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Exploring traditional and complementary medicine use by Indigenous Australian women undergoing gynaecological cancer investigations

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ABSTRACT

Background: Indigenous Australian women experience worse gynaecological cancer outcomes than non-Indigenous women. While traditional and complementary medicine (T&CM) is increasingly used by cancer patients alongside conventional treatments, little is known about T&CM use by Indigenous women. This study aimed to explore the beliefs, attitudes and experiences related to T&CM use and disclosure among Indigenous women undergoing gynaecological cancer investigations.

Methods: A mixed-methods design explored T&CM use among Indigenous women who presented for gynaecological cancer investigation at an urban Queensland hospital (September 2016 and January 2018).

Results: Fourteen women participated. The reported use (86%) and perceived value of T&CM was high among the participants, however, women reported major challenges in communicating with healthcare providers about T&CM, commonly associated with trust and rapport.

Conclusions: These findings highlight the need for strategies to facilitate culturally-appropriate doctor-patient communication around T&CM to foster trust and transparency in gynaecological cancer care for Indigenous women.

1. Introduction

Aboriginal and Torres Strait Islander women (respectfully referred herein as Indigenous women) are more likely to be diagnosed with gynaecological cancer compared to non-Indigenous women [1]. Specifically, Indigenous women are 2.5 times as likely to be diagnosed with cervical cancer, 1.8 times as likely to be diagnosed with uterine cancer and 1.4 times as likely to be diagnosed with ovarian cancer than non-Indigenous women [1]. Furthermore, Indigenous women were 3.8 times more likely to die from cervical cancer, 0.9 times as likely to die from ovarian cancer, and 2.2 times as likely to die from uterine cancer as non-Indigenous women [1].

These inequities in cancer outcomes are largely attributed to being diagnosed later, receiving less treatment [2–4] and challenges Indigenous Australians face in accessing equitable health care [5,6]. In order to identify the mechanisms through which these inequities occur, there remains a need for a more nuanced understanding of the experiences of Indigenous Australians with cancer, particularly around the point of diagnosis.

The use of traditional and complementary medicine (T&CM) alongside conventional cancer treatments, such as chemotherapy and radiotherapy, has increased among cancer patients in recent years [7,8]. A study of women in Victoria, Australia diagnosed with gynaecological cancer found 30% of the 52 women attending hospital for their cancer treatment self-reported T&CM use [9]. A Queensland study of Indigenous people diagnosed with cancer in the last five years and attending public hospitals for treatment, included 18 women diagnosed with a gynaecological cancers and 14% of these women reported using Traditional Indigenous therapy, 4% complementary medicine, and 17% used a complementary medicine practitioner [10]. T&CM use is important to Indigenous cancer patients, due to the perceived spiritual, emotional and cultural benefits [11].

T&CM includes a broad range of practices, technologies, products (including topical and ingested), knowledge systems and approaches for

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preventing or treating illness and promoting wellbeing that are either indigenous to the local culture (traditional) or exotic to the culture of users (complementary) and not historically associated with conventional medicine [12–14]. The holistic approach to healthcare that is characteristic of T&CM may appeal to Indigenous Australians [15] who traditionally view health as encompassing the spiritual, emotional, cultural and physical aspects of health and wellbeing [11,15,16]. This understanding of health extends beyond the physical to a whole of person approach, and beyond the individual to encompass their family, community and environment [11,15,16]. While there are benefits to the use of T&CM [17], there are also risks associated with its use alongside conventional medical treatments [18], including variability in product information and quality; the potential for missed diagnoses and delayed guideline-concordant treatment; and economic risks associated with over-prescribing or costly diagnostic tests. Due to the unorthodoxy of T&CM, patients may be fearful of disclosing usage with their healthcare professionals which may have a negative impact on their conventional treatment. These issues underscore the importance of understanding cancer patients' decision-making around T&CM use and disclosure is vital.

