# Arthritis and Health Related Quality of Life in Adult Outpatients in Trinidad: A Cross Sectional Study

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#### ABSTRACT

#### Objectives

Arthritis is a major public health concern due to the high prevalence reported globally and its impact on healthrelated quality of life (HRQOL). The main objectives of this study were to determine the prevalence of selfreported joint pain in Trinidad, arthritis and its associations with HRQOL in a Trinidadian primary care population.

#### Method

A cross-sectional study was conducted on adult primary care attendees from 16 randomly selected centres during the period January to June 2016 using an interviewer administered de novo questionnaire. Data was analysed using Statistical Package for the Social Sciences for predictors of HRQOL.

#### Results

Of 421 subjects approached, 392 (93%) completed this survey. The average age was 46 ± 17.8 years with 60.5% of respondents being female and 75% being of either East Indian or African descent. Joint pain in the past 6 months, reported by 57.9% of participants, was associated with older age (P < 0.001), female gender (P =0.016), East Indian descent (P = 0.001) and unemployment (P < 0.001) Joint swelling was reported by 48% of those who reported joint pain (28% of entire sample). A self-reported diagnosis of Chikungunya related arthritis, osteoarthritis, lupus, rheumatoid arthritis, and gout was made by 12.0%, 9.8%, 9.3%, 7.6% and 1.3% of the sample, respectively. There was significant (P<0.005) upset in all domains of quality of life in those with joint pain.

#### Conclusion

One third of adult primary care attendees reported arthritis with upset in all HRQOL domains. These findings lend support for the improvement in rheumatology services in this setting.

Keywords: Arthritis, Trinidad, Quality of life, Joint pain

# INTRODUCTION

Health related quality of life (HRQOL) refers to "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"<sup>1</sup>. Arthritis refers to a group of over 100 conditions where there is inflammation in a joint, characterized by pain and swelling. It is a common condition that can considerably affect patients' HRQOL and it appears to be increasing in prevalence. A 2018 United States study highlighted that the prevalence of arthritis may be higher than previous estimates, affecting as much as 36.8% of adults in 2015<sup>2</sup>. This study also estimated that in adults aged 18 to 64, nearly one in three (both sexes) have doctor-diagnosed arthritis and/or report joint symptoms and in adults older than 65 years, more than half of men, and more than two thirds of women may have arthritis<sup>2</sup>. Similarly, high prevalence and disease burdens have been documented in Africa, Europe and Asia<sup>3-5</sup>.

The global burden of disease highlighted musculoskeletal disorders were responsible for 150 million disability adjusted life years (DALYs) or 5.9% of total DALYs in 2019, 98.1% of which were years lost to disability<sup>6</sup>. The existing burden on the health care system and economy owing to musculoskeletal disorders has been highlighted and the number of people affected by musculoskeletal diseases is projected to rise in the coming decades<sup>7,8</sup>. In 2013, total medical costs and earning losses due to arthritis were \$304 billion (about one percent of the U.S. gross domestic product for 2013) and total earning losses were higher than medical costs<sup>7</sup>. Using the National Health Interview Survey (NHIS) for 2013-2015, the estimated number of adults with doctor-diagnosed arthritis (DDA), on average, was 54.4 million, and is projected to reach 78.4 million, or 26% of the adult population, by 2040. The estimated number of adults, on average, with arthritis-attributable activity limitation (AAAL) was 23.7 million, projected to reach 34.6 million, or 11.4% of all adults, in 2040<sup>8</sup>.

The most common forms of arthritis are osteoarthritis and the inflammatory arthritides<sup>9</sup>. The negative impact that various arthritides have on HRQOL has been well described for osteoarthritis (OA), rheumatoid arthritis (RA), gout, Chikungunya related arthritis and psoriatic arthritis<sup>10-16</sup>. Despite the documented international prevalence of arthritis, in Trinidad and by extension the Caribbean region, there are no available reports on the epidemiology or impact of the condition. The region represents unique and ethnically diverse groups of small island nations. Published data on prevalence of arthritis in these populations are limited to studies external to the region in migrants<sup>17-18</sup>. In the absence of local or regional data, the objectives of this study were 1) to establish the prevalence of arthritis, joint related symptoms and associated risk factors in Trinidad and 2) to compare HRQOL in adult outpatients in Trinidad who report joint pain with those who do not. Such knowledge gained would help document the burden of disease in the Caribbean context, which can serve as the basis for optimized management for both clinicians, and informed public health policy.

