

Assessing disease-specific health-related quality of life in patients with stones in the urinary tract (urolithiasis) using the Wisconsin Stone Quality of Life Questionnaire at Groote Schuur Hospital renal stone service

NN Sigasa,  LA Kaestner 

Department of Urology, University Of Cape Town, South Africa

Corresponding author, email: nkasigasa@gmail.com

Purpose: This study aimed to assess the disease-specific health-related quality of life (HRQOL) of patients with urolithiasis using the Wisconsin Stone Quality of Life (WISQOL) questionnaire at the Groote Schuur Hospital (GSH) renal stone service.

Materials and methods: This was a prospective, descriptive study using the validated WISQOL questionnaire. Participants were recruited from the GSH urology department, urology ward, and metabolic stone clinic. The primary objectives were to assess the disease-specific HRQOL of patients with urolithiasis and record their demographic information. Secondary objectives were to record patients' double J (DJ) stent status, body mass index (BMI), and the number of stone procedures.

Results: A total of 100 questionnaires were administered. Participants' median age was 46 years, and 60% were males and 40% were females. The average BMI was 28 kg/m². The median total score on the WISQOL questionnaire was 62/140 points (53–91). The most affected domains were energy, daily function, and psychological health. There was no statistical difference in HRQOL between patients with or without a DJ stent. Of the participants, 66% had a history of urolithiasis, and 88% had one or more urological procedures.

Conclusion: Using the WISQOL questionnaire, we found that patients with urolithiasis have poor HRQOL. The domains mostly affected were energy, daily function, and psychological health. Risk factors contributing towards stone formation in our study were increased BMI, male gender, and age. Understanding the holistic effects of urolithiasis on patients' health can assist in providing more comprehensive patient-centred healthcare.

Keywords: disease-specific health-related quality of life, urolithiasis

Introduction

Globally, there is an increased incidence of stone disease due to population growth and risk factors such as obesity and diabetes. Recurrent kidney stones are associated with a higher incidence of chronic kidney disease and significantly affect patients' quality of life (QOL).^{1,2} In modern healthcare, more attention is given to the effects of diseases on QOL and health-related quality of life (HRQOL) to address and mitigate chronic diseases' effects on patients' mental health, emotional well-being, and social functioning.³ Stone disease is one such chronic disease.³

QOL is a broad, subjective, multidimensional concept, including the evaluation of positive and negative aspects of life by assessing psychosocial, physical, emotional status, and patient autonomy. Health is one of the important domains of overall QOL.⁴ Other domains include employment, housing, and aspects of culture and spirituality.⁴ HRQOL helps to identify how a disease and its treatment impact an individual's perceptions, mental health, and social circumstances. It promotes patient-centred care through consideration of medical outcomes along with the psychosocial implications of the disease and its therapy.^{3,4} Patients with stone disease have long been suspected of having significantly impaired HRQOL. The chronicity of the disease and its management strategies may affect patients' HRQOL.^{2,3,5}

The effects of urolithiasis on patients' QOL have only recently been explored, with studies mainly conducted in the United States

of America and other developed countries. No studies have been done on the African population. Many of these studies used non-specific, generic tools to measure QOL. These studies have consistently reported stone formers to have poor HRQOL compared to the public, with patients experiencing physical symptoms that can disrupt functions of daily living and cause anxiety and low mood.^{3,5-9}

The Wisconsin Stone Quality of Life (WISQOL) questionnaire was developed by Penniston et al.¹⁰ They initially used generic, non-disease-specific tools to assess HRQOL in patients with stone disease and identified the need for a disease-specific tool to assess HRQOL in these patients. They developed the WISQOL questionnaire by conducting interviews and focus groups with stone patients, urologists, and providers to identify important issues and symptoms related to QOL in patients with stone disease.¹¹

A 28-question questionnaire was developed with seven domains. The WISQOL questionnaire has been externally validated, has good internal consistency, and can identify stone-specific decrements in HRQOL identified with other generic HRQOL tools.¹¹ A disease-specific instrument to assess stones' symptomatic and functional impact has never been developed.¹² The WISQOL questionnaire is thus the only such instrument in existence.¹² This study assessed the disease-specific HRQOL in patients with stones in the urinary tract (urolithiasis) in an African country's population using the validated WISQOL questionnaire.

