Experiences of families of men with prostate cancer on supportive care received from nurses



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Scan this QR code with your smart phone or mobile device to read online. **Background:** Family members of men diagnosed with prostate cancer (PCa) experience a range of supportive care needs. Literature indicated inconsistent supportive care from nurses to families of men diagnosed with PCa.

Aim: Exploring and describing the experiences of family members of men diagnosed with PCa on the supportive care received from nurses.

Setting: The study was conducted in the oncology departments of the Intermediate Hospital Oshakati.

Methods: Qualitative, exploratory, descriptive, phenomenological and contextual designs were adopted. A sample of seven family members of men diagnosed with PCa was selected using a non-probability purposive sampling technique. Individual face-to-face interviews were conducted. Interview guide and field notes were used to collect data. All interviews were recorded with an audio recorder and transcribed verbatim. Content analysis using Tesch's eight steps of open coding was adopted to analyse data. Criteria for establishing trustworthiness of the data were used. Fundamental ethical principles were adhered to.

Results: The study revealed lack of family involvement in treatment and decision-making. Two themes emerged: (1) feeling of being devalued in the healthcare system, and (2) non-conducive environment for counselling men.

Conclusion: It became evident that family members of men diagnosed with PCa are rarely considered in clinical practice. Recommendations are made in terms of policy formulation, organisational changes in the hospital protocols and staff training.

Contribution: The study proposed the introduction of national policy on supportive care of men with PCa and an inclusion of their families during treatment and decision-making.

Keywords: experiences; family; men; supportive care; prostate cancer; nurses.

Introduction

Supportive care refers to the services beyond treatment that assist an individual with cancer and their family to cope with the disease as of pre-diagnosis, through the course of diagnosis and treatment to cure, palliative care, and bereavement care.¹ Supportive care delivery is multidimensional and entails several health disciplines and people working in numerous organisations.² Prostate cancer (PCa) is among the main contributors to the acceleration in cancer incidence, making it to be ranked as the second most common cancer among men. Globally, 32.5 million people are living with cancer, 14.2 million are lately diagnosed and 8.1 million deaths.³ Although developing countries account for less than 30% of all PCa cases, they have the highest estimated mortalities from the disease.⁴ In 2020, PCa was reported as the most common cancer type in sub-Sahara Africa (SSA), which accounted for 77 300 cases, followed by liver cancer (24 400 cases) and colorectal cancer (23400 cases).⁵ The disease is among the most leading cause of premature deaths in African men, responsible for one in seven premature deaths overall and one in four deaths from non-communicable diseases. Annually, SSA reports more deaths per capita (15-27 vs. 7.7 per 100000) in comparison with North America.⁶ According to Morhason-Bello et al.,⁷ the burden of PCa in SSA might be underrated because of poor access to care, lack of proper diagnosis, inadequate infrastructure, insufficient specialised personnel and the poor quality of cancer data registries in Africa compared with those in advanced countries.

In Namibia, the disease is amid the top five of cancer incidences mostly affecting men psychologically.⁸ In the Intermediate Hospital Oshakati, PCa remains on the increase, with 95 new cases and 13 deaths recorded in 2017, 87 new cases and 11 deaths in 2018, 98 new cases and

16 deaths in 2019, 79 new cases and nine deaths in 2020, and 92 new cases and 12 deaths in 2021.9 A study by Salomo et al.¹⁰ on experiences of men diagnosed with PCa in the four northern regions of Namibia, revealed lack of supportive care to family members of men diagnosed with the disease. Literature has it that as with any serious disease, PCa affects the whole family, mostly spouses.11 The sexuality-associated side effects of PCa treatment impact intimate relationships and boost the anxiety of coping with a loved one's disease, therefore resulting in major quality of life distress that requires supportive care to family members. King et al.¹² emphasised that the consequence of psychological distress that most family members of men with PCa encounter and that may need supportive care, is not constantly assessed or monitored appropriately. Similarly, Sinfield et al.¹³ stressed that family members of men with PCa should be educated about the sources of supportive care as to allow coping with the social and psychological distress associated with the disease and its treatment.