#### **METHODS**

#### Design

This cross-sectional study was performed in primary health care centres in the four major Regional Health Authorities (RHAs) throughout Trinidad. Ethical approval was obtained from all RHAs and from the Ethics Committee of the University of the West Indies. This study population was limited to adult outpatients who attended walk-in clinics at primary care centres in Trinidad during the period January to June 2016. A random sample of four health centres was selected from each RHA.

# Participants

Eligible participants from each health centre were selected while in the waiting area. The inclusion criteria were adults over 18 years of age who were resident in Trinidad for the past 10 years seeking ambulatory care at the general practice service at each health centre. Such patients who attend the walk-in service at each clinic do so without an appointment for acute or sub-acute nonemergent complaints. This group of primary care attendees excluded persons seeking care primarily for chronic disease, antenatal, child health and family planning services which are strictly by appointment. Additional exclusion criteria were non-nationals, those who were mentally incapacitated, hearing or visually impaired. A sample size of 383 was determined using an estimated arthritis prevalence of 50% with 95% confidence intervals and a 5% margin of error<sup>1</sup>. The

study targeted 400 patients who were conveniently sampled while awaiting consultation with the physician or nurse in the waiting area.

# **Survey Instrument**

The questionnaire was designed to be generic as opposed to the disease-specific inventories which exist for certain arthritides. It was piloted with feedback from community dwelling adults, not used in the final sample, with amendments made to phrasing. The final survey instrument consisted of three sections: demographics, joint related symptoms and HRQOL which included six key domains. Joint related symptoms included selfreported diagnosis of physician diagnosed arthritis, joint pain and severity, joint swelling and location, duration of symptoms and medication use. The HRQOL domains and questions were adapted from an existing questionnaire which examined the domains of mobility, activities of daily life, leisure and social activities, general health perception, jobs around the house and mental function<sup>19</sup>. The survey was reviewed by the authors for face and content validity. The first draft of the instrument was pre-tested in 15 adults who were not part of the final study. Minor revisions were made to phrasing and wording of some items based on feedback received in the pre-test. A pilot test of the final instrument was also done. Reliability indices for each of the HRQOL domains were calculated to ensure consistency of items within each domain. A total of 32 HROOL questions, each scored on a Likert scale, were used in the final instrument.

# **Data Collection**

The primary data was collected using a paper-based questionnaire which was interviewer administered face to face with participants. Although nursing and administration staff at each clinic directed the interviewer to the waiting area, only the researcher and participant were present for the duration of the interview. A brief guide was created for the interviewer to introduce themselves, state the purpose of the survey and clarify any queries raised by respondents. Paper based abstraction sheets were used to record all responses during the interviews which would later be coded. Interviews lasted, on average, 20 minutes and the next available consenting subject was interviewed whenever the researcher encountered a non-responder. Categorical data were described as percentages. Continuous data were reported using means ± standard deviation and medians with interguartile ranges, for normal and non-normally distributed data respectively. Associations for categorical variables were done using Fisher's exact and chi squared testing. T-tests were used for comparison of means and Pearson's correlation for relationship between continuous data. Linear regression analyses for joint pain in the past six months (independent variable) and its effect on quality-of-life domain scores (dependent variable) were done using general linear models with adjustment for socio demographic confounders. Except for the social and leisure activities QOL domain, a higher score on QOL domains meant greater upset in quality of life. Cronbach's alpha was used to determine internal consistency of questions within each domain. A P value <0.05 was deemed statistically significant and reported for all associations. We analysed the data using Statistical Package for the Social Sciences (SPSS, version 21).

#### **Ethical Issues**

Participation in this study was voluntary and signed informed consent was obtained from all respondents. The methods for this study were approved by the Research Ethics Committee (CEC114/01/16) of the University of the West Indies, St. Augustine, Trinidad. All ethical standards were compliant with the 1964 Helsinki declaration and its later amendments. All respondents were encouraged to seek medical care at the clinic on the same or at a later date if they voiced any physical complaints or reported pain. Respondents were approached in the waiting areas so as to cause no disruptions to their consultations with the clinic personnel.

