Ngu-ngi-la-nha (to exchange) knowledge. How is Aboriginal and Torres Strait Islander people’s empowerment being upheld and reported in smoking cessation interventions during pregnancy: a systematic review

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Abstract. Smoking during pregnancy is a national priority to improve Aboriginal health. Empowerment approaches underpin the priorities set by the government to improve Aboriginal health and wellbeing; however, empowerment is seldom evaluated within interventions for Aboriginal people. Literature was searched to April 2018 and data was extracted using an assessment tool with domains of \textit{individual} and \textit{community empowerment} in smoking cessation during pregnancy studies with Aboriginal women. Three interventions were found in published and grey literature. Elements of \textit{individual empowerment} were embedded in all interventions. Interventions considered barriers for Aboriginal women to quit smoking and areas for capacity building. Interventions used health education resources. There was limited reporting of \textit{community empowerment} domains. Aboriginal ethics and capacity building was the only criterium addressed by all studies. Interventions are incorporating \textit{individual empowerment}, but seldom report \textit{community empowerment}. The development of reporting guidelines or extensions of current guidelines would be beneficial to set a consistently high standard reporting across Aboriginal health interventions, similar to the work conducted to develop the extension of Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Equity (PRISMA-E) for health equity in systematic review reporting. Reporting empowerment domains would reflect the government priority of empowerment to improve Aboriginal health, as well as enhancing knowledge translation into practice.

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Introduction

Colonisation and dispossession has influenced tobacco use and the normalisation of smoking among Aboriginal\textsuperscript{1} people, including tobacco being used as payment for work and rationing of resources on cattle stations and missions (Brady 2002). In 2014–15, 38.9\% of Aboriginal people aged over 15 years were daily smokers; a reduction from 44.6\% in 2008 (Australian Institute of Health and Welfare 2017). Although the prevalence of smoking in Aboriginal communities is declining, more support is needed to match the smoking rates of other Australians. Aboriginal people have reported sound knowledge of the harms of smoking (Nicholson \textit{et al}. 2015) and want to maintain ownership over the quitting journey (Bond \textit{et al}. 2012; Bovill \textit{et al}. 2018), but have experienced difficulties with their most recent quit attempt (Thomas \textit{et al}. 2015b). Most Aboriginal smokers reported that they were asked by health professionals if they smoked (93\%), but less than half (49\%) were offered information on how to quit (Thomas \textit{et al}. 2015a). A review of smoking cessation interventions in Indigenous communities around the world suggested that multifaceted programs that simultaneously address behavioural, psychological and biochemical aspects of addiction, and those that offered culturally tailored resources, were more likely to be effective (Carson \textit{et al}. 2014). Aboriginal leadership, long-term community investment and culturally appropriate materials and activities have also been identified as important influences to address tobacco use (Minichiello \textit{et al}. 2016). However, there is currently limited Indigenous-specific evidence of effective interventions for reducing smoking (Chamberlain \textit{et al}. 2017a) that incorporate this tailoring.

\textsuperscript{1}This paper refers to Aboriginal and Torres Strait Islander people as Aboriginal, with acknowledgement and respect of the sovereignty of the two distinct groups.
Maternal smoking among pregnant Aboriginal women continues to be of national concern, reflected in key targets to improve maternal and child health risk factors in the Closing the Gap campaign (Commonwealth of Australia 2015). In 2013, 45% of Aboriginal women reported smoking during pregnancy (Australian Institute of Health and Welfare 2016). Smoking during pregnancy is one of the strongest risk factors for the high rates of low birthweight of infants born to Aboriginal mothers (Commonwealth of Australia 2015). Low birthweight has been linked to shorter life expectancy among Aboriginal people (Hoy and Nicol 2019). Providing effective smoking cessation interventions can reduce the number of babies born with low birthweight (Lumley et al. 2009; Chamberlain et al. 2017). Previous systematic reviews of smoking cessation interventions for pregnant women found strong evidence of effectiveness of incentive-based interventions, and feedback in conjunction with counselling. However, interventions to reduce smoking during pregnancy in Aboriginal communities have not yet demonstrated a significant increase in smoking abstinence. Developing and implementing effective and meaningful interventions to support smoking cessation among pregnant Aboriginal women is critical to addressing the long-term health of Aboriginal Australians.

