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Knowledge levels and sociodemographic influences on dementia awareness in the Eastern Province of Saudi Arabia

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ARTICLE INFO	ABSTRACT
	Purpose: This study aims to examine the level of knowledge about dementia among the public and explore differences in knowledge between sociodemographic groups. **Materials & methods:** This cross-sectional questionnaire-based study surveyed individuals living in the Eastern Province of Saudi Arabia. Dementia knowledge assessment scale (DKAS) was used to measure knowledge about dementia. Multiple regression was used to identify the significant predictors of higher levels of knowledge about dementia. **Results:** Among 1,030 participants, the mean DKAS score was 20.5 (standard deviation=10.3) out of 50. A higher level knowledge about dementia was significantly and positively associated with university education (β=2.42; p=0.010) and income higher (β=2.78; p=0.001). On the other hand, the total DKAS score was significantly and negatively associated with being male (β=-1.78; p=0.003), not knowing a person with dementia (PwD) (β=-.56; p<0.001), and not living with a PwD (β=-1.57; p=0.120). **Conclusions:** The level of knowledge about dementia is low among people living in Saudi Arabia's Eastern Province. Enhancing the community's knowledge and awareness about dementia and its related topics should be considered at the regional or national levels. **Keywords:** dementia, knowledge, literacy, misconceptions, population

INTRODUCTION

Dementia is one of the most common causes of disability among older adults. This disease can cause significant economic, social, medical, and psychological burdens on affected individuals. In 2020, approximately 55 million people were suffering from dementia globally. By 2050, the number is expected to rise to 139 million [1].

Greater awareness of dementia symptoms will likely prompt people to utilize counseling and health care services in a timely manner. Numerous studies have shown that people who better understand the disease are more likely to detect it and seek treatment early [2, 3]. We expect that families and caregivers who care for a person with dementia (PwD) will cope more effectively with the illness if they gain more knowledge about dementia.

A key element of most national strategies related to dementia is increasing public awareness of the disease, which has been identified as a crucial area of public health policy [4].

Raising public awareness of dementia is essential for enhancing care and improving the quality of life of PwD and their caregivers. A more knowledgeable public is more likely to question misconceptions about dementia, recognize early dementia symptoms, and seek early interventions [5].

There are several misconceptions about dementia, most of which stem from insufficient knowledge about the disease. Some of these misconceptions are similar across various countries, such as the idea that dementia is a normal part of aging [6]. If dementia symptoms are viewed as a normal part of aging, an older adult or a family member is unlikely to seek treatment. Accurate information is crucial since family and friends are usually the first to notice cognitive and behavioral changes [7]. Knowledge and awareness of dementia are essential across all age groups, not just older persons at a higher risk of developing the disease. However, few data are available to compare how well people in different sociodemographic categories understand dementia [8].

In Saudi Arabia, research on dementia and Alzheimer's disease is scarce. These were carried out in the provinces of

Jazan [9], Medina [10], Jeddah [11], the Aseer Region [12], and Mecca [13]. The findings of those papers revealed significant gaps in knowledge in several areas, including etiology, caregiving, and management. Across all studies, knowledge of dementia risk factors such as hypertension and diabetes were also lacking. One common misconception is that dementia is a normal part of ageing. In those studies, various scales were used. The majority of these studies found that higher knowledge was associated with a higher educational level, female gender, and having a relative affected with the disease. Furthermore, studies in the Middle East region are extremely limited, with only one or two studies conducted in each country. According to what we know, these countries include Qatar [14], Jordan [15], Lebanon [16], Iran [17], and India [18]. Poor knowledge and misconceptions were also prevalent.

Several scales have been designed to assess knowledge about dementia, and some of them have demonstrated adequate reliability and validity [19]. Dementia knowledge assessment scale (DKAS) is a recent scale that has been proven to be a reliable and valid measure of knowledge about dementia [20]. It is considered a psychometrically sound tool that overcomes the limitations of existing instruments, and it can be administered to various populations to measure their knowledge about dementia [21].

To the best of our knowledge, there are no published papers assessing dementia knowledge in the Eastern Province of Saudi Arabia. The current study aims to examine and quantify knowledge about dementia in a community sample. This cross-sectional study was carried out in Saudi Arabia's Eastern province, which accounts for 15.9% of the total Saudi population. Given that previous research found differences in knowledge across sociodemographic factors, we investigated whether age, gender, income, education, and exposure to dementia patients influenced the level of knowledge about dementia.