To date, no studies have comprehensively investigated the use of T&CM or issues around disclosure of T&CM use by Australian Indigenous women newly diagnosed with, or being investigated for, gynecological cancer. Considering the possible use of T&CM among this group and the potential for risk, we aimed to investigate these issues using a mixed-methods study design.

2. Methods

2.1. Study design and participants

We used a sequential explanatory mixed-methods design to conduct face-to-face quantitative questionnaire (phase 1) and in-depth interviews (phase 2) [19]. All Indigenous Australian women who were referred to the participating hospital cancer clinic for diagnostic investigations of suspected gynaecological cancer between September 2016 and January 2018 (n = 18) were approached by hospital staff for inclusion in the study. The study clinic is a specialist gynaecology cancer clinic located in a major urban setting and attached to a large public hospital. Women from across the state are referred to this clinic, thus attendance requires travel for those living outside this area.

We anticipated that we would recruit between 15 and 25 Indigenous women from the specialist gynaecological cancer clinic for this study. This was based on our previous experience; among a larger sample of 248 Indigenous people who had been diagnosed with cancer and were recruited over a two-year period of which 18 women with gynaecological cancer were included. Even though the current study (n = 18) included only one centre and a shorter study period, we had support from the centre staff to assist in identifying, approaching and inviting all Indigenous women attending the clinic to participate.

2.2. Data collection

Phase 1: face-to-face interviews were conducted to collect participant responses to the R-I-CAM-Q [20], a quantitative survey of T&CM use that has been validated for the Australian population, although not specifically for Indigenous Australians or people diagnosed with cancer. This questionnaire included questions on participants use of T&CM in the past 12 months for 10 specific T&CM therapies: four traditional and complementary medicine services (e.g. naturopath), three products (e.g. herbal remedies), and three self-help practices (e.g. aromatherapy). In addition, participants were asked if they initiated T&CM use due to their cancer diagnosis (yes/no) and whether they had chosen to disclose their T&CM use to their healthcare practitioners (yes/no) and, if yes, to whom (general practitioner (GP), oncologist, nurse, Indigenous Liaison Officer (ILO), other, or none).

Phase 2: In-depth semi-structured interviews were conducted to elicit rich accounts of the women's subjective experiences of T&CM use during their cancer investigations and diagnosis and the challenges they faced in communicating their T&CM use with their healthcare practitioners. The interview schedule was informed by Phase 1 and the participant responses, and included three broad topic areas: reasons for non-use; communication with health professionals about T&CM use, and; personal experiences of using T&CM. These topics were used to prompt discussion and help the interviewer facilitate in-depth accounts of the participants' experiences. The interviews mostly occurred at the hospital when the women returned for their follow-up appointments.

Both the Phase 1 and Phase 2 interviews were conducted by an experienced female Indigenous interviewer, who is a cancer survivor and has a nursing background. There were no prior relationships between the interviewer and the women who participated in this study.

Socio-demographic data: During the initial face-to-face interview, participants were asked to self-report socio-demographic information which was recorded by the interviewer on a standardised data collection form. Information included: indigeneity (Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander), age, marital status, employment status, main language spoken at home, number of dependent children, and postcode of residence.

Clinical data: Clinical information was obtained by a clinical nurse from medical charts using a standardised template. Charts were reviewed approximately 6–9 months after the initial interview to confirm and ascertain information regarding the participants' cancer diagnosis, date of diagnosis, gynaecological cancer type, and comorbidities (presence/absence of diabetes, hypertension, cardiovascular disease, renal disease and/or respiratory disease). Patient age was also confirmed from the medical records. Information on cancer stage and treatments was collected, however, due to incompleteness or lack of specificity this information was unable to be used in this analysis.

2.3. Data analysis

Phase 1: Descriptive statistics were used to describe the proportion of women who used T&CM, by type and timing (ever used/use in past 12 months). Due to small participant numbers, differences in the type and timing of T&CM use were not compared across demographic or clinical sub-groups and inferential statistics were not used. Participants' socio-demographic and clinical characteristics were described using means and standard deviation (for age) and proportions., socio-demographic and clinical variables were dichotomised and percentages were rounded to the whole number. The following variables were dichotomised to protect participant anonymity: marital status (partnered versus not partnered), employment status (paid employment versus not employment/in unpaid work), main language (English versus other), and number of dependent children (have children/don't have children). Indigeneity categories were too small to report the number of participants or outcome by each of these population groups.

