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Title: Lessons learned from a pilot study of an Indigenous patient navigator intervention in Queensland, Australia

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Abstract:

Indigenous patient navigator (IPN) programs show promise in addressing these barriers to cancer care and facilitation of patient self-efficacy. The purpose of this paper is to describe and reflect upon the experience of training an IPN and implementation of the intervention in the Australian context with Indigenous cancer patients. RCT might provide the best available evaluation measure of an intervention but caution should be taken in the implementation process. Socio-cultural aspects and training can affect the conduct of this type of intervention. We report here five issues needing consideration prior to implementing such intervention. Specifically: (1) Recognition of the collective bonds within Indigenous community and understanding by IPN of the degree of personal assistance perceived as not intrusive by the patient; (2) Conduct ongoing evaluation of the different role of an IPN involved in this intervention care provider versus researcher. (3) Meaningful engagement develops from a trusting/collaborative relationship between research team and study site staff which may not occur in the study time frame; (4) existing skills as well as training provided may not translate in the IPN understanding and aligning with the study objectives/research values; (5) recruitment of participants requires innovative and highly flexible strategies to be successful.

Key words: Indigenous Australians, cancer, navigator, supportive care needs

Introduction

Cancer is the second leading cause of death for Indigenous Australians (Australian Bureau of Statistics, 2008b) and when compared to other Australians, they have higher incidence of cancers with poorer prognosis (Australian Institute of Health and Welfare, 2014), higher cancer mortality and lower cancer survival (Condon et al., 2005, Valery et al., 2006). There are multiple reasons underlying these disparities including disease related factors (e.g. delays in diagnosis (Condon et al., 2004, Valery et al., 2006) lower rates of treatment (Valery et al., 2006), higher rates of co-morbidities (Valery et al., 2006)) socioeconomic (Condon et al., 2004, Gracey and King, 2009), and cultural factors (Condon et al., 2004, Cunningham et al., 2008, Valery et al., 2006). Furthermore, the survival disparities between Indigenous and non-Indigenous cancer patients is more pronounced in the first year after diagnosis (Cramb et al., 2012). This time period may be an ideal opportunity for intervention.

Navigating one's way through the complex health care system for cancer care can be arduous and fraught with uncertainty and fear (Wells et al., 2008). This common problem can be exacerbated for an Indigenous person, who might not always utilize nor understand Western health care systems. Interventions to reduce disparities in cancer care are being explored across the world. One such intervention is the use of patient navigation. The United States and Canada have been pioneers on using patient navigators as an attempt to reduce cancer disparities by addressing barriers to appropriate supportive care. Navigator programs aim at not only informing patients about cancer and the availability of services, but also addressing cultural, educational, language barriers to screening and treatment through community outreach by utilising community health care workers (Freeman et al., 1995). A review of patient navigator programs for Indigenous patients (Whop et al., 2012) identified two programs, Native Sisters Program and Walking Forward Program, that have positively contributed to improve outcomes to patients by increasing adherence to breast screening and

reducing delays to treatment. While several Patient Navigation interventions (Burhansstipanov et al., 1998, Kanekar and Petereit, 2009, Petereit et al., 2008) have been implemented, only a few have been evaluated through randomised clinical trials (RCTs), and have included Indigenous cancer patients (Braun et al., 2015, Dignan et al., 2005).

In 2013, we proposed for the first time in Australia to examine the feasibility of an intervention aimed to reduce the inequity in cancer outcomes for Indigenous patients. Through a RCT we proposed to examine whether introduction of an Indigenous Patient Navigator (IPN) will improve adherence to planned chemotherapy or radiotherapy, and improve access to and engagement with cancer support services. Other outcomes of interest also include decrease in unmet needs and improved quality of life. In preparation for a larger RCT to test the Patient Navigator intervention, we developed a protocol for training IPNs to link patients with support networks and cancer services. The purpose of this paper is to describe and reflect on the lessons learnt while training an IPN and implementing an intervention with Indigenous cancer patients in an Australian context. With this, we hope to highlight to health professionals and researchers the methodological challenges faced when implementing such intervention with this group.