MATERIALS & METHODS

This is a cross-sectional study conducted in Saudi Arabia's Eastern Province. We collected data using a secure online survey platform (QuestionPro) between February and May 2023. The survey was self-administered and presented in the Arabic language, and the information was collected anonymously. All procedures were performed in accordance with ethical standards and regulations. The study employed a convenience sampling method, whereby participants were selected based on their availability and willingness to participate. A total of eight medical students participated in data collection. Each medical student was assigned to cover certain geographical area in Saudi Arabia Eastern province. Recruitment efforts involved reaching out to individuals through various channels, such as social media platforms (Instagram, Twitter, & WhatsApp), hospital waiting area, malls, and mosques. Participants who agreed on participation were provided with either a QR code to scan or sending the survey link to their social media account.

The survey took approximately 10-15 minutes to complete. Men and women aged 18 years or older who were literate in Arabic and willing to participate were eligible for this study. According to the General Authority for Statistics in Saudi Arabia, the population of the Eastern Province is estimated to be five million. We used the online software Raosoft (Raosoft

Inc., Gary Trujillo, WA, USA) to calculate the sample size. The minimum required sample size to reach a confidence interval of 97% was 471. At the end of the data collection period, we received 1,030 responses; all responses were included in the analysis.

The first section of the survey consisted of sociodemographic questions such as gender, age, education level, socioeconomic status, and contact with a person living with dementia. DKAS was used in the second part of the survey. DKAS scale [22], which originally consisted of 27 items and was eventually reduced to 25 [20]. DKAS has been used in the past to evaluate dementia literacy in many populations, including health care providers [23, 24] and family caregivers [25] and members of the general population [6, 26, 27]. DKAS included development and design, pretesting, piolet testing, psychometric evaluation, and principal component analysis [22].

In this research, we utilized the 25-item DKAS scale [20]. Each item consists of a statement or information about dementia that could be either correct or incorrect. Therefore, the respondent needs to identify whether the information is accurate or not. Questions are answered using a modified 5-point Likert scale: true, probably true, probably false, false, or do not know. Subscales of DKAS include the following:

a. causes and characteristics (seven items),
b. communication and behavior (six items),
c. care considerations (six items), and
d. risk factors and health promotion (six questions).

Each item has a maximum score of two, with zero being the lowest possible score. The maximum possible DKAS score is 50 points. A higher score corresponds to a better knowledge of dementia.

We translated DKAS scale into Arabic using the guidelines recommended and tested its validity [28]. Two Arabic-speaking bilingual and bicultural translators translated DKAS into Arabic first. Both translators knew health terminology, instrument construct content, and cultural and linguistic idiosyncrasies. They translated the questionnaire items, instructions, and responses. A committee synthesized one Arabic version from the two translated versions (synthesis I). Two multilingual and bicultural translators back-translated the synthesized Arabic questionnaire to English. After resolving ambiguities and contradictions, a committee evaluated all questionnaire versions and agreed on the prefinal version (synthesis II). We piloted the prefinal version on twenty participants who were not part of our present study. After reviewing the results and resolving issues, the Arabic DKAS scale was finalized. The authors of this study only translated the questionnaire using the aforementioned translation process and conducting reliability analysis via SPSS to compare Cronbach's alpha values of the original and translated versions. The psychometric properties of the Arabic translated DKAS were not performed. The translated Arabic scale exhibited good reliability ($\alpha=0.84$, overall scale); Cronbach's alpha coefficient for the original English scale was 0.85.

We conducted all data analyses using SPSS version 29 (IBM Corp., Armonk, NY, US). Descriptive and inferential statistics were used. The items on DKAS were summed to calculate the composite score of each subscale of knowledge about dementia. Multiple regression analysis was performed to determine the significant predictors of higher knowledge

about dementia. All sociodemographic variables were entered into a linear regression model to control for multicollinearity. The assumptions of linear regression (non-collinearity, linearity, homoscedasticity, normality and independence) were confirmed for all models prior to the execution of the test. Sociodemographic variables were considered independent variables to predict the level of knowledge about dementia. DKAS total score was considered dependent variable. Due to the nature of these variables, a dummy coding procedure was used to assess the effect of each level of each categorical variable in the model. We had no missing data because the electronic survey did not allow participants to submit their responses unless all the survey's questions were answered.