Women's postcodes were used to assign an Accessibility/Remoteness Index of Australia (ARIA+ 2011) score [21], which was then categorised into highly accessible areas and all other areas. Postcode was also used to assign participants to an Australian Bureau of Statistics (ABS) Socio-Economic Indexes for Areas (SEIFA 2011) Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) percentile, which was then categorised into quintile 1–2 (Most-disadvantaged areas) and quintile 3–5 (less disadvantaged and advantaged areas) [22].

Phase 2: The qualitative data was analysed using an interpretative phenomenological approach (IPA) [23] to explore the lived experience of the participants. The qualitative data was analysed iteratively, through a process of being coded separately by two researchers (AG and KA), who then repeatedly met to discuss and refine a shared thematic framework. The final shared framework underpins the qualitative results presented in this study.

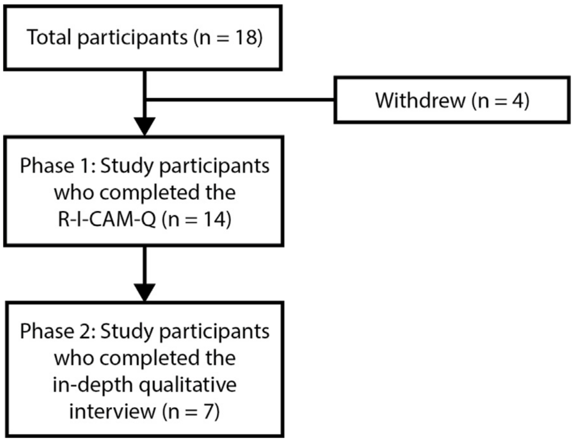

Fig. 1. Participant flow diagram.

2.4. Ethics

Ethics approval was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research, the Endeavour Human Research Ethics Committee and from the participating site specific Human Research Ethics Committee.

3. Results

3.1. Participants

Eighteen Indigenous women attending the participating hospital clinic were approached to participate in the study. While all provided consent, only 14 women (mean age 48.5, SD 14.9) completed Phase 1; four women did not complete the interview due to feeling too unwell or distressed or not having time due to other commitments (see Fig. 1). All participants were Indigenous Australian women and most identified as being of Aboriginal descent (57%), spoke English as their main language at home (57%), had children (85%), were not employed at the time of interview (57%), had an education beyond year 10 (57%) and lived in the most socioeconomically disadvantaged areas (57%). Half of the participants lived in non-urban areas (50%). Approximately two-thirds of the participants had comorbid conditions including diabetes, hypertension, cardiovascular disease, renal disease, and/or respiratory disease, with diabetes being most prevalent (54%).

Seven of the 14 women who completed Phase 1, returned to the clinic for a follow-up appointment and had their cancer diagnosis confirmed. These seven women were invited to participate in the qualitative interview (Phase 2). The mean age of these participants was 56 years (SD 11) from across both urban and non-urban areas, and the most common cancer diagnosed was endometrial cancer (data not shown due to small sample numbers).

3.2. Phase 1

Most women self-reported using at least one form of T&CM in the past (86%) and 79% reported using T&CM in the last 12 months. Of those who reported ever using T&CM, 75% reported using vitamins and minerals, 42% meditation, relaxation or visualisation techniques, and 33% reported using a traditional healer. Only 21% of women reported initiating T&CM use because of their cancer investigation and less than half (36%) disclosed their T&CM use to at least one healthcare provider. Of those women who did disclose, they always informed their general practitioner, but did not always inform their hospital health care providers such as their oncologist, nurse or Indigenous liaison officer.