Methods

Assessment tool and moderate to high unmet needs identification

Participants were assessed through a face-to-face interview for their needs using a Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)(Garvey et al., 2015); distress using the Distress Thermometer (DT) (Roth et al., 1998); and on worry using the Worry Chart (CWC) (Gramling et al., 2007). Inclusion criteria included being ≥ 18 years, identified as Aboriginal and/or Torres Strait Islander, had a cancer diagnosis, and attended the Princess Alexandra Hospital for their care.

The SCNAT-IP is a screening tool composed by 26 items where responses included an initial yes/no response for help. If they answered 'yes' the level of help needed was recorded using a 5-point response scale (1 indicates no need; 2 indicates satisfied with help received; 3 indicates need a little more help; 4 indicates need some more help; and 5 indicated need a lot more help). Responses were then grouped as: 'no need, satisfied with help received, or needed a little more help' vs. 'needed some or a lot more help' (referred to here as 'high needs') (Garvey et al., 2015). Distress was measured according to the National Comprehensive Cancer Network Guidelines on distress management (National Comprehensive Cancer Network, 2015), where patients scoring four (≥ 4) or higher on the DT were considered distressed and in need to be referred to an appropriate supportive service. Worry was measured by a single-item screening measure of worry, where participants would indicate how much they have been bothered during the last four weeks about their cancer (1 not at all; 2 slightly; 3 moderately; 4 quite a bit; 5 extremely). Responses were grouped in 'not at all, slightly' vs. 'moderately, quite a bit and extremely'.

The SCNAT-IP was found to have adequate overall and in the 4 domains Cronbach alpha coefficients ≥ 0.70 (range, 0.70-0.89). Additionally, the SCNAT-IP good discriminant validity and correlated moderately with the two psychosocial tools, DT (Spearman correlation coefficient, 0.60; $p < 0.001$) and CWC (Spearman correlation coefficient, 0.58; $p < 0.001$).

Participants were then assisted through the following actions: referral, accompaniment, arrangements, support and education.

The nature and number of needs reported by the patient would determine the frequency of encounters with the IPN.

Participants were assessed by the IPN at two points in time: at enrolment and two months after enrolment. The Research Nurse (referred to here as RN) accompanied the IPN to the recruitment areas and observed how the IPN approached patients and conducted the

supportive care needs assessment. Experiences, observations and impressions of the study team members were discussed at the end of the intervention they compose the body of the lessons learned discussed in this paper.

A research assistant conducted a satisfaction survey with participants who completed the follow-up questionnaire. The satisfaction of participants was measured through a combination of seven closed and five open-ended questions. Participants were asked to rate their cancer care in a scale of 0 (extremely dissatisfied) to 10 (extremely satisfied) and included the following items: *'communication with the IPN'*; *'the responsiveness of the IPN for requests of support and advice'*; *'the information about cancer the IPN'*; *'assistance given for appointments at support services'*; *'assistance given by the IPN in writing down some questions to be used in their next doctors' appointment'*; *'the assistance given by the Navigator in providing information about the Qld Cancer Council Helpline'*. Open-ended questions included: *'What have been the greatest contributions of the IPN to your cancer care experience'*; *'Were you disappointed by anything that the IPN has done in particular?'*; *'Is there anything that the IPN could have done to improve your experience of care?'*. *'Do you have any other comments or suggestions of how to improve the support provided by the IPN?'*; *'Are there any additional comments you would like to make? For example, is there anything in the health care system that could have been done differently to improve your care experience?'*.

This study was approved by the Human Research Ethics Committees of Menzies School of Health Research and Princess Alexandra Hospital.

IPN Program and Content

The Indigenous Patient Navigation (IPN) combines patient navigation, cancer education, and communication coaching to improve patient outcomes for Indigenous people diagnosed with cancer.

The protocol was the result of a collaborative work between hospital oncologists, cancer care nurses, cancer support services staff, Indigenous Health Liaison Officers and the research team. It includes a guidebook for training IPNs and a 'step-by-step' manual to be used by IPNs to conduct screening and address the patients' needs. The content of the guidebook includes a selection of topics that are fundamental to the navigation of cancer patients aimed at enhancing the trainees' understanding of the cancer burden to patients and their families; introduce the concept of navigation; factors that can affect in inequity of outcomes; and the resources available to assist cancer patients. Some of the existing cancer support material (e.g. Cancer Australia, Cancer Councils around Australia, National Health and Medical Research Council of Australia guidelines) were used to organize the lectures and readings. Culturally appropriate cancer fact sheets developed by the research team at the Menzies School of Health Research (Jacka et al., 2011) were also included. These fact sheets have been added to the limited suite of 'understanding' booklets available for Indigenous cancer patients and their families. The Cancer Council New South Wales (CCNSW) versions which were used by the IPN have been released for public use (<http://www.cancercouncil.com.au/1904/cc-publications/aboriginal-torres-strait-islander-resources/aboriginal-and-torres-strait-islander-cancer-resources/living-with-cancer-3/>).