RESULTS

1,030 participants responded to the questionnaire. Of them, 48.4% were men, 45.3% were middle-aged adults (41-60 years old), 59.0% had a bachelor's degree or diploma, and 73.8% were married. Furthermore, 10.8% of the participants were health care workers. Nearly one-third of the participants (27.6%) reported living with a PwD, while 67.8% reported that they had known a PwD. **Table 1** illustrates the sociodemographic characteristics of our sample.

The mean DKAS score was 20.5 (standard deviation [SD]=10.3) out of 50, with higher scores indicating a higher level of knowledge about dementia. DKAS score at the 60th percentile (i.e., a score of 30) was chosen to correspond to sufficient knowledge about dementia. The literature has utilized similar procedures to identify cutoff scores [8, 26]. **Table 2** shows the mean and SD for each DKAS item. Each item has a maximum score of two, with zero being the lowest possible score. Participants scored lowest in questions related to risk factors of dementia (Q20-Q25) and communication with PwD (Q6-Q10). Most of respondents were not aware of importance of environment changes on the behavior of PwD (mean 0.42±0.81), and large proportion felt communication will be impossible in advanced dementia (mean 0.75±0.97). Majority of respondents were unaware that high blood

Table 1. Descriptive statistics of participants' sociodemographic variables

Character	N (%)
Age Group (years)	
18 to 25	150 (14.6%)
26-40	222 (21.6%)
41-60	467 (45.3%)
Above 60	155 (15.0%)
Gender	
Male	499 (48.4%)
Female	527 (51.2%)
Level of Education	
Less than high school	73 (7.1%)
High school	240 (23.3%)
Bachelor or diploma	608 (59.0%)
Master or PhD	100 (9.7%)
Medical occupation	
Yes	112 (10.9%)
No	915 (88.8%)
Marital status	
Single	191(18.5%)
Married	760 (73.8%)
Divorced/separated	38 (3.7%)
Widow	26 (2.5%)
Monthly income (Saudi Riyals)	
No income	128 (12.4%)
Less than 5000	114 (11.1%)
5000 to 10,000	243 (23.6%)
10,000 to 20,000	328 (31.8%)
More than 20,000	213 (20.7%)
Residence geographical area	
Khobar	185 (18.0%)
Dammam	260 (25.2%)
Qatif	213 (20.7%)
Ahsa	266 (25.8%)
Jubail	71 (6.9%)
Other	31 (3.0%)
Living with a dementia patient	
Yes	280 (27.2%)
No	747 (72.5%)
Knowing a relative with dementia	
Yes	693 (67.3%)
No	334 (32.4%)

Table 2. Mean and standard deviation calculated for each DKAS item

Statement	Mean	SD
1. Most forms of dementia do not generally shorten a person's life	0.24	0.43
2. Blood vessel disease (vascular dementia) is the most common form of dementia	0.17	0.56
3. People can recover from the most common forms of dementia	1.02	1.00
4. Dementia is a normal part of the ageing process	0.82	0.98
5. Dementia does not result from physical changes in the brain	0.89	0.99
6. Planning for end-of-life care is generally not necessary following a diagnosis of dementia	1.03	1.00
7. Alzheimer's disease is the most common form of dementia	1.20	0.80
8. It is impossible to communicate with a person who has advanced dementia	0.75	0.97
9. A person experiencing advanced dementia will not generally respond to changes in their physical environment	0.42	0.81
10. It is important to correct a person with dementia when they are confused	0.71	0.96
11. People experiencing advanced dementia often communicate through body language	0.63	0.81
12. Uncharacteristic behaviors in a person experiencing dementia are generally a response to unmet needs	0.61	0.76
13. Medications are the most effective way of treating behavioral symptoms of dementia	0.43	0.82
14. People experiencing dementia do not generally have problems making decisions	1.36	0.93
15. Movement is generally affected in the later stages of dementia	0.95	0.84
16. Difficulty eating and drinking generally occurs in the later stages of dementia	1.03	0.84
17. People with advanced dementia may have difficulty speaking	1.06	0.84
18. People experiencing dementia often have difficulty learning new skills	1.32	0.78
19. Daily care for a person with advanced dementia is effective when it focuses on providing comfort	1.26	0.79