#### RESULTS

Of the 421 candidates approached, 392 patients chose to participate in this study (response rate = 93%). The average age of the respondents was  $46 \pm 17.8$  years. Of the 392 respondents, 60.5% were female. The ethnic groups were Indo Trinidadian (38%) and Afro Trinidadian (36.7%) followed by 'Mixed' (23.2%). The majority of respondents were unemployed (52%). Primary, secondary and tertiary education was the highest level of education attained by 29.1%, 48.2% and 15.2% of the sample, respectively.

Fifty eight percent of the respondents (225) reported experiencing joint pain within the last 6 months prior to their interview. Table 1 shows the associated features of this subset of participants. Of note, one third of subjects reported pain everyday with one fifth complaining of pain all day. The knees, shoulders and ankles were the three most frequently affected joints. Almost half of these participants reported joint swelling and approximately one third reported that they had been diagnosed with arthritis. Chikungunya related arthritis, OA and lupus were the three most commonly reported diagnosed arthritides.

Table 1: Frequency of	joint related symptoms and self-reported arthritides in those who reported
joint pain in the past 6	i months (n=225).

Variable	Value
(N= 225)	
<sup>#</sup> Duration of joint pain in months	24.0 (6.0,72.0)
Days per week experiencing joint pain	
1 day or less per week	17.0%
2-3 days per week	37.5%
4-6 days per week	12.1%
Everyday	33.5%
Time of day joint pain occurs	
Daytime	47.8%
Nighttime	31.4%
All day	20.8%
<sup>+</sup> Severity of joint pains	
"on average"	5.09 ± 2.32
"at its worst"	7.83 ± 2.16
Location of Joint Pain	
Shoulder	37.4%
Elbow	18.5%
Wrists	22.9%
Knees	63.4%
Ankles	29.1%
Fingers	22.9%
Others	33.5%
Presence of Joint Pain in Immediate Family	
Yes	58.1%
No	30.0%
Unsure	11.9%
Joint Swelling	
Yes	48.2%
No	51.8%
Joint Stiffness	
Yes	70.8%
No	29.2%

Joint affected by change in weather	
Yes	63.3%
No	31.0%
I don't know	5.8%
Received a prior diagnosis of arthritis	
Yes	29.2%
No	68.6%
Self-reported diagnosis of:	
Rheumatoid Arthritis	7.6%
Osteoarthritis	9.8%
Gout	1.3%
Chikungunya	12.0%
Lupus	9.3%

<sup>*±*</sup>median (interquartile ranges; Q1, Q3) <sup>+</sup>mean  $\pm$  standard deviation

Table 2 shows the associations between self-reported joint pains in the past 6 months and demographics. The average age in those reporting joints pain was significantly higher compared to those who did not (50.8 vs. 41.2 years, P < 0.001). Seventy four percent of those older than 50 years of age reported joint pain compared

to 45% of those in the 18-50 age group (P < 0.001). Of persons that reported pain, 65.5% were women compared to 34.5% of men (P = 0.016). Other factors that were positively associated with joint pain were East Indian ethnicity, being unemployed and attaining only a primary school education.

Table 2: Relationship between	self-reported joint pain in	the past six months and	demographics
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	Joint pain within the past 6 months		
Demographic	YES	NO	P value
<b>*Age</b> (years, Mean±SD)	50.8 ± 17.2	41.2 ± 17.2	< 0.001
*Gender			
Male	78 (34.5%)	78 (47%)	0.016
Female	148 (65.5%)	88 (53%)	
*Ethnicity			
African	76 (33.6%)	67 (40.4%)	0.200
East Indian	102 (45.1%)	47 (28.3%)	0.001
Other	48 (21.2%)	52 (31.3%)	0.026
*Employment status			
Unemployed	135 (59.7%)	68 (41%)	<0.001
Employed (Public Sector)	42 (18.6%)	36 (21.7%)	0.446
Employed (Private Sector)	49 (21.7%)	62 (37.3%)	<0.001
*Education Level			
Primary	82 (36.3%)	32 (19.3%)	<0.001
Secondary	90 (39.8%)	98 (59.0%)	<0.001
Tertiary, advanced degree or professional cer-	54 (23.9%)	36 (21.7%)	0.629

#Independent sample t test, \*Fisher's exact test

Of the 226 patients reporting joint pain in the past 6 months the severity of joint pain "on average" and "at its worst" was gauged on a 1-10 scale with 1 being the least and 10 being the worst. For average pain, there were significant associations between ethnicity and RHA. In post hoc Bonferroni adjusted analyses, "average pain" scores were remarkably higher in East Indian vs. Other (P = 0.09) and African vs. Other (P = 0.037) Similar analyses for "worst pain" revealed significantly higher scores in East Indians vs. Other (P = 0.001) and primary education level vs. tertiary level (P = 0.004).