The need to tailor interventions to address specific needs of disadvantaged populations, including Indigenous people worldwide, has been called for (Lumley et al. 2009). Effective implementation maximises the effect and benefit of health service delivery. However, knowledge of how interventions are being implemented in Aboriginal communities is seldom reported and reviewed, as most systematic reviews are focussed on measuring efficacy. Appropriate interventions for Aboriginal people also require a process of evaluation in real-world settings to measure effectiveness. For interventions to be effective in an Aboriginal primary healthcare setting, we must also examine acceptability and uptake at a population level. This knowledge will assist in refining appropriate interventions for primary healthcare settings, particularly Aboriginal Community-Controlled Healthcare Services, who are best placed to deliver health prevention initiatives (Panaretto et al. 2014).

Aboriginal people define health not only as a state of physical wellbeing, but rather a holistic construct that incorporates social, emotional and cultural wellbeing (National Aboriginal Health Strategy Working Party 1989). Acceptable interventions need to align with Aboriginal definitions, values and priorities to report specific details that will lead to innovation and practice change in primary healthcare settings. One such approach is the evaluation of empowerment, specifically individual and community empowerment. Empowerment approaches have been increasingly interwoven in health interventions, programs and across Australia (Fredericks 2008; Haswell-Elkins et al. 2009; Whiteside et al. 2009; Bainbridge et al. 2011; Bond et al. 2012; Laliberté et al. 2012), and underpin the priorities set by the Australian Government to improve Aboriginal health and wellbeing (Australian Government 2013; Commonwealth of Australia 2015). Although the term empowerment is used within the context of Aboriginal health, it is seldom defined or described. Empowerment domains are focussed on choices, self-determination and enhanced health and wellbeing (Kabeer 1999).

The term empowerment is complex and subjective, it’s use varies widely depending on the context and population. Empowerment research is strength-based, identifying capabilities rather than cataloguing risk factors and reporting deficits (Perkins and Zimmerman 1995); it values the process in which individuals and communities are engaged and gain greater access to and control of their lives (Wallerstein 1992). Empowerment approaches are particularly relevant for ethical Aboriginal health research to counteract the effects of colonisation, imperialism and dispossession on Aboriginal culture, and their resulting detriment to health and wellbeing. Recognising that we were once sovereign people with control over our lives (Fredericks 2008), empowerment approaches also connect with Aboriginal culture and spirituality (Whiteside et al. 2011). Applying domains of empowerment to evaluations offers unique insights to innovative intervention development and implementation that is appropriate and meaningful to Aboriginal people.

The need, effect and effectiveness of initiatives driven by Aboriginal people for Aboriginal peoples are well reported (Smith 1999; Bainbridge et al. 2011; Bainbridge et al. 2015). This review aims to build on this body of evidence to:

1. Provide an overview of what smoking cessation interventions have been offered to Aboriginal women during pregnancy, as reported in the literature;
2. Describe domains of individual empowerment evident in published reports of smoking cessation interventions for pregnant Aboriginal women;
3. Describe domains of community empowerment evident in published reports of smoking cessation interventions for pregnant Aboriginal women in line with Aboriginal research ethical guidelines.

**Methods**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines for systematic reviews were used to inform a protocol for this review, which was registered with PROSPERO CRD42018096399. The systematic review used the following:

**Inclusion criteria**

The participants for this study included pregnant Australian Aboriginal women (including post-natal women).
Smoking cessation interventions were delivered in any setting where the study design is described in detail; this includes protocols and evaluations.

For comparative purposes, study designs included: randomised controlled trials, pre-post study design, non-randomised controlled trials, quasi-experimental studies, protocols and evaluations.

The outcomes were either individual empowerment and community empowerment. Individual empowerment domains include: experiences and capacities; actions and behaviours throughout the intervention; control and ownership; and skills/education development (Barr et al. 2015). Community empowerment domains were assessed using the ‘Cultural identity interventions systematic review proforma’ (MacLean et al. 2015) and include: involvement of Aboriginal researchers, relationships of researchers and participants, community involvement with study design and implementation; training and capacity building of researchers and community members; reporting back to communities; and the value of the research to the community.

Exclusion criteria
The exclusion criteria for this study included: interventions not delivered specifically to Aboriginal women during pregnancy and articles that did not include a description of the intervention.

All other systematic review methods are outlined in the Supplementary Material.