Methods

This prospective descriptive study used the WISQOL questionnaire to assess the disease-specific HRQOL in patients with stones in the urinary tract. An additional, self-designed urolithiasis questionnaire was used to record patients' demographic information and urological history. Ethical approval for the study was obtained from the University of Cape Town Human Research and Ethics Committee (Ref: 2021/273).

Study inclusion criteria:

- Adult patients aged over 18 years.
- Patients willing and able to consent.
- Patients with previous or current confirmed calculi in the urinary tract.

Study exclusion criteria:

- Patients unwilling or unable to consent.
- Patients without a history of calculi in the urinary tract.

Recruitment processes

Figure 1 depicts the recruitment process. The study population were patients treated for urolithiasis at the Groote Schuur Hospital (GSH) Department of Urology. GSH is a tertiary academic government hospital in the Western Cape, South Africa. Patients were recruited from the urology metabolic stone clinic (E26) and the urology ward (F26) from May to December 2023. If patients agreed to participate in the study, they were counselled by an investigator, and informed consent was taken. The patient then completed the WISQOL questionnaire in a private room to ensure confidentiality. The participant completed the questionnaire independently or with assistance from the investigator or a translator if required. The investigator completed the additional self-designed urolithiasis questionnaire using information collected from patients' medical records. The planned care pathway was not affected by patients' participation or refusal to participate in the study.

Primary study objectives:

- Assess the disease-specific HRQOL in patients with stones in the urinary tract using the WISQOL questionnaire.
- Record patients' demographic information.

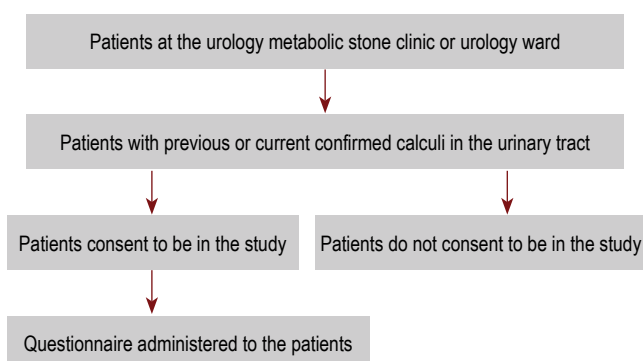


Figure 1: Recruitment process

Secondary study objectives:

- Record patients' double J (DJ) stent status.
- Record patients' BMI.
- Record patients' number of stone-related, in-hospital procedures.

A data-capturing sheet in Excel was used to facilitate the information-gathering process from the questionnaires. An exploratory analysis was done using RStudio with tidyverse and tibble packages. Summaries of the scores from the WISQOL questionnaires were stratified by domain, and overall scores were obtained. Secondary information from the WISQOL and self-designed questionnaires was summarised.

Results

A total of 100 participants consented and completed the WISQOL questionnaire. The participants' demographics are summarised in Table 1. The participants' median age was 46 years, with a majority being male 60% (60/100). The participants' average BMI was 28 kg/m² (range 23–33). At the time of questionnaire completion, 77% of participants (77/100) had proven calculi in the urinary tract, and 13% (13/100) had no calculi but had a history of calculi. Of the study participants, 62% (62/100) were experiencing pain at that moment, and 38% (38/100) had no pain. Moreover, 66% of the participants (66/100) had a history of urolithiasis.

The WISQOL questionnaire consists of 28 questions with a five-point Likert scale for each item, which are grouped into seven domains. The maximum score of 140 is a combination of all 28 questions, with a maximum of five points for each question. A high score correlates with good HRQOL.¹³ In our study, the median total score of the WISQOL questionnaire obtained was 62 points (range 53–91), indicating poor HRQOL. The median scores per domain were: energy 6/15, sleep 10/20, daily function 10/25, health behaviour 9/15, physical symptoms 10/20, sexual function 8/15, and psychological symptoms 12/30 (Figure 2).

A sub-analysis was conducted between patients with and without DJ stents. The total median score on the WISQOL questionnaire for the stented group (64/140) and non-stented group (62/140) was comparable, with no statistical difference ($p > 0.9$). Figure 3 shows the median scores per domain in the stented ($n = 50$) and non-stented ($n = 50$) participants.