In Namibia, nurses serve as advocates for men diagnosed with PCa and their families by representing their health needs to other members of multidisciplinary team (MDT). Similarly, nurses assist men to make informed decisions about treatment by availing them with health information regarding the diagnosis and the outcome of the diagnostic tests. Other members of the MDT in Namibia include: medical doctors, dieticians, physiotherapists, social workers, pathologists, pharmacists, radiographers, urologists, chaplains and psychologists. Adopting MDT approach enables a greater chance of providing supportive care to men in line with clinical guidelines, reduction in timeframe from diagnosis to treatment and care, and increased survival of men with PCa. Similarly, MDT enables continuity of holistic care to ensure that men diagnosed with PCa receive timely support and treatment from diverse and experienced professionals.5

Despite the magnitude of PCa in Namibia, the country has no existing guidelines or policies to facilitate supportive care to family members of men with the disease. Therefore, although obtaining informed consent from patients and family to conduct treatment and breaking bad news are not the main tasks of the nursing staff, in Namibia these roles are commonly being carried out by nurses in consultation with medical doctors because of lack of clear specifications in the guiding tool in terms of roles. To the contrary, King et al.¹² emphasised that it is imperative for nurses involved with the care provision to men diagnosed with PCa to extend supportive care to family members of those diagnosed with the disease. The purpose of this study was to explore and describe the experiences of family members of men diagnosed with PCa on the supportive care received from nurses to identify the dynamics to supportive care in health facilities.

Problem statement

Prostate cancer remains one of the five top male cancers in Namibia; however, the country has no guidelines or model to facilitate supportive care for family members of men living with the disease.⁹ During 2010–2014, Oshana region documented the topmost incidences of PCa in Namibia with 32.2%, followed by Khomas with 31.4%.⁸ The Patient Charter of Namibia, as a guiding tool, emphasised the support of patients with chronic diseases; however, the document did not stipulate the types of supportive care to be provided by nurses to family members of men diagnosed with PCa in health facilities. In Oshana region, the non-governmental organisations (NGOs) have played a limited role in supporting men diagnosed with PCa despite the disease causing the bulk of morbidity and mortality in the region. In most instances, support has been vertical, focussing on specific diseases such as tuberculosis but not seen improving the general healthcare system.

Through clinical encounters with family members of men diagnosed with PCa at oncology departments of Intermediate Hospital Oshakati, as a registered nurse, the researcher observed with concern that family members of men diagnosed with PCa are hardly being provided with supportive care to deal with the long-term effects of the disease of their loved ones. Frequently, family members report lack of information, and that their social and psychological supportive care needs are neither recognised nor taken care of. Equally, family members divulge thoughts about the likelihoods of survival for their loved ones which often leave them psychologically affected, hence the necessity for supportive care. Literature reveals that 79% of family members of men diagnosed with PCa experienced unmet supportive care needs such as sexual and psychological.14 Hinkle and Cheever¹ stressed that partners of men diagnosed with PCa frequently report higher degrees of distress than men. Frequently, family members express feelings of doubt about the future and frustrations of not knowing what to anticipate as PCa advanced. The aforesaid background triggered the research question, 'What are the experiences of family members of men diagnosed with PCa on the supportive care they receive from nurses after their family members were diagnosed with the disease?'

Purpose of the study

The purpose of this study was to explore and describe the experiences of family members of men diagnosed with PCa on the supportive care received from nurses to identify the dynamics to supportive care in health facilities.

Paradigmatic perspective

This study comprised of a paradigm with a set of philosophical assumptions that influenced the logic of the study, namely; meta-theoretical assumptions (ontological, epistemological and axiological), as well as methodological and rhetorical assumptions.¹⁵ The significance of a paradigm in this study is that it dictates the conduct of research in a field of inquiry, influences the identification of a researchable problem, best suitable methods, appropriate techniques by which data is collected, questions to be asked and how these questions should be asked.¹⁶ Equally, the paradigm mounted the

approach in which the subject concerns were observed and the route that the research project undertook.¹⁷

Methods

A qualitative research design was adopted as it allows the researcher to explore the complexity and abundance, inherent in the phenomena namely the experiences of family members of men diagnosed with PCa on supportive care received from nurses in health facilities. Phenomenological, exploratory, descriptive and contextual designs were used to explore and describe family members' perceptions.¹⁸ Phenomenological design enabled the description of a phenomenon of everyday experience, permitting the researcher to comprehend the meaning of the experiences on supportive care from nurses as lived by family members.¹⁷ Exploratory design enabled the researcher to explore the experiences of family members on supportive care received from nurses in health facilities. The descriptive portion of this study embraced a rich narrative of men in this situation.¹⁹