Data collection and synthesis
Searches generated 489 publications following removal of duplicates. 465 were excluded during title and abstract screening, leaving 19 articles for full-text review (Figure S1, available as Supplementary Material to this paper). Of these, 11 were excluded because they did not meet the inclusion criteria. A list of excluded reviews and reasons are outlined in Table S1, available as Supplementary Material to this paper. Of the eight remaining articles, three interventions were described, and articles were divided into two categories; 1) primary source, either study protocol or evaluation paper, and 2) secondary source, including developmental papers, PhD thesis and supplementary files. All articles, and all content within both the primary and secondary sources, were included in the data collection and synthesis. Risk of bias was assessed and is reported in Table S2. Table S3 outlines each of the included interventions and their descriptions. Authors of included manuscripts for Study 1 and 2 were contacted to seek any additional publications, reports or presentations to articulate intervention development and/or Aboriginal community involvement. Authors M. Bovill, Y. Bar-Zeev, M. Gruppetta and G. S. Gould were investigators for Study 3. C. Chamberlain was not involved in this study in anyway. Only published manuscripts were used for this study.

Results
Study characteristics
Three smoking cessation interventions for Aboriginal women during their pregnancy between 2005 and 2018 were sourced using both primary (Eades et al. 2012; Bar-Zeev et al. 2017a; Passey and Stirling 2018) and secondary sources (Gilligan 2008; Bovill et al. 2017; Gould et al. 2017; Passey and Stirling 2018; Bar-Zeev et al. 2017b) available for all three interventions (Table S3). Both primary papers and secondary sources were analysed together. Studies will be referred to as: Study 1 (Eades et al. 2012), Study 2 (Passey and Stirling 2018) and Study 3 (Bar-Zeev et al. 2017a).

Studies 1 and 2 reported evaluations of the intervention and Study 3 reported the study protocol. These studies consisted of: one randomised control trial (Study 1), one program implementation evaluation (Study 2) and one step-wedge cluster randomised trial (Study 3). Studies 1 and 3 involved partnerships with Aboriginal Community Controlled Health Services (ACCHS) and Study 2 was a partnership with an Aboriginal Maternal and Infant Health Service’s to conduct the trials. All interventions were conducted in multiple sites across: Queensland (Qld; Studies 1 and 3), Western Australia (WA; Study 1), New South Wales (NSW; Studies 2 and 3) and South Australia (SA; Study 3). All interventions incorporated health provider (HP) training and resources (for both HP and Aboriginal women) and offered nicotine replacement therapy (NRT) to women who were unable to quit unaided. Study 2 also included peer support groups and financial incentives in the study design.

Individual empowerment domains
Consideration of women’s experiences and capacities in the studies
All interventions acknowledged the high rates of smoking during pregnancy among Aboriginal women and the need to develop appropriate interventions to effectively support cessation in their introductions. Interventions were designed to take into consideration particular experiences and capacities of Aboriginal women achieving smoking cessation during pregnancy, drawing on qualitative and quantitative background research.

Experiences of Aboriginal women quitting smoking during pregnancy considered by interventions included:
- Stress (Studies 1–3)
- Social disadvantage (Studies 1 and 2)
- Appropriate approaches needed for Aboriginal women (Study 1)
- Acknowledgement of social and cultural factors associated with smoking (Studies 1–3)
- Aboriginal women have adequate knowledge regarding smoking during pregnancy (Study 1)
- Significance of partner smoking (Study 1)
- The value of family and children in motivating women to make healthier choices (Study 2)
- Poor knowledge of smoking cessation strategies (Study 2)
- Misconception regarding smoking risks (Study 2)
- Quitting is too hard, given other stressors (Study 2)
- Lack of support for cessation messages and targeted programs (Study 3)

Aboriginal women’s capacity to achieve smoking cessation during pregnancy considered:
- The importance of HP to offer cessation support and advice on an ongoing basis throughout pregnancy (Studies 1 and 2)
• Potential for successful psychosocial interventions involving behavioural counselling (Studies 1 and 3)
• Importance of Aboriginal Health Workers’ involvement in a culturally sensitive intervention (Studies 1 and 3)
• Involving household and social supports (Study 2)

How studies offered women control/ownership over the quitting process

Studies 1 and 2 reported offering women ownership of the quitting process; both studies reported that it was the women’s choice to quit smoking and used a motivational interviewing approach to strengthen the individual’s self-efficacy to achieve change. Emphasis was given to the HP role to encourage women to keep thinking about smoking cessation (Study 1). Studies 1–3 offered women resources to address smoking in pregnancy. Studies 1 and 2 offered women oral NRT after two failed quit attempts; Study 3 planned to offer NRT after 1–2 days of an unsuccessful quit attempt.