Table 1: Participants' demographic information

Characteristics	Value
Number of participants	100
Age (median, range)	46 years (37–56)
Female	40% (40/100)
Male	60% (60/100)
Weight (median, range)	78 kg (66–90)
Height (median, range)	168 cm (160–176)
BMI (median, range)	28 kg/m ² (23–33)
Current urolithiasis	77% (77/100)
Previous urolithiasis	66% (66/100)
Current pain	62% (62/100)

BMI – body mass index

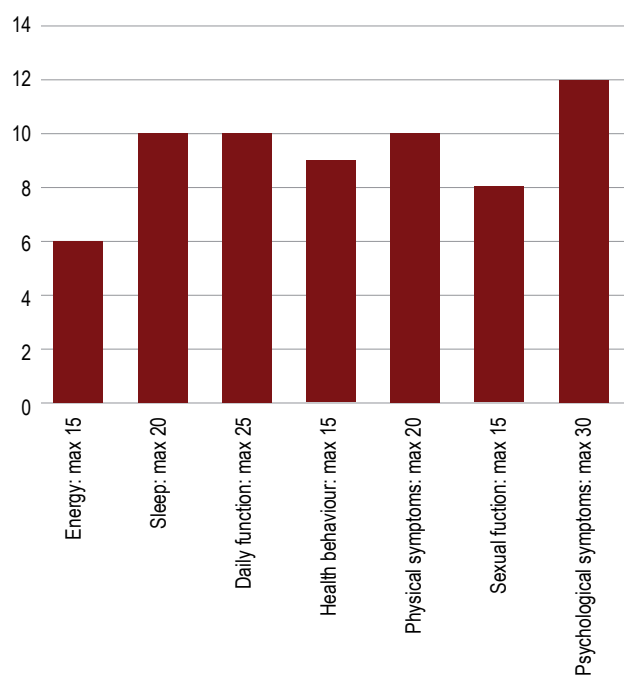


Figure 2: Median points in each domain for all participants
Max – maximum

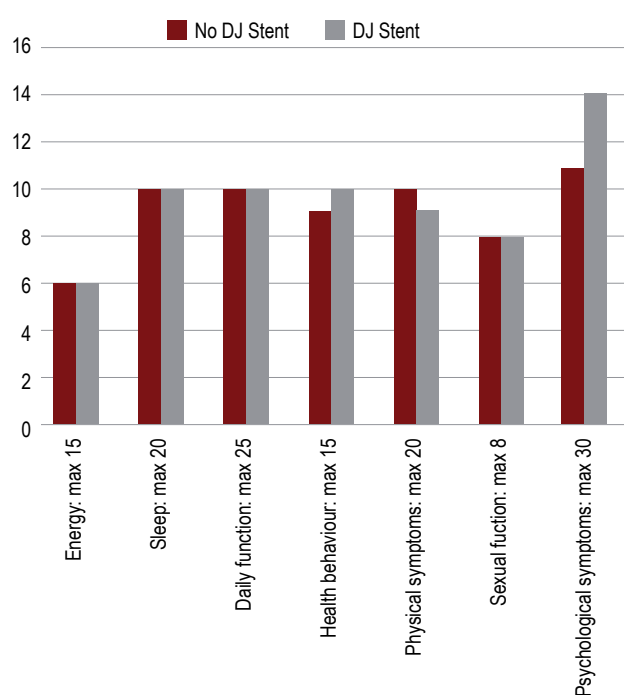


Figure 3: Median points in each domain for all stented ($n = 50$) versus non-stented ($n = 50$) participants
DJ – double J, Max – maximum

Our study found that 88/100 participants (88%) had one or more urological procedures. In total, 97 procedures were performed on these 88 patients. Of the procedures, 51% were DJ stent insertion ($n = 50$). The procedures performed included: 21% ($n = 20$) ureteroscopy (URS) laser, 13% ($n = 13$) percutaneous nephrolithotomy (PCNL), 10% ($n = 9$) extracorporeal shock wave lithotripsy (ESWL), and 5% ($n = 5$) electrokinetic lithotripsy (EKL) (Figure 4).