Population and sampling

The population of this study is made up of family members of men diagnosed with PCa. A non-probability purposive sampling technique was adopted.¹⁵ Seven participants were purposively sampled based on inclusion criteria. Data saturation was reached in the sample population.¹⁸

The following inclusion criteria were applied during sampling:

- A participant should have been a family member of a man between 60 and 90 years of age diagnosed with PCa stage 1 to stage 2 and who is still receiving treatment at the Intermediate Hospital Oshakati.
- Participation had to be on voluntary basis.

Data collection

Data were collected using in-depth individual face-to-face interviews, interview guide, field notes, and a tape recorder.²⁰ The researcher opted for in-depth individual face-to-face interviews because of their potential to produce rich data about the experiences of family members of men diagnosed with PCa on supportive care received from nurses in health facilities.¹⁹ By using an interview guide, the following central question was posed to participants, 'Tell me about your experiences on supportive care received from nurses in health facilities after your family member was diagnosed with prostate cancer'. The researcher took field notes to capture non-verbal aspects from participants during the interviews such as eye contact, gestures, postures, and tone of voice.21 Both verbal and non-verbal communication techniques were applied during the interview to encourage participants to articulate their experiences about the supportive care received from nurses. When responses entail inadequate information, complexity or accuracy, the researcher probed for more precision of the responses as recommended by Botma et al.22 who emphasised that the

value of the interview is being determined mainly by the competence of the researcher as a correspondent. All interviews were audio-recorded, with participants' consent, to guarantee that all data were transcribed verbatim as participants articulated their opinions.¹⁵ The process of data collection continued till saturation of data was attained. Each interview lasted approximately 35–45 min. All interviews were conducted with consents from participants.

Data analysis

Interview transcripts were analysed using the Tesch's eight steps of coding process.17 Themes were obtained inductively from the data by reading and re-reading the interview narratives and thereby gaining an understanding of family members' lived experiences through their words. Transcripts were coded iteratively with constant comparison between the codes generated and the data to confirm that consistent and diverging responses were incorporated. An independent coder went through the transcribed interviews in which the fragments that were coded by the researcher were highlighted. Conducting intercoder reliability test facilitated to assess if two coders can apply identical codes to similar transcript fragments.¹⁶ Differentially coded fragments were discussed between the researcher and the independent coder in consultation with the data, and consensus was reached across all aspects with regards to the identified themes and subthemes. Measures to ensure trustworthiness of the data were considered as discussed in the following section.¹⁹

Measures to ensure trustworthiness of the data

The study adopted the criteria for establishing the trustworthiness of qualitative data, namely, credibility, dependability, confirmability, transferability and authenticity.¹⁹ Credibility was ensured by prolonged engagement with participants and creating rapport before the interviews commenced.17 Credibility of the data was validated through debriefing, discussions and rerunning the tape with participants for them to confirm the accurateness of the themes and subthemes.¹⁹ The interviews were transcribed instantly after data collection took place to reduce the risk of misinterpretation. Comprehensive transcripts of the interviews were provided. The findings of the study were reviewed by an external auditor who examined whether the findings, interpretation and conclusions were supported by the data.21 To ensure dependability, an interview guide was initially piloted to ascertain whether participants understood the questions and that the questions elicited appropriate discussions. Interviews were tape-recorded. The process and procedures used by the researcher for data analysis were verified by the external auditor to establish their applicability.15 Rigorous review of interview transcripts was done to ensure confirmability. Transferability was ensured through thick description of the methodology, use of purposive sampling and by linking the study findings to similar findings of research studies conducted in Africa and beyond.¹⁸ With regards to authenticity, interviews were tape-recorded to capture participants' experiences. Similarly, the report of the study contains the direct excerpts

from the participants portraying the lived experiences of supportive care received from nurses.