3.3. Phase 2

Three main themes arose from the women's in-depth interviews: (i) types of T&CM used; (ii) reasons for use; and (iii) disclosure of T&CM. Underlying each of these themes we found that the clinical encounters described by the participants was rarely conducive to discussion outside the scope of conventional medicine.

3.3.1. Types of T&CM used

The interviews confirmed the finding from Phase 1 that T&CM use is common among Indigenous women with (or undergoing investigations for) gynaecological cancer. There was variation in the type of T&CM used by participants. A range of nutritional supplements were reported to be used to help with the side-effects and symptoms of the cancer (Glucosamine, multivitamins, magnesium, vitamin D and C, B12 injection, and iron). Others spoke of eating traditional Indigenous foods from their homelands that they believed culturally to hold healing properties. Some participants were given a '*healing gemstone*' or a '*healing bracelet*' by family members that they kept with them throughout their cancer journey. The use of visualisation was reported by a few participants, as one participant explained ' … [*I was*] *going through the bush, and I just sit there, imagined myself in there walking around* … ' she further explained how this helped ' … *like walking in I was struggling, and then as soon as I walked into the bush it was like "I'm free" … just imagined myself like that*'. There was also a strong sense of spirituality and faith reported by some of the participants:

> *' … I do believe in something up there … [I] go out to the bush and sit under the stars and just pray … '*
>
> *' … I don't think my spirit people are ready for me yet. I might have to stay here'*
>
> *' … I'm a firm believer in my culture, my spirit people up there looking after me'*

3.3.2. Reasons for use

While a few participants indicated in Phase 1 that they initiated T&CM use due to their suspected cancer, none of the participants reported during the interviews (Phase 2) that they were using T&CM to directly treat their cancer. Several reasons for their T&CM use were reported and these were predominantly associated with emotional needs and/or unrelated conditions.

Two participants spoke of using traditional medicine. One participant's husband explained ' … *I've got that traditional medicine, I give it to her* … '. Three other participants spoke of using complementary medicines for reasons completely unrelated to their cancer diagnosis. One participant spoke of using both a multivitamin and glucosamine for her arthritis, and another participant reported using Magnesium for leg cramps and Vitamin D for her bones: '*I only take Magnesium* [*for severe leg cramps*] *and something for bones*, *that's all I'm taking at the moment, Vitamin D*'. One participant spoke of how she used complementary medicines to stop herself from dying as part of her after-care associated with an invasive medical procedure: *'if I stop, I don't get up. I'd die'*. She reported having B12 injections, taking iron and multi-vitamin tablets daily, and eating eggs regularly. One participant expressed a strong dissatisfaction for *'medicine'* when asked about her T&CM use, however, it is unclear what *medicine* she is referring to: *'I'm at the stage where I'm sick of medication, I'm sick of doctors, and I don't really want to have anything to do with them. I'm tired of taking medicine because it doesn't help. I am still miserable, still in pain, and it's not helping'*.

3.3.3. Disclosure of T&CM use

Many participants reported communication difficulties between them and their healthcare providers. While varying reasons were cited for why there were challenges in communication, the implications of this on disclosure of T&CM usage appear to be substantial.

Two participants spoke directly about disclosure of their T&CM use. One participant stated that she had not told her healthcare providers about her T&CM use, however, she also noted that they did not ask. The other participant when asked if her healthcare providers asked if she used T&CM, she responded: *'Yes, they did, and I said, "No"'*. However, she did not further specify why she said no, even though she was using T&CM.

In some cases, the participants spoke of feeling unheard and that their concerns were of no consequence to the healthcare providers: *' … it's like talking to a vacuum cleaner. He takes it all in and then [he] dumps it in the rubbish'*. Others explain it as feeling like they are a *'number'*, elaborating *' … you just feel like you're one of these hundreds of cattle that are going through this … '*. While one participant made their stance very clear, stating *'The communication is really bad'*, leaving participants feeling that communicating with their healthcare provider was pointless. This was further evidenced by another participant who stated *'I'm tired of asking. I don't want it, I don't want the help, because there isn't any'*.