# Associations Between Self-Reported Joint Pain in Past 6 Months and Quality of Life Indicators

Table 3 shows the regression analyses for joint pain in the past 6 months and its effect on quality-of-life domain scores. There was significantly greater upset in adjusted mean QOL scores in those who experienced joint pains compared to those who did not for all domains, even after adjustment for age, gender, ethnicity and education level. The Crohnbach's alpha coefficients for the mobility, activities of daily life, leisure and social activities, general health perception, jobs around the house and mental function domains were 0.819, 0.566, 0.321, 0.690, 0.798 and 0.610, respectively. Additionally, several significant associations between selfreported diagnoses of various forms of arthritis were also found. OA sufferers experienced greater disruption in mobility compared to those who did not admit to being diagnosed with OA (P = 0.03). Interference with mobility, jobs around the house and activities of daily living scores were also significantly higher for those participants who self-reported a diagnosis of RA compared to those who did not (P < 0.001, P < 0.001 and P = 0.014 respectively). Systemic lupus erythematosus was associated with worse scores for jobs around the house (P = 0.006) and interestingly higher scores for leisure and social activities (P = 0.004), general health perception (P = 0.038) and mental function (P < 0.001.) For participants who reported a past diagnosis of gout or chikungunya arthritis, there was no significant worsening of any quality -of-life domains, in comparison to those who did not.

# Relationship Between Pain Severity, Duration And Quality-of-life Indicators

Correlations between pain duration, severity and QOL domains were also done which are shown in Table 4. There were significant positive correlations between pain duration and severity, and interference with mobility, activities of daily life, general health perception and jobs around the house.

Upset in Quality-of-Life Do- main	Estimated Marginal Means <sup>#</sup>		P value
	Joint pain	No joint pain	
Mobility	12.63	9.78	<0.001
Activities of daily life	6.25	5.41	0.001
Leisure and social activities	4.13	4.96	0.015
General health perception	7.99	6.64	<0.001
Jobs around the house	8.65	6.99	< 0.001
Mental function	18.87	17.38	0.027

# Table 3: Regression analysis for joint pain in the past six months and its effects on adjusted quality-of -life mean domain scores.

<sup>#</sup>Adjusted for age, gender, ethnicity and employment.

#### Table 4: Correlations between pain severity, duration and quality of life indicators.

Quality of Life Domain	Duration of joint pain in months	Severity of pain at its worst	Severity of pain on average
(Range of scores)	r* ( <i>P</i> value)	r* ( <i>P</i> value)	r* ( <i>P</i> value)
Mobility	0.25 (<0.001)	0.34 (<0.001)	0.31 (<0.001)
Activities of daily life	0.19 (0.004)	0.27 (<0.001)	0.22 (0.001)
Leisure and social activ-	-0.13 (0.055)	-0.10 (0.133)	-0.05 (0.450)
General health percep-	0.14 (0.032)	0.21 (0.002)	0.14 (0.037)
Jobs around the house	0.19 (0.004)	0.26 (<0.001)	0.23 (<0.001)
Mental function	0.11 (0.103)	0.07 (0.297)	0.09 (0.164)

\*Pearson's Correlation

#### Self-reported Arthritides and Correlates

There were no significant associations between a selfreported diagnosis of lupus, gout, OA, Chkungunya or RA and gender. With regards to age, however, patients selfreporting OA were significantly older 65 years vs. 45 years in those who did not report OA, P < 0.001. Similarly, those who reported RA (62 years) were significantly older than those without this condition (50 years), P0.03. Interruptions in function were noted in the following domains: Mobility for OA (P = 0.033) and RA (P<0.001), Activities of daily living for RA (P < 0.001) and Jobs around the house for OA (P = 0.039) RA (P < 0.001) and lupus (P = 0.006). There were no significant associations when the mean "pain on average" was compared between those with or without the various selfreported arthritides. There was, however, a significant association when the average "pain at its worst" was examined in those who self-reported RA (8.9) vs. those who did not (7.8), *P* = 0.005.