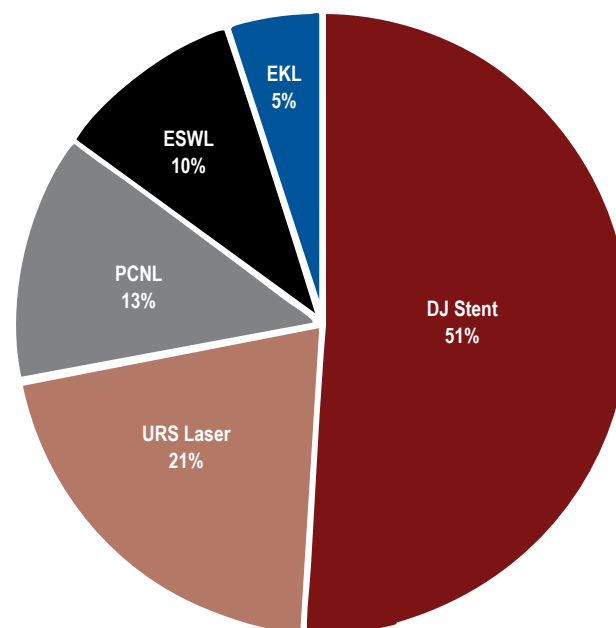


Figure 4: Percentage of all urological procedures done
DJ – double J, EKL – electrokinetic lithotripsy, ESWL – extracorporeal shock wave lithotripsy, PCNL – percutaneous nephrolithotomy, URS – ureteroscopy

Discussion

Globally, there is an increased incidence of stone disease due to more modifiable risk factors, such as a higher BMI, diabetes, and diet changes. Globally, a higher BMI has been associated with stone formation.^{1,2} In a study by Choi et al.,¹² they found that metabolically healthy, obese individuals have a higher risk of developing symptomatic urolithiasis than non-obese, where “obese” or “non-obese” was defined using a BMI cutoff of 25 kg/m².¹³ In our study, a higher BMI was associated with stone disease. The median BMI of the participants was 28 kg/m², classifying them as overweight, consistent with global data. Other risk factors for stone disease include male gender and age.² Again, findings in our study correlate with these facts as 60% of the participants were male, and the average age was 46 years.

Patients with stone disease have long been suspected to have significantly impaired HRQOL and QOL. HRQOL differs from QOL. Although, in some literature, these terms are used interchangeably. In a paper by Karimi et al.,¹³ the authors aim to define these terms and suggest their appropriate use. They define QOL as a conscious cognitive judgment of satisfaction with one’s life and an individual’s perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns.¹⁴ They found that defining HRQOL was problematic, and many definitions could be identified in the literature. They defined HRQOL as how well a person functions in their life and their perceived well-being in physical, mental, and social domains of health.¹⁴ HRQOL focuses on the aspects of QOL affected by health, those aspects of self-perceived well-being related to or affected by the presence of disease or treatment.¹⁴

The chronicity of a disease and its management strategies affect patients’ HRQOL.^{2,3,5} Biological and physiological disease outcomes have been historically assessed in medicine. These measures do

not always correlate with a patient's functional capacity or perception of their own health. Thus, patient-related outcome measures, such as HRQOL questionnaires, are increasingly recognised and useful in treatment-related outcomes.¹⁵ HRQOL questionnaires could be said to measure self-perceived health status.^{14,15}

Before the WISQOL questionnaire, there was no standardised measure for assessing the symptomatic and functional impact of urolithiasis.¹² After conducting substantial research on HRQOL in patients with stone disease, Penniston et al.¹⁰ developed the WISQOL questionnaire. They initially used generic, non-disease-specific tools to assess HRQOL in patients with stone disease. Though their findings were significant, they identified the need for a disease-specific tool to assess HRQOL in patients with stone disease. The WISQOL questionnaire has since been translated into various languages and used in various population types in different countries, except African countries, to assess HRQOL in patients with urolithiasis.