The importance of building rapport in patient-clinician relationships was evident in the interviews with the participants. It was apparent that the lack of rapport between the healthcare providers and the participants was a pre-cursor to communication difficulties. Where rapport was built, the participants had more positive views of their healthcare providers, compared with those where the healthcare provider did not take time to build rapport with the participant. One participant illustrates this clearly when she speaks about the large contrast between the first healthcare provider she encountered when compared to the next: *' … she was a grand doctor, lovely doctor, very, very good, lovely bedside manner … and then the next [doctor] was horrible'*. Another participant explained how the healthcare provider built rapport with her: *'The anaesthesia people were beautiful. They get in there, they talk to you, and I had fun with them'*. This idea of having fun with the healthcare provider is one way rapport we found was quickly built, and another reflected in the interviews was respect. Some participants explained how the healthcare providers *' … make you feel important'* and they *' … don't dwell on it'* when the participant has done something perceived as '*naughty'*. In contrast to this was one participants' experience where the doctor *' … treated me like a drug addict'* which resulted in a complete break-down in respect and the participants long-term care as she states she is now *'in the middle of looking for another GP'*. She further illustrates this break-down in the clinical relationship clearly when she stated *' … it just made me angry. I just don't feel like going to see doctors anymore'*. Further, the perception that being treated with respect was unusual was reflected in the positive experiences represented in the interviews.

> *'I like the doctors, [they] treat you special. Well, I have, I got treated special'*
>
> *'I'm lucky that I had a nice doctor … '*
>
> *'I wish there was a lot of doctors like that'*

4. Discussion

The findings of this study suggest that T&CM usage is common and perceived as important to the participants of this study, however, substantial obstacles to effective patient-clinician communication were evident, which reduces the likelihood of patients' disclosing their T&CM use. Such barriers are likely to arise at the personal, practitioner, service, or system level.

T&CM use alongside conventional cancer treatment may be more prevalent than previously thought [7–9]; 79% of the women in the current study self-reported using T&CM in the past 12 months. Adams et al. previously reported that Queensland Indigenous women diagnosed with a gynaecological cancer in the previous five years did not commonly use traditional Indigenous therapies (14% used) or complementary medicine practitioners or medicines (17% and 4% used, respectively) [10]. In the current study, the most commonly used T&CM were vitamins and minerals, followed by meditation, visualisation and relaxation techniques. Our qualitative interviews also identified traditional foods as being used and seen as having healing properties, however this was not captured in the R-I-CAM-Q. Potential modification of this survey to include questions about traditional foods for healing and health would be appropriate when assessing T&CM use in the Indigenous Australian population.

In the current study, 64% of women who reported using some form of T&CM said they did not divulge this information to their healthcare provider. However, of those who did report their T&CM usage, all told their general practitioner. While this highlights the central role the general practitioner plays in the holistic healthcare for Indigenous women, as has previously been reported [24–26], it also shines a light on apparent difficulties that patients may have in disclosing this information to other healthcare providers. While some women in the current study reported having positive interactions with their providers, others reported feeling unheard and judged. While these findings were not necessarily specifically regarding the use or disclosure of T&CM use, it is plausible that these factors were significant in patients' decision to disclose. However, there are other plausible explanations for non-disclosure, including inadequate health literacy around T&CM use, for both the patient and the practitioner, and this warrants further investigation.

To our knowledge only one Australian hospital has employed traditional Indigenous healers to work alongside doctors and nurses to safely deliver complementary traditional care to Indigenous patients [27]. Having an Indigenous healer working from within state hospitals are likely to play a significant role in reducing the inequities in the receipt of timely and optimal treatment for cancer and other chronic disease experienced by Indigenous Australians [4,28] and improve patient experiences with the healthcare system, which have traditionally been underpinned by feelings of mistrust, fear, isolation, and dislocation [5,16]. One way in which patient experiences may be improved, besides the access to traditional therapies, is the healer may facilitate open two-way communication between the clinical staff and patients and their families. Improving communication between clinical staff and patients, will likely strengthen trust and rapport, and may increase the proportion of Indigenous Australian patients disclosing their T&CM use. This will have positive ramification for clinical decision-making, which in turn may lead to improved outcomes for the patient.

