective_Action_Best_Practices_in_Migration_HIV_and_Mental_Health

Vaughan, E., & Tinker, T. (2009). Effective health risk communication about pandemic influenza for vulnerable populations. *American journal of public health*, *99*(S2), S324-S332. https://doi.org/10.2105/AJPH.2009.162537

Wolf, M. S., Serper, M., Opsasnick, L., O'Conor, R. M., Curtis, L., Benavente, J. Y., ... & Bailey, S. C. (2020). Awareness, attitudes, and actions related to COVID-19 among adults with chronic conditions at the onset of the US outbreak: a cross-sectional survey. *Annals of internal medicine*, *173*(2), 100-109. https://doi.org/10.7326/M20-1239

Women on the Front Line (2/3): Cashiers Face "warlike" Conditions Working under Covid-19. (2020). France 24. Retrieved April 29, 2021, from https://www.france24.com/en/20200429-women-on-the-frontline-2-3-cashiers-face-warlike-conditions-working-under-covid-19

Zhabokritsky, A., Nelson, L. E., Tharao, W., Husbands, W., Sa, T., Zhang, N., ... & Kaul, R. (2019). Barriers to HIV pre-exposure prophylaxis among African, Caribbean and Black men in Toronto, Canada. *Plos one*, *14*(3), e0213740. https://doi.org/10.1371/journal.pone.0213740

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