Table 2 (continued). Mean and standard deviation calculated for each DKAS item

Statement	Mean	SD
20. Having high blood pressure increases a person's risk of developing dementia	0.45	0.75
21. Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia	0.99	1.00
22. Symptoms of depression can be mistaken for symptoms of dementia	0.72	0.83
23. The sudden onset of cognitive problems is characteristic of common forms of dementia	0.18	0.58
24. Exercise is generally beneficial for people experiencing dementia	1.17	0.81
25. Early diagnosis of dementia does not generally improve the quality of life for people experiencing the condition	1.16	0.99
Total	20.57	10.3

Table 3. Mean and SD for each subscale

Subscale	Mean	SD
Causes and characteristics (Range = 0–14)	5.38	3.05
Communication & behavior (Range = 0–12)	3.56	2.58
Care considerations (Range = 0–12)	6.99	3.24
Risks & health promotion (Range = 0–12)	4.67	2.70

pressure increases a person's risk of dementia (mean 0.45±0.75). In the study sample, misconceptions about dementia were prevalent. 75.0% (n=803) of the sample was unaware that most forms of dementia generally shorten the patient's life. Furthermore, 58.8% (n=621) believed that dementia is a normal part of aging. Seventy-five percent of the study participants knew Alzheimer's disease was the most common form of dementia.

Table 3 shows the mean and SD of each subscale. The mean score for the "communication and behavior" subscale (mean=3.56; SD=2.58; range=0-12) was the lowest, and the mean score for the "care and considerations" subscale (mean=6.99; SD=3.24; range=0-12) was the highest. The mean for the "risks and health promotion" subscale was 4.67 (SD=2.7; range=0-12), while the mean score of the "causes and characteristics" subscale was 5.38 (SD=3.05; range=0-14). The significant variation in subscale scoring.

Table 4 shows the results of multiple regression analysis to determine the significant predictors of higher knowledge about dementia. Coefficients were assessed to ascertain the influence of each of the factors on the total DKAS score. The results revealed that a higher level of knowledge about dementia was significantly and positively associated with university education (β=2.42; p=0.010) and income higher than 20,000 Saudi Riyals (SR) (β=2.78; p=0.001). On the other hand, the total DKAS score was significantly and negatively associated with being male (β=-1.78; p=0.003), not knowing a PwD (β=-3.56; p<0.001), and not living with a PwD (β=-1.57; p=0.012). As a result, individuals in lower socioeconomic subgroups had less dementia knowledge. Furthermore, exposure to a relative with dementia is a strong predictor of higher dementia knowledge, as participants who did not live with or know a PwD scored significantly lower on the instrument.

DISCUSSION

This study demonstrates that the Saudi population in the Eastern province has limited knowledge about dementia. Many participants (58.8%), for example, believed that dementia is a normal part of ageing. This figure is higher than in previous

Table 4. Multiple regression analysis of predictors of dementia knowledge levels

Predictor	B	SE(B)	β	t	Sig. (P)
Gender					
Male	-1.781	.601	-.103	-2.965	.003**
Age group					
18 to 25 years	1.513	1.138	.062	1.330	.184
26-40 years	.828	.708	.040	1.168	.243
Above 60	-.907	.794	-.037	-1.142	.254
Education					
No education	4.471	3.712	.040	1.205	.229
Less than high school	-1.480	1.131	-.044	-1.308	.191
High school	-1.315	.654	-.064	-2.010	.045*
Master or PhD degree	2.426	.969	.084	2.505	.012*
Working in medical field					
Yes	3.457	.864	-.125	-4.001	.000***
Marital status					
Single	1.234	1.017	.056	1.214	.225
Divorced/separated	1.450	1.416	.031	1.024	.306
Widow	-.939	1.690	-.017	-.555	.579
Income					
Less than 5000 SR	.538	.963	.020	.559	.576
10,000 to 20,000 SR	1.851	.710	.100	2.607	.009**
More than 20,000 SR	2.791	.837	.131	3.334	.001***
Living with dementia patient					
No	-1.578	.627	-.081	-2.514	.012*
Knowing a person with dementia					
No	-3.563	.603	-.193	-5.911	.000***