Globally, studies have consistently reported stone formers to have poor HRQOL, with patients experiencing physical symptoms that can disrupt functions of daily living and cause anxiety and low mood.^{3,5-10} This finding is consistent with our study, where 62% of the participants (62/100) were experiencing pain at the time of questionnaire completion. The median total score of the WISQOL questionnaire was 62/140 points (53–91), where a high score correlates with good HRQOL.¹⁰ This score is significantly lower than obtained in a North American study by Assad et al.⁹ They found that patients who were at a higher risk of forming kidney stones, those with underlying anatomical or metabolic disorders (medullary sponge kidney, renal tubular acidosis, malabsorption, and hypertension), had a 98 HRQOL score on the WISQOL questionnaire versus a control group with a score of 109/140 points.¹⁰ These findings could be due to multiple factors, such as limited analgesia options in our practice. In our study, the most affected domains were energy, with a median score of 6/15, daily function, with a median score of 10/25, and psychological health, with a median score of 12/30.

Disease-related factors contributing to HRQOL in patients with stone disease were identified in a study by Bryant et al.⁷ These factors included surgical complications, time from the last stone episode, number of emergency room visits, and number of surgical procedures.⁷ Our study found that disease-related factors might play a role in patients' HRQOL. The identified disease factors possibly contributing to our patients' poor HRQOL are previous episodes of stone disease, as 66% of our participants (66/100) had a history of urolithiasis, and the number of surgical procedures, where 88% of the participants (88/100) underwent one or more urological procedures.

Investigators noted in multiple studies that the number of urethroscopy procedures has a negative impact on a patient's well-being.^{5,11,16,17} Over one-fifth of the procedures participants underwent in our study were URS lasers, where 21% of patients had a URS laser. This finding may contribute to the significantly poor HRQOL of our study's participants. These studies also compared other types of urological procedures. When comparing ESWL and PCNL, they

found that ESWL had no influence on QOL, and patients who had PCNL expressed a surprisingly significant improvement in physical symptom scores.^{5,11,16,17}

Our study further compared HRQOL between patients with and without a DJ stent. To our knowledge, no studies have compared HRQOL in patients with and without a DJ stent. When comparing these two groups, we found no significant differences regarding HRQOL. The total median score on the WISQOL questionnaire for the stented group was 64/140 and 62/140 for the non-stented group ($p > 0.9$). This difference was not statistically significant.

These results are surprising as it is understood that patients with DJ stents experience a range of symptoms thought to cause poor HRQOL. The pathophysiology of stent-related symptoms is not clearly known but is thought to be related to stent length, diameter, material, softness, position, loop integrity, and the stent implantation procedure. These symptoms significantly affect patients' QOL, general health, and work performance in both sexes and seriously affect sexual life.¹⁷ Therefore, one would have thought patients with DJ stents would have dramatically poorer HRQOL than those without them. Further studies are needed to confirm these results and explore facts that might contribute to this finding.

Study limitations

The limitations of our study were a small sample size and the language in which the questionnaires were written. Only 100 questionnaires were completed and analysed. The questionnaire was written in English and not translated into the other two main languages spoken by the patient population at GSH, which are isiXhosa and Afrikaans. To mitigate this potential limitation for patients unable to read English, nursing staff or doctors were used as translators to help the participants understand and answer the questionnaire. Most participants presented acutely to the urology ward or metabolic stone clinic; therefore, it was not possible to gauge whether a stone-free status predicted improved QOL.

Conclusion

Patients with stone disease have long been suspected of having significantly impaired HRQOL and QOL. Many studies have been conducted worldwide to assess this, except in Africa. We conducted the first study of its kind in Africa to assess HRQOL in patients with stone disease using a validated tool, the WISQOL questionnaire. Our study results show that patients with urolithiasis at GSH have poor overall HRQOL across multiple domains. The domains mostly affected are energy, daily function, and psychological health. This study also found no significant difference in HRQOL between stented and non-stented stone patients.

More work is needed to measure HRQOL in patients with stone disease, especially in Africa. Assessing HRQOL helps identify how diseases and treatments impact individuals' perceptions, mental health, and social circumstances. It promotes patient-centred care by considering medical outcomes and the psychosocial implications of the disease and its therapy. Understanding the holistic effects of urolithiasis on patients' health can assist in providing more comprehensive and patient-directed healthcare.

Acknowledgements

Dr Kariema Baulackey and Dr Lauren Viljoen for assistance with the patient questionnaire completion and data capturing.

Conflict of interest

The authors declare no conflict of interest.

Funding source

No funding source to be declared.

Ethical approval

Ethical approval was obtained from the University of Cape Town Human Research and Ethics Committee (Ref: 2021/273).