# DISCUSSION

This study aimed to establish the prevalence of arthritis in Trinidad as well as to compare the Health-Related Quality of Life in patients with and without joint pain. The prevalence of self-reported joint pain was found to be almost two-thirds, with half reporting joint swelling (arthritis). Joint pain was more common in older, unemployed, East Indian women. The three most common self-reported arthritides were Chikungunya related arthritis, OA and lupus. Our research revealed

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upsets in all quality-of-life domains especially in mobility, jobs around the house and general health perception.

The high prevalence of joint pain as reported in this study was in keeping with that in South American and other Caribbean countries<sup>20</sup>. In previous research, the prevalence of self-reported joint pain was noted to be higher in females than males and the average age of those reporting joint pain was significantly higher compared to those who did not<sup>20,21</sup>. Our data revealed the prevalence of self-reported joint pain being more in Trinidadian women as opposed to men which can be due to reduced physical activity or muscle weakness. The knee joint was most commonly affected (63.4%) and this can be explained by the age-associated increase in the incidence of knee OA as highlighted in The Framingham Osteoarthritis study<sup>22</sup>. OA was the second most common self-reported arthritis in our study group.

Low education level and unemployment were associated with joint pain in this survey. This seems to mirror the findings of other studies that show an inverse relationship between osteoarthritis and rheumatoid arthritis and socioeconomic status<sup>23,24</sup>. The level of education attained may also be related to unemployment<sup>25</sup>. Joint pain may have been a contributing factor to the inability to work as highlighted by Mayo Clinic researchers<sup>26</sup>. The majority of persons suffering from joint pain were unemployed, however, this category also includes persons who were retired. As it has already been established that the prevalence of joint pain increases with age, this, too, may have been a confounding factor that could explain the aforementioned associations<sup>27</sup>.

Persons of East Indian descent reported experiencing more severe joint pains both "on average" and when the joint pain was "at its worst" as compared to persons of the ethnic group "Other" which included multiracial, Caucasian, Chinese and other respondents. In a crosssectional study conducted in Malaysia, it was found that knee pain was more prevalent in Indians than compared to Malays and Chinese<sup>27</sup>. In our study, persons of African descent reported less severe joint pain in both domains. In a 2010 study conducted by Bolen et al in the United States, it was found that Blacks and Hispanics were 1.8 -1.9 times as likely to have severe joint pain as Whites, and MRO (Multi-Racial and Other) were 1.9 times as likely<sup>28</sup>. Some reasons given for the disparities between severities of joint pain in ethnic groups were: access to healthcare and use of healthcare services as well as "cultural differences in understanding of survey questions", willingness to report pain, "variations in patterns of medication use and self-management approaches to manage pain"<sup>28</sup>. In addition to such factors, genetics and cultural factors unique to the Trinidadian setting may explain the ethnic predispositions seen and warrant further exploration.

A previous Trinidadian survey sought to investigate inequalities in health using the EQ-5D instrument. Pain and discomfort were found to be the dimension with the highest prevalence of reported problems with one fifth of the adult population surveyed reporting pain at any level<sup>29</sup>. In this study, older age, female gender and lower educational level were also significant predictors of pain or discomfort<sup>29</sup>. This may be explained by the higher burden of arthritis in older women as seen in this study. Persons who self-reported joint pain experienced significantly greater difficulty with mobility, activities of daily life, social activities, general health perception, jobs around the house and mental function as compared to those who did not. Similarly, patients who were diagnosed with some form of arthritis suffered more in mobility, activities of daily life, jobs around the house and mental function. These findings are similar to those of other studies in which patients diagnosed with various forms of arthritis experienced an overall reduced quality of life compared to those who were not<sup>30,31</sup>.

In this study, Chikungunya related arthritis attained the highest percentage (12%) of self-reported cases. In December 2013, confirmation of the first cases of transmission of Chikungunya in the Caribbean was documented<sup>32</sup>. The chronicity of Chikungunya related arthritis has been well explored<sup>33</sup>. This systematic review also highlighted that quality of life was reduced in many for months to years and it was worse in females of an older age. This may explain why it was the most common self-reported form of arthritis as well as the associations between age and gender seen in this study.