The language used in the Training Protocol is plain language and the content is very visual to facilitate the understanding of IPNs with any educational level.

Indigenous Patient Navigator Training (IPN)

The Indigenous Patient Navigator involved in this study had previously worked as a health worker in a regional hospital. Therefore, this person had experience that was relevant to the patient navigator role; however, not to cancer specifically. The IPN training took place during July-December 2013 and included an individualized learning plan through one-to-one sessions with the IPN and the Research Nurse (referred to here as RN) to discuss the topics listed in the Training Protocol. Additionally, practical sessions with case scenarios were used to introduce study forms, patients' needs assessment procedure, possible 'actions' to assist patients using the resources and support services available. IPN 'action plans' focused on treatment and recovery phases of the cancer care continuum. While screening navigation at primary care centres in the community was not carried out, the concept was covered in the training program. The RN introduced the IPN to the Indigenous Health Liaison Officers (IHLOs) of the participating Hospital and together they visited the different wards and cancer care services. They also met other health professionals involved in the provision of care and support for Indigenous cancer patients (e.g. social workers and cancer care coordinators). The RN and IPN discussed SCN assessment and case management of every patient recruited. In addition, the IPN attended other activities such as a the Pre-Congress Workshop at the 17th Winter Congress: Cancer Basics a workshop for nurses and allied health professionals, 'Understanding Colorectal Cancer' session organized by the Cancer Council Queensland, and a training session offered by the Cancer Council Queensland entitled 'Introduction to cancer care: short course'. By the end of December 2013 the IPN had completed the reading material and one-to-one sessions with the RN, therefore training was considered complete. Nevertheless, the RN and IPN continued to discuss every patient recruited and the RN continued to support the IPN's role.

Results

Piloting the intervention

A convenience sample of twenty six (N=26) Aboriginal and Torres Strait Islander adult cancer patients receiving care at a major public hospital in Queensland were approached from July, 2013 to March, 2014. Of those, eighteen (69%) were interviewed and 8 (31%) declined to participate in the study.

Participants had their two assessments (enrolment and follow-up) within an interval of average 66 days (sd= 10.7).

The majority of the 18 Indigenous participants included in the study identified as Aboriginal (94%). They were on average 55 years of age; half were female, with a range of cancer types (breast, gastrointestinal tract, lung, male genital organ, lymphoma, throat, adrenal gland, and multiple myeloma). Most patients were receiving cancer treatment at the time of enrolment in the study (3 had surgery, 12 chemotherapy and 10 radiotherapy). The majority lived in major cities (61%) (Australian Institute of Health and Welfare, 2004) and their socio-economic status (Australian Bureau of Statistics, 2008a) was similarly distributed across the categories: most advantaged (33%), low to intermediate advantage (33%) and disadvantaged (33%).

At the baseline assessment, commonly reported 'moderate or high needs' items included: 'worrying about the illness spreading' (28%), 'concerns about the worries of those close to you' (22%), 'feeling down or sad' (17%), 'anxiety' (17%), and 'work around home' (17%). Of the thirteen patients who provided responses (72%) to the Distress Thermometer: 65% indicated no distress to slight distress (scores 0-3), 31% indicated a moderate to high level of distress (scores ≥ 4). The average score was 3.62 (SD=3.04). Of the twelve patients who provided answers to the Worry Chart: 25% (n=3) patients reported to be moderately-extremely worry.

Education and support was provided to all participants in this study and their families. The IPN increased patients' awareness about cancer, cancer treatment, and available support

services. The IPN informed patients about resources, community and allied health services, support groups, lifestyle programs or hospice programs that were available to them. The aim was that patients have a more active role in seeking support for their cancer. A description of the case management is illustrated in the report of the IPN's action plan to assist patients (Table 1).