Elements of the interventions for women’s skills/educational development

All three studies developed health education resources for Aboriginal women to increase understanding of the effects of smoking during pregnancy and the cessation journey during pregnancy. HP offered clear advice that quitting ‘cold turkey’ (without NRT) was the best way to quit smoking when pregnant, and Aboriginal Health Workers offered cessation advice and educational resources (Study 1).

• Education resource topics included:
  - Reasons to quit, how to manage quitting, household support, staying smoke free after birth (Study 2)
  - Adverse effects of smoking, triggers for smoking, ways to cope with cravings (Studies 1–3)
  - Benefits of quitting smoking, multiple attempts needed to quit, trying again if relapse occurs (Study 1)

• Study 1 also ran group sessions that started with relaxation techniques and followed with an education session and group activity related to quitting smoking. Group session topics included: harms of smoking; managing cravings; benefits of quitting; costs of smoking; managing stress; a tobacco quiz; dealing with boredom; passive smoking; positive self-talk and avoiding relapse; and staying quit, postpartum. Women were able to join the group at any point and could request different sessions if desired.

Domains of community empowerment described in interventions

Table S4 summarises domains of community empowerment described in the interventions. Limited reporting of community empowerment was described in primary sources. Obtaining Aboriginal Ethics approvals, describing what training and capacity building was included, and whether the capacity building was needed by the community, were addressed by all studies. Identification of Aboriginal researchers was found Studies 2 and 3; however, Study 1 included Aboriginal researchers. Nine out of 19 (47%) of the a priori criteria for community empowerment were not addressed in any of the studies including: relationship of researchers to participants; and community involvement including: the research question development and implementation; resources to promote involvement; and reporting back to the community. Studies 2 and 3 involved Aboriginal community in the design of the intervention and formed Aboriginal community reference groups in an ongoing dialogue throughout the study to oversee all implementation, data collection and reporting. Study 2 measured the value of the research through qualitative interviews and Study 3 planned to measure value to the ACCHS staff through qualitative interviews, and to the women, through growth and empowerment measure and critical success factors surveys. Across all three studies, limited details of community empowerment were described in the primary and secondary sources combined.

Discussion

The three interventions included in the analysis offered limited detail of individual and community empowerment in the primary papers. Depth of knowledge was obtained through the inclusion of secondary papers in the analysis such as: a PhD thesis (Gilligan 2008), a supplementary file (Passey and Stirling 2017) and developmental papers (Bovill et al. 2017; Gould et al. 2017; Bar-Zeew et al. 2017b).

Some elements of individual empowerment were embedded in all three interventions; namely, drawing on experiences that presented barriers for Aboriginal women to quit smoking during pregnancy and considered areas to build capacity to reduce these barriers. Opportunities for women’s control and ownership of the cessation process were reported in Studies 1 and 2, which used motivational interviewing to build self-efficacy. All three interventions emphasised the role of the HP to provide information and offer ongoing support so women feel supported when ready to quit, supporting ownership and choice. All studies used health education resources, and Study 2 created groups to enhance skills and education.

There are few published reports of smoking cessation interventions and programs implemented and rigorously evaluated for Aboriginal pregnant women; however, there are a few ongoing community-driven programs and social marketing campaigns that have been implemented for many years that would benefit from reporting and evaluation (Ahmat et al. 2012; Aboriginal Health Council of South Australia 2016). Currently, there are new models and interventions being rolled out across the country to address smoking cessation during pregnancy with Aboriginal women that, once evaluated, will offer new knowledge, practice change and innovations to primary healthcare settings. The Quit for New Life program in New South Wales is currently under evaluation and will further provide knowledge to the acceptability of brief interventions and oral NRT (NSW Ministry of Health 2018, pers. comm.). In Queensland, Inala Health Services’ Empowering Strong Families’ intervention is using a holistic and ecological approach (Askew et al. 2017); outcomes resulting from this study are currently being analysed. A women-centred and trauma-informed approach is being developed to support Aboriginal women in the Pilbara region of Western Australia (Wyndow et al. 2018) and is currently in the early stages of development. Once evaluated, these interventions will provide new knowledge on
 alternate models of smoking cessation care for Aboriginal mothers and would make important contributions to this review.