There was no indication from the women in the current study that use of T&CMs would have an impact on the women's perceptions and use of conventional medicines. However, this study only recruited women who attended the specialist tertiary clinic for their cancer diagnostic investigations. It is possible that some women who were referred to the clinic did not attend. While, by definition T&CM is complementary, it is unclear if some women believe it to be an alternative model of care. Given the high usage of T&CM reported here, it is paramount that this is better understood.

The women in the current study spoke of the non-clinical effects of cancer on their wellbeing, and how they sought T&CM to help alleviate these effects. The role of T&CM in coping with the emotional experience of cancer, including anxiety, fear, shock, anger, overwhelm, hopelessness, frustration and feeling unsupported, emerged as an important theme for these women. Shahid et al. [16], reported similar themes in their study of Traditional Medicine use among Indigenous Australians with cancer. Therefore, these experiences may be common for Indigenous people undergoing diagnostic investigations for cancer, regardless of what the cancer type is. Additionally, the women in this study spoke of using T&CM for comorbid conditions, again suggesting that the use and disclosure of T&CM use among Indigenous cancer patients is something all healthcare providers, and not just oncologists and cancer care physicians, need to be aware of. There was a strong sense of spirituality and faith among some of the participants. Thomson and colleagues' [29] reported spirituality in the primary psychosocial predictor of complementary medicine use.

5. Considerations

The small number of participants in this study limits the scope of the statistical analysis and generalisability of the quantitative results; however these findings are meant to compliment the qualitative findings. The purpose of our study was to reach conceptual saturation of themes, rather than empirical generalisability, which we believe we have achieved through the convergence and divergence of themes. This study adds to the existing literature as our sample was restricted to women at the point of diagnostic investigations for cancer, and the depth of interviews providing rich data meant a thorough picture of the experiences of Indigenous women being investigated for cancer and using T&CM could be painted.

Participants in this study were all recruited from an urban hospital setting and thus lower numbers of women from regional and remote settings were included. It is possible that the use of T&CM varies across geographical settings. Likewise, the reasons to use T&CM, experiences of use, decisions about disclosure, and decisions regarding conventional cancer treatment may vary across treatment settings.

The interviewer in this study is an Indigenous woman, therefore, there is potential for her own values and impressions of life as an Indigenous woman to have introduced some bias into collection of data. Despite this, it has been shown that vulnerable and hard-to-reach populations like those included in our study, benefit from the use of peer interviewers to help the participants to feel safe to tell their stories [30]. The benefits of the use of peer-interviewing to access and engage with this population far outweigh the potential for bias.

6. Conclusion

The current study builds on the growing body of evidence that T&CM use is important to Indigenous Australians with cancer. The reasons for use are far-reaching, encompassing their physical, emotional and spiritual needs. T&CM use did not appear to reduce participant engagement with conventional cancer treatment, although this is an under-explored area that warrants further investigation. Our research strengthens the premise that healthcare providers must build rapport with Indigenous cancer patients, be equipped to broach the subject of T&CM use, and encourage full disclosure for informed and shared decision-making with the patient.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ctcp.2019.06.005.

Declarations of interest

None.

Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contributions towards the manuscript, and their approval of the final manuscript for submission.

Author contributions

AG, KA, VM, JA, TT and GG conceptualised the study and contributed to the development of the study design and methodology. KA managed the data collection. AG and KA extracted and analysed the qualitative data, and AG and AD managed and analysed the quantitative data. AG, KA and AD drafted the first version of the manuscript. AG, KA, AD, VM, JA, TT and GG all provided extensive feedback and then AG finalised the manuscript for publication. Lastly, GG held the primary advisor role across all parts of the process.

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