As part of piloting the intervention, a 'Patient satisfaction' survey was administered to seven patients. Briefly, feedback obtained from the selected patients interviewed was that the IPN was beneficial to cancer patients and their families in dealing with the emotional turmoil, informational needs and logistical challenges associated with having cancer. Most patients were "extremely satisfied" with the communication with the IPN; responsiveness of the IPN for requests to support and advice; information provided (cancer pamphlets); assistance given by the IPN in making appointments at clinics/supportive services; and the assistance given by the Navigator in writing down some questions to be used at their next doctors' appointment.

Of the seven patients who completed the follow-up survey, six indicated that the greatest contribution to their experience with the IPN was having someone to talk to and show compassion. Examples of patient's feedback about the IPN are: *"Have someone show compassion on that day. Taking the time for me. Made me feel better about myself"*; *"In my case it was more about having someone talking to me than helping with things. I'm satisfied with the support I have, I just want to talk and have a cuppa"*; *"Somebody to talk to who knows about it and who you don't know"*; *"Company during treatment and having someone who understands"*. None of the patients expressed disappointment in their experience and interactions with the IPN. When asked if there was anything the Navigator could have done to improve their experience only one patient provided feedback that "for each different culture there should be someone to help. Some people don't want to stay away from home."

Lessons learned

We report here the perspectives of the research team's experience in implementing this pilot study.

Lesson 1. Linking research and target population: cultural challenges.

During the implementation of the intervention the research team observed two different experiences. The first confirmed that when having an Indigenous person as the IPN, the relationship between IPN-patient-family was more personal, and the information provided was easier to understand and readily accepted. Patients and their family members appeared to be highly satisfied with the assistance received.

In contrast, the second experience revealed that some patients felt uncomfortable having an Indigenous person as an IPN. Some patients did not like to share their condition with someone known in their community.

Lesson 2. Patient recruitment: a person-to-person approach can represent a challenge to cultural boundaries.

The IPN targeted patient population in this study consisted of Aboriginal and/or Torres Strait Islander cancer patients. The IPN would recruit patients for the study on a person-to-person approach. At this point the IPN always needed to confirm the person's identity and Indigenous status. As an Indigenous person, the IPN felt the requirement to confirm the Indigenous status of a patient difficult. There was some level of embarrassment in clarifying the Indigenous status and the IPN initially tried to determine the Indigenous status of the person through the knowledge of Indigenous family's surnames in the area, which proved inaccurate.

The other challenging aspect of the recruitment process was in that the IPN had to actively seek out patients to participate in the study. As the IPN had previous experience as a health worker, patients would normally seek them out. Thus to begin with, there was some difficulty to adjust to the different role. We learned that ongoing training is required in addition to initial training about the role of a researcher and research team member to carry out certain research requirements for example, the Indigenous status confirmation.

Lesson 3. Fitting the intervention into the health system: building relationships with health services.

The initial challenge to roll-out the intervention was to fit physically the IPN into the hospital setting. While the hospital direction/staff members were supportive of the intervention, finding a physical space to conduct assessments and follow-ups was not straight forward. The availability of physical space in the hospital was quite limited. This situation clearly illustrates that previous relationships between the research team and hosting institute was essential to overcome this barrier. It took several visits to the hospital until a physical space was found and allocated. Additionally, the IPN needed to have access to clinical data (information system access, telephone) and services provided in the hospital and primary care. The IPN created a directory of services to be able to refer and assist patients. The compilation of services proved to be difficult due to the various services with similar and/or complementary services that worked independently. There was very limited interaction between the hospital-based services and primary care services. We learned that for real engagement with services to happen it requires a relationship built on trust and collaboration; and this does not happen suddenly just because of the study time frame.

Lesson 4. Research versus usual care: there is a challenge for systematic measurements.

During the IPN training the assessment forms and procedures of the intervention was discussed and demonstrated. However, we encountered a number of challenges to implement the procedures/measurements in the field. The IPN would easily engage in informal conversation with participants in the study; however did not systematically conduct the assessment using the study tool. The IPN appeared not to share the same understanding of the study objectives and research values as other members of the research team. There was a personal perception of the IPN that the study tool was unnecessary and too laborious to go through. The information could be gathered in a more informal way. We learned that we should not assume that the training provided will necessarily be translated in