# **Strengths and Limitations**

Strengths of this study included that it was the first national survey of its kind to measure joint pain, arthritis and related symptoms. It was based on self-reported data which, according to the Centres for Disease Control, recommends using self-reported, doctor-diagnosed arthritis as the case definition for estimating the prevalence of arthritis<sup>34</sup>. This study also adds to the QOL research done in the Trinidadian setting. A large representative sample from 16 based primary care institutions was used spanning all geographic areas of the island. Additionally, the instrument demonstrated good reliability among the domains tested.

There were, however, some limitations of this work. The self-reported arthritides were not verified with physician diagnosis from patient records. This may have resulted in misdiagnosis of forms of all arthritides and overdiagnosis of Chikungunya related arthritis given the recent Caribbean epidemics. The cross-sectional design of this survey provided no causal evidence of a relationship between risk factors, joint symptoms and quality of life. Data collection did not include other possible confounding factors such as body mass index, history of physical trauma, comorbidities and other lifestyle factors which may impact HRQOL outcomes.

# Recommendations

Continuing education for clinicians on the latest and best practices for the diagnosis and screening of arthritis may help in earlier diagnosis and result in better health related quality of life. Physician education has been linked to improved management of arthritis<sup>35</sup>. At the time of this

study, there were three practicing rheumatologists for a population of 1.3 million. A systematic review of the literature on workforce planning for rheumatologists suggested a conservative estimate of 0.7 per 100,000 or nine (9) rheumatologists for our population<sup>36</sup>. There is clearly a need for training, hiring and retention of rheumatologists in the local setting.

Primary care physicians (PCPs), being on the front line, need also to be aware of most recent guidelines. A toolkit specifically designed to update PCPs on latest rheumatology guidelines has been shown to be effective in improving PCP competence in diagnosis and management of common rheumatic conditions<sup>37</sup>. Patients should be educated about the modifiable risk factors of arthritis including smoking cessation, weight loss, dietary modification and infection prevention to decrease morbidity and mortality. Education of the public about the treatment services available for arthritis, such as rheumatology clinics, would enable them to have a better standard of care. This can be done through media and social media. Structured patient education programs have been shown to be effective for rheumatic diseases<sup>38</sup>.

The treatment services for arthritis should be increased to accommodate the national prevalence rate. Rheumatology clinics as well as other treatment services for arthritis and its comorbidities should be available in each Regional Health Authority in Trinidad and guality standards for these outpatient clinics need to be adopted<sup>39</sup>. Ancillary services such as physiotherapy and rehabilitation services should also be strengthened as there is strong evidence supporting their role in managing arthritis<sup>40</sup>. Provision of essential medications including steroid sparing drugs and biologic agents is also recommended. Testing for Chikungunya related arthritis is also warranted due the high self-reported prevalence of this tropical infection and the recent 2014 Caribbean epidemic. Provided these measures are instituted, screening at risk groups, such as the older women as identified in this study, for joint pain and reduced quality of life is justified.

#### CONCLUSION

In conclusion, this study was the first to highlight that almost two thirds of adult outpatients attending walk-in clinics in Trinidad complained of recent joint pain of moderate severity which was associated with significant disruption in all quality-of-life domains. While this study was based on self-reported symptoms and diagnosis, it served as a representation of an outpatient walk-in primary care population in Trinidad and its findings lend support for the need to improve rheumatologic services in Trinidad. Training and retention of rheumatologists, primary care physician education, increased ancillary services, patient education and screening are proposed in this regard, to improve quality of life in this setting.

**Ethical Approval statement:** The methods for this study were approved by the Research Ethics Committee (CEC114/01/16) of the University of the West Indies, St. Augustine, Trinidad. All ethical standards are comparable with the 1964 Helsinki declaration and its later amendments.

#### Conflict of interest statement: None declared

**Informed Consent statement:** Participation in this study was voluntary and signed consent was obtained from all those providing feedback.

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**Authors Contribution:** All authors contributed toward data analysis, drafting and revising the paper and agree to be accountable for all aspects of the work.

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