Knowledge of how interventions are being implemented in partnership with Aboriginal communities is critical to explore innovative, ethical and meaningful change in the delivery of preventative healthcare interventions. There was limited reporting of community empowerment domains across the three interventions. This offers empirical evidence that would be relevant for intervention studies across areas of Aboriginal health. Articulation of Aboriginal ethics and capacity building were the only criteria addressed by all interventions. All interventions had Aboriginal researchers on their teams, including chief investigators, associate investigators and research assistants; however, one did not specify this in the publication (Eades et al. 2012). There are significant areas for enhanced reporting, including how Aboriginal communities are involved in ongoing dialogue and how information is valued and reported back to the community. This information is paramount to upholding meaningful research that leads to health improvements and outcomes for Aboriginal people. This is also crucial information when planning knowledge translation into primary healthcare practice. The development of governance structures for Aboriginal community research governance has been recommended (Gwynn et al. 2015), and this might be being adopted by researchers; however, current reporting is not articulating this.

Recommendations for practice, policy and research

Although the reporting of community empowerment in interventions is seldom articulated in peer-reviewed literature, this does not necessarily reflect the way research is being conducted in Aboriginal communities. Potential influences on what is reported can include barriers such as limitations to word counts and restrictive journal guidelines. Health researchers have a series of reporting guidelines that are internationally accepted and expected when publishing studies such as the PRISMA for systematic reviews (Liberati et al. 2009) and Consolidated Standards of Reporting Trials (CONSORT) for randomised controlled trials (Moher et al. 2010). With the rise of Aboriginal health interventions being conducted, a systematically developed reporting guideline or extensions made to established guidelines, as evident with the extension PRISMA-E health equity (Welch et al. 2012), should be considered. Such reporting guidelines should acknowledge the effect of colonisation and unethical research previously conducted with Aboriginal communities, and incorporate domains of individual and community empowerment. A comprehensive consultation process would also be required to reach a consensus across diverse Aboriginal communities to ensure reporting of Aboriginal health interventions is appropriate and meaningful to Aboriginal people. This reporting may also improve knowledge translation into healthcare practice, which we know to be crucial to effective health research.

Limitations and strengths

To the best of our knowledge, this is the first systematic review to describe empowerment domains of maternal smoking cessation interventions delivered to Aboriginal women. Due to the limited available publications meeting eligibility criteria, limited findings are available. There is a need for Aboriginal communities to rigorously evaluate and report on their interventions and programs to add to the Ngu-ngi-la-nha (exchange) of knowledge. Four authors from Study 3 also authored this review (M. Bovill, Y. Bar-Zeev, M. Gruppetta, G. Gould) and were involved in the development and implementation; this might have biased unintentionally the analysis and reporting. Nonetheless, the fifth author (C. Chamberlain) had no involvement in any of the included interventions, but checked all of the data extraction and analysis.

Conclusion

Research in Aboriginal communities has progressed significantly from the enlightenment period of enquiry and measurement; to mutual benefit and partnership. Today, Aboriginal health research calls for meaningful and ethical research that can incorporate knowledge translation to improve health and wellbeing of first peoples. While key Governmental documents articulate empowerment as a key criterion to improve Aboriginal health, this is seldom described. Likewise, empowerment is rarely used in the evaluation of interventions aimed at improving Aboriginal health, but often used in primary health care and community settings. What does ‘empowerment’ mean in practice? Authors assert that articulating empowerment, incorporating individual and community empowerment, connecting to the Aboriginal definition of health, is crucial to Ngu-ngi-la-nha (exchange) knowledge that is practical, meaningful and translatable to practice.

In the area of smoking cessation interventions for pregnant Aboriginal women, there are limited protocols and evaluations reported in the published literature. Interventions appear to be incorporating individual empowerment well, but seldom describe community empowerment. Enhanced evaluation and reporting on smoking cessation interventions and programs is required to provide a body of knowledge to assist in measuring effective supports for Aboriginal mothers.

Current literature may not be articulating the meaningful and ethical ways research is being conducted in partnership with Aboriginal communities, due to restrictions in the publishing sector. The development of reporting guidelines or extensions of current guidelines, similar to the work conducted to develop the PRISMA-E for health equity, would be beneficial to set a consistently high standard of appropriate reporting across Aboriginal health interventions that can be translated into practice, and particularly applied to Aboriginal community settings.

Conflicts of interest

The authors declare that they have no conflicts of interest.

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References


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