***P < .001; **P < .01; *P < .05.

international surveys conducted outside of the Middle East in which nearly half of the participants (median 48.0%, range 39.0%-75.0%, n=12,026) believed dementia was a normal part of ageing [29]. In comparison to other Saudi Arabian geographical areas, the misconception that dementia is a normal aspect of ageing was found to be 44.9% in Jeddah, 86.2% in Medina, and 60.0% in the Aseer region [10-12]. Although this misconception is common across countries [30], its widespread prevalence is concerning because PwD or their families may miss out on the benefits of early intervention. Viewing memory impairment as normal in older people may delay the early detection of Alzheimer's disease and other forms of dementia [31].

We also found that 50.6% of our sample mistakenly believed that a healthy lifestyle was not associated with a decreased risk of developing dementia. This proportion is significantly higher than the 32.4% found in a recent Dutch general population study [6]. In the Middle East, a study with 925 participants in Jazan province, Saudi Arabia, revealed that only 18.0% were aware that high cholesterol raises the risk and 22.4% were aware that high blood pressure raises the risk. Other Saudi Arabian regions (Medina, Aseer, and Mecca) were also found to have an inadequate level of understanding of risk factors [10, 12, 13]. This is also supported by research from other Middle Eastern countries [15, 16]. For example, in a study of 346 Jordanians using the Alzheimer's disease knowledge scale, participants performed the worst in the component related knowledge of risk factors (42.6% correct answer) [15]. It was discovered that 12 modifiable risk factors (i.e., education, hypertension, hearing loss, obesity, depression, smoking, physical inactivity, poor social contact, diabetes, excessive alcohol use, air pollution, and traumatic brain injury) may contribute to the global incidence of dementia [32]. Despite the considerable potential for prevention, past research has revealed that most people are unaware of these risk factors that can lower their risk of dementia [29, 30, 33, 34]. Inadequate knowledge of modifiable risk factors may preclude people from engaging in preventive health behaviors, thus increasing their risk of acquiring the disease.

The mean score for the "communication and behavior" subscale was lower (mean=3.56; SD=2.58; range=0-12) than that of other subscales. Given that dementia affects language, the questions in this subscale focused on communication considerations when dealing with a PwD and the practices to manage such a communication barrier. In a survey conducted in Jeddah, Saudi Arabia, nearly half (47.1%) of the 1698 respondents reported being unprepared to interact with someone who has Alzheimer's disease. Research in other Middle Eastern nations has indicated similarly low levels of knowledge regarding caregiving communication skills [16]. An increasing amount of research indicates that communication challenges between PwD and their caregivers significantly influence their quality of life, care, and dyadic relationships [35]. Health care workers in Saudi Arabia who deal with caregivers of PwD should be aware that caregivers may need training and guidance to meet the specific communication needs of PwD. It has been proven that training in communication skills improves care outcomes and the quality of life of both PwD and their caregivers [36].

Our study, the low dementia knowledge among our participants could have resulted from several causes. First, while the elderly population is expected to grow [37], residents of the community may not have had a lot of interaction with PwD because only 4.4% of the population is over the age of 60, while 70.0% of the population is under the age of 30 [38]. Therefore, it's possible that families did not actively seek information from organizations like of the Alzheimer's Association or healthcare professionals, via the internet, and social media, etc. Second, individuals with cognitive impairment may avoid or not seek learning about dementia due to the social stigma associated with this condition [39]. Unfortunately, no consensus among research studies regarding how best to evaluate stigma associated with dementia [40]. Third, low dementia knowledge among elderly in Saudi Arabia might be related to health literacy given that many Saudi adults over 65 have only completed elementary school [41]. Fourth, while doctors and healthcare professionals have significant potential as public health educators [42], there are a number of factors that may influence this process in Saudi Arabia, particularly in the area of dementia knowledge. One of the factors is the scarcity of geriatric specialists and the limited dementia training available to trainees [43]. This may also result in underdeveloped geriatric services such as nursing homes and home health care [44]. Fifth, In the Middle Eastern world, caring for the elderly is considered a sacred and familial obligation [45]. Because of this, it is considered a betrayal of family and religious obligations to place an elderly PwD in a nursing home or long-term care facility [46]. The problem with this view is that it leads to a lack of policies, programs, and services for older people living with dementia and their families [47], as it assumes families can care for their loved ones with dementia without government assistance and support.