Ethical considerations

Approval to conduct the study was acquired from the Center for Postgraduate Studies of the University of Namibia. An ethical clearance certificate (Ref no: SoN/462/2019) was issued by the Research Ethics Committee (UREC) of the University of Namibia. Additional approval to conduct the study (Ref no. 17/3/3 SS) was issued by the Ministry of Health Social Services. Written informed consent was obtained from each of the participants after the purpose of the study was clarified to them. The following research fundamental ethical principles of the World Medical Association (WMA) guided the study as stipulated in the Declaration of Helsinki,15 namely, respect for persons, beneficence and justice. Anonymity was upheld by coding the data in a way that participants could not be identified in any presentation of the study findings. No participant was compelled or coerced to take part in the study.

Results

Seven family members of men between the age of 60 years and 90 years diagnosed with PCa stage 1 to stage 2 and who are still receiving treatment at the Intermediate Hospital Oshakati were interviewed, namely, four spouses between ages 46 years to 57 years, two sons of 33 years and 44 years of age, and a daughter of 40 years of age. Through data analysis, the following two themes were identified: (1) a feeling of being devalued in the healthcare system and (2) nonconducive environment for counselling men. Table 1 forms the basis for discussion of the themes and subthemes discovered by data analysis.

Theme 1: Feeling of being devalued in the healthcare system

This theme emerged after most family members (n-5) expressed lack of family involvement in treatment and decision-making, as well as lack of psychological supportive care from nurses. In this study, devalue implies giving a lower worth to a person by making him or her less valuable that he or she is'.²³ The following sub-themes were identified under the theme 'feeling of being devalued in the healthcare system'.

Subtheme 1.1: Lack of family involvement in treatment and decision-making

Family members of men diagnosed with PCa expressed a lack of family involvement in treatment and decision-

TABLE 1: Themes and subthemes of the experiences of family on the supportive care received from nurses in health facilities.

Themes	Subthemes
Theme 1: Feeling of being devalued in the healthcare system	 Lack of family involvement in treatment and decision-making Lack of psychological supportive care from nurses to families Lack of spiritual support for family
Theme 2: Non-conducive environment for counselling men	Lack of privacy

'No, they did not involve us ... [*shaking her head*]. My father came here three times from the day he was diagnosed but none of the nurse cared to call a family member.' (P1, female, 31 years old)

'You only see them treating your patient without even talking to you. Is that how it should be? Otherwise, why should we keep on coming here? Just to sit or what ... [pointing to the chairs].' (P3, female, 33 years old)

'Prostate cancer was not explained to us as a family. I expected nurses to add more health information for me to know how to take care of him. This was not done.' (P4, female, 67 years old)

'The presence as family members seems not to be valued here. Most of the time, nurses are only talking to patients while ignoring family members. Is it not us who take care of cancer patients at home? They must change ... [*shaking her head*].' (P7, female, 40 years old)

The researcher found it evident from the findings that nurses do not actively involve family members of men diagnosed with PCa when delivering health information and therefore resulted in most family members to feel undervalued and considered as less significant in the healthcare system. Similarly, the negative experiences expressed by family members reflect the healthcare delivery systems that do not consider the informational needs of family members of men diagnosed with cancer.

When asked about family involvement in treatment and decision-making by nurses at the oncology department, this is what some participants had to say:

'No, you only go there and visit your patient and came out of the ward without being informed of anything about your patient's condition.' (P4, female, 67 years old)

'They did not give me any health information on how we should take care of him at home [*shaking his head*].' (P5, male, 44 years old)

'I need to be informed as to the time medicines should be taken, and what time he should eat. That was not done.' (P4, female, 67 years old)

Some participants recommended the following regarding family involvement:

'Nurses should train us on how to take care of these pipes at home as family members. They should also tell us to clean them.' (P5, male, 44 years old)

'I am urging nurses to give us health information as families. They should inform us how patients with prostate cancer should be handled.' (P5, male, 44 years old)

Subtheme 1.2: Lack of psychological supportive care from nurses to family

Family members of men diagnosed with PCa expressed a lack of psychological support from nurses. This is evidenced by the following quotes from participants:

'As his wife, I never got counselling. At least I should be informed of things that I should do and those that I should not do. I need to be well informed.' (P6, male, 42 years old) 'Most of the time nurses only give health information after being asked. They are failing to give us health information as families.' (P5, male, 44 years old)

When asked to describe the psychological support they receive from nurses in oncology departments, this is what some family members had to say:

'I did not receive any counselling regarding my father's condition.' (P1, female, 31 years old)

'No, I was never counselled. Counselling was never given to me. Never!' (P3, female, 33 years old)

'No, I have not yet been counselled. Maybe they are still to do it. Yes, one really needs to be counselled.' (P6, male, 42 years old)

Subtheme 1.3: Lack of spiritual support to family

Family members in this study expressed lack of spiritual support after the diagnosis of PCa to their loved ones. This is evidenced by the following quotes:

'I heard there is a pastor in the hospital for patients only. As a family, we are not spiritually supported in the hospital. Nothing!' (P6, male, 42 years old)

Other family members had this to say:

'As a family, we never come across any spiritual support. Maybe it is being given to the patients only.' (P4, female, 67 years old)

'Pastors only pray for the patients but not for their families. Never!' (P6, male, 42 years old) $\,$

Theme 2: Non-conducive environment for counselling men

Most family members raised a concern that congested and dilapidated structures make it difficult for counselling men. Family members also revealed their shocking experiences of seeing men being counselled in overcrowded and noisy rooms. The following subtheme was identified during the data analysis:

Subtheme 2.1: Lack of privacy

Family members who participated in this study revealed numerous experiences of lack of privacy in oncology departments. This was evidenced by the following accounts:

'I think the consulting room is not appropriate for counselling. I do not see any other better room specifically for counselling here.' (P5, male, 44 years old)

'Rooms should at least reflect the hospital setting. There is no privacy here.' (P5, male, 44 years old)

This is what some family members had to say when asked to describe their experiences of oncology departments in terms of counselling men:

'The rooms are not conducive for counselling. Most of the windows are broken and some are not even closing.' (P7, female, 40 years old)

'Cancer department should be on its own. Just listen to these noises ... [*pointing to the patient's room*]. Just listen ... [*shaking his head*].' (P1, female, 31 years old)

In support of the above quotes, some family members had the following to say:

'The rooms are so overcrowded with patients. How can a nurse discuss a private issue with a patient in such a situation?' (P8, female, 47 years old)

'Patients' beds are too close to each other. How do you engage a patient in a private conversation?' (P1, female, 31 years old)

'Keep rooms for a specific patient and relatives only, but not a lot of people. Where is privacy?' (P1, female, 31 years old)

Discussion

In this study, family members were asked to describe their experiences on the supportive care received from nurses in health facilities after their family members were diagnosed with PCa. The findings revealed lack of family involvement in treatment and decision-making by nurses in oncology departments. Røen et al.²⁴ concur with these findings because in their study on supporting family members of cancer patients, family members were reported to be less satisfied with the coordination of care and involvement of family in treatment and decision-making. Bowen²⁵ emphasised that effective shared decision-making in PCa insists clinicians to efficiently engage and inform both patients and family members about the anticipated treatment alternatives. Hinkle and Cheever¹ underscored that it is an obligation of all nurses working in cancer care to involve the patient and their families as fully as possible in the process of clinical care and decision-making.

Participants of this study expressed experiences of being devalued in the healthcare system. The study by Wang et al.²⁶ about unmet care needs of advanced cancer patients and their informal caregivers revealed that the disease-related information needs were the highest reported unmet needs of family members. In this study, participants reported lack of clarifications of information provided by nurses, and that most information received was too general, vague and often confusing. Literature has it that ambiguous or unclear health information regarding cancer and its treatment is constantly emphasised in most research with cancer patients and family.11 Hinkle and Cheever1 cautioned that poor communication with cancer patients and family is associated mostly with psychological distress and lower satisfaction of healthcare. The result of this study revealed that family support was hampered by a lack of education and by healthcare systems being tailored to the patients and not to the family. Most family members felt entirely left out and uninformed about choices regarding the treatment and care of their loved ones. The above sentiments agree with the findings of a study by Lavallee et al.27 about cancer patients' family members' experiences of the information and support provided by healthcare professionals which revealed that most participants valued online platforms as the most significant source of cancer-related information and support than healthcare specialists. A study by Wang et al.²⁶ about the unmet care needs of advanced cancer patients and their informal caregivers, discovered strong feelings among members of the family that they ought to be considered as

credible by healthcare professionals and treated based on their needs as family members of cancer patients. Literature stressed that providing health information to patients and members of the family is a legal, moral and professional obligation of all nurses.¹