ORCID

NN Sigasa  <https://orcid.org/0009-0005-4494-9634>

LA Kaestner  <https://orcid.org/0000-0001-7417-735X>

References

1. Sorokin I, Mamoulakis C, Miyazawa K, et al. Epidemiology of stone disease across the world. *World J Urol.* 2017;35(9):1301-20. <https://doi.org/10.1007/s00345-017-2008-6>.
2. Partin AW, Dmochowski RR, Kavoussi LR, Peters CA, Wein AJ, editors. *Campbell-Walsh-Wein urology*. 12th ed. Elsevier; 2020. Available from: <https://shop.elsevier.com/books/campbell-walsh-wein-urology/partin/978-0-323-54642-3>.
3. Sharadin C, Lowry P. Health-related quality of life and urolithiasis. In: Lowry P, Penniston K, editors. *Nutrition therapy for urolithiasis*. Cham: Springer; 2018. p. 17-27. https://doi.org/10.1007/978-3-319-16414-4_2.
4. The WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med.* 1998;46(12):1569-85. [https://doi.org/10.1016/S0277-9536\(98\)00009-4](https://doi.org/10.1016/S0277-9536(98)00009-4).
5. Penniston KL, Nakada SY. Health related quality of life differs between male and female stone formers. *J Urol.* 2007;178(6):2435-40. <https://doi.org/10.1016/j.juro.2007.08.009>.
6. Bensalah K, Tuncel A, Gupta A, et al. Determinants of quality of life for patients with kidney stones. *J Urol.* 2008;179(6):2238-43. <https://doi.org/10.1016/j.juro.2008.01.116>.
7. Bryant M, Angell J, Tu H, et al. Health related quality of life for stone formers. *J Urol.* 2012;188(2):436-40. <https://doi.org/10.1016/j.juro.2012.04.015>.
8. Penniston KL, Sninsky BC, Nakada SY. Preliminary evidence of decreased disease-specific health-related quality of life in asymptomatic stone patients. *J Endourol.* 2016;30(S1):42-5. <https://doi.org/10.1089/end.2016.0074>.
9. Assad A, Raizenne BL, El Mehdi El Yamani M, et al. The impact of kidney stone disease on quality of life in high-risk stone formers. *BJU Int.* 2024;133(5):570-8. <https://doi.org/10.1111/bju.16294>.
10. Penniston KL, Nakada SY. Development of an instrument to assess the health-related quality of life of kidney stone formers. *J Urol.* 2013;189(3):921-30. <https://doi.org/10.1016/j.juro.2012.08.247>.
11. Penniston KL, Antonelli JA, Viprakasit DP, et al. Validation and reliability of the Wisconsin Stone Quality of Life Questionnaire. *J Urol.* 2017;197(5):1280-8. <https://doi.org/10.1016/j.juro.2016.11.097>.
12. Choi C, Kim JK, Han K, Lee YG, Han JH. Effect of obesity and metabolic health on urolithiasis: a nationwide population-based study. *Investig Clin Urol.* 2021;63(1):63-70. <https://doi.org/10.4111/icu.20210332>.
13. Karimi M, Brazier J. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics.* 2016;34(7):645-9. <https://doi.org/10.1007/s40273-016-0389-9>.
14. Deem S, DeFate B, Modak A, et al. Percutaneous nephrolithotomy versus extracorporeal shock wave lithotripsy for moderate sized kidney stones. *Urology.* 2011;78(4):739-43. <https://doi.org/10.1016/j.urol.2011.04.010>.
15. Rabah DM, AlOmar M, Binsaleh S, Arafa MA. Health related quality of life in ureteral stone patients: post-ureterolithiasis. *Urol Res.* 2011;39(5):385-8. <https://doi.org/10.1007/s00240-011-0375-9>.
16. Diniz DHMP, Blay SL, Schor N. Anxiety and depression symptoms in recurrent painful renal lithiasis colic. *Braz J Med Biol Res.* 2007;40(7):949-55. <https://doi.org/10.1590/S0100-879X2007000700009>.
17. Camtosun A, Bicer S. The impact of double J stent on the quality of sexual life and job performance. *Clin Exp Obstet Gynecol.* 2020;47(2):199-201. <https://doi.org/10.31083/j.ceog.2020.02.5064>.