The results of our study indicate that levels of knowledge about dementia varied across socioeconomic groups. Similar to other studies [48-51], we found that people with higher income had a higher level of knowledge about dementia than those with lower income (p<0.050) in all DKAS subscales. Additionally, we found that people with higher education, particularly those who attained a postgraduate degree (β=2.42, p=0.012), had a higher level of knowledge of dementia. This observation aligns with previous studies investigating the public knowledge of dementia [6, 8, 52-54]. Socioeconomic factors strongly predict health results, as shown many times in the scientific literature [55]. Socioeconomically poor people are more likely to have a worse risk profile and to use the health care system less frequently for preventative interventions [56]. This implies targeting them with more focused health education programs.

The current study found that women had more knowledge about dementia than men, consistent with earlier research [8, 51, 57]. This could be because women are more likely than men to actively seek health-related information [58]. Women in Saudi culture are more involved in caregiving than men [59, 60], thus giving more consideration to health problems, such as dementia. We also observed that living with or knowing a PwD was associated with a higher level of knowledge about dementia, consistent with similar studies in different nations [26, 50, 61]. This is likely because individuals are more interested in learning about diseases when they perceive a personal connection.

It is vital to determine the predictors of knowledge about dementia and tailor educational programs that fit the needs of a population. Our study showed that predictors of poor knowledge of dementia are male gender, lower income, lower education, and not knowing or caring for a PwD.

World Health Organization's global action plan on dementia encourages all countries to conduct dementia awareness initiatives [62]. This emphasis reflects that population risk reduction and appropriate dementia treatment depend on the general public's awareness of these factors. Hope for possible treatment may motivate early detection and diagnosis, allowing for future planning and easier access to supportive resources, which has been shown to reduce psychological suffering [63].

Our study is one of very few studies that investigated knowledge about dementia in the general population in Saudi Arabia. Most of the previously published papers examined knowledge among students or health care professionals. Furthermore, this study is the first to translate and internally validate the Arabic version of DKAS. Our study in had certain limitations that may influence the results. Although the study sample was large, it does not represent the Saudi population. Our recruitment strategy might have led to selection bias because of the conventional approach. As we collected data online, adults with higher education and higher digital literacy may be overrepresented. Furthermore, most individuals who participated in this study were from large cities in Saudi Arabia's Eastern Province. Thus, the level of knowledge about dementia might be different in rural areas. Therefore, the results should be interpreted with caution. Moreover, our sample comprised fewer adults above 60 years (15.0%). Additionally, 50.0% of our sample was middle and upper class (income>10,000 SR). Considering that the predominant group was a group of highly educated (bachelor or diploma, 59.0%) and young people (≤60 years, 85.0%), the actual awareness rate of the public could be even lower.

CONCLUSIONS

To the best of our knowledge, this is the first study to assess dementia knowledge in Saudi Arabia's eastern province. Participants in our study had limited knowledge of dementia in general, especially its risk factors and caregiving skills. To address knowledge gaps, educational interventions are required. Future research focusing on knowledge exploration in the elderly will be beneficial in generalizing the findings of our study. Lower socioeconomic subgroups should be prioritized in these efforts due to their lower level of knowledge. Additional research examining the effects of social, cultural, and stigmatization could help in overcoming barriers. Such interventions are likely to improve early detection of dementia and, if present, reduce stigma and negative attitudes. National health programs and policymaking are required to improve the health outcomes of PwD. It is strongly advised to evaluate the psychometric properties of our translated DKAS instrument and compare it to other similar instruments. We also recommend conducting the study on a larger population, using a systematic randomized sampling procedure, using paper pencil surveying for those with low digital literacy, and involving all age groups equally in order to generalize the findings of our study.

Author contributions: FAA, AA, MAS, SNR, KA, ASM, MAA, & DMA: conceptualization; **FAA, AA, KA, MAA, & DMA:** data curation; **FAA & MAS:** investigation; **FAA:** methodology, validation, & writing–original draft; **SNR:** software; & **AA, MAS, SNR, KA, ASM, MAA, DMA, FA, MA, & AA:** writing–review & editing. All authors have agreed with the results and conclusions.

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