When asked to describe the psychological support they receive from nurses in oncology departments, most participants expressed lack of psychological supportive care from nurses to families. Most participants expressed that they rarely get psychological support tailored to family members' psychological needs. The above experiences are being supported by literature that stressed that negative family experiences can reflect healthcare delivery systems that do not consider family needs.²⁷ This is in line with a review of the psychological adjustment of female partners of men with PCa by Chambers²⁸ which established that partners report more distress than do men themselves. Krumwiede and Krumwiede14 stressed that the psychological support provided for the people adjacent to men diagnosed with PCa is very fundamental, particularly at the time of receiving a cancer diagnosis and undertaking treatment. To the contrary, a study by Solberg et al.29 about experiences of family members as caregivers during cancer trajectory revealed that the psychological support needs of family members regarding their own emotional distress are often overlooked and ignored during healthcare planning. Literature emphasised that the psychological support from the relevant qualified health personnel is critical as it enables patients and families to cope with psychological and emotional stress of cancer.³⁰

One of the experiences expressed by participants in this study was lack of spiritual support for family members of men diagnosed with PCa. In contrast with the previous findings, a study conducted in the United States revealed that several cancer patients and their families, even when not religious, feel it is appropriate for physicians and other members of the health team to enquire about their spirituality.⁵ The study suggested that the patient's and family's spiritual needs should be met by creating an empathic connection with patients and their families, by engaging with them in spiritual discussions and introducing them to members of a spiritual team, when accessible. Literature stressed that spiritual assessment is a key element of comprehensive nursing assessment for critically ill patients and their families.^{31,32}

When asked to describe their experiences in terms of counselling men diagnosed with PCa, most participants in this study revealed various experiences of lack of privacy in oncology departments. These experiences agree with the findings of a study by Chan³³ that revealed overcrowded ward environment whereby patients' beds were so close to each other to an extent that their discussions with nurses were visibly overheard by their neighbours.

Limitations of the study

This study was restricted to family members of men diagnosed with PCa. The use of purposive sampling signifies that the

findings are contextual and therefore cannot be representative of all family members of men diagnosed with PCa in Namibia. The study was conducted in oncology departments of a single public hospital only. However, the findings of this study will be beneficial for references and future research.

Conclusion

This study explored and described the experiences of family members of men diagnosed with PCa on the supportive care received from nurses at oncology departments. The findings reveal that family members felt devalued by the healthcare system owing to a lack of family involvement in treatment and decision-making. The study established that lack of privacy in oncology departments could deter patients from engaging in private conversations with nurses and family members alike.

Recommendations

Recommendations are made in terms of policies formulation, organisational changes in the hospital protocols and staff training. There is a need for management to develop an educational and psychological interventions policy to assist men with PCa and their families in coping with the diagnosis and treatment. To ensure effective implementation of the policy, all nurses and other members of the MDT should be oriented to the content of the policy through in-service trainings and the induction of the newly recruited staff. Similarly, the policy should prioritise PCa cancer advocacy and consider PCa cancer as among high priority in the hospital. There is a need for the Patient Charter of Namibia to be revised to specify the roles of nurses on supporting cancer patients in terms of patients and family involvement in decision-making and treatment.

With regards to organisational changes in the hospital protocols, the hospital should consider the establishment of an accredited and well-resourced oncology unit, characterised by specialisation and multidisciplinary collaboration for the effective facilitation of supportive care to men diagnosed with PCa and their families. Interested local organisations could partner with the hospital in this regard. The accreditation should be solely centred on the structure of the facility, the quality of health services the facility offers and the capability of workforce. On staff training, the hospital management should consider liaising with local accredited health training institutions to consider the introduction of a postgraduate oncology nursing course as a specialty to prepare nurses to provide quality supportive care to men with PCa and their families across the cancer trajectory.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

S.S. is the original author. He collected the data, conducted data analysis and wrote the whole draft of the manuscript. H.J.A. made immense contribution on methodologies and interpretation of the results. A.P.K.S. cleaned and refined the final draft.

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Data availability

The data set is obtainable from the main author, S.S., upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors, and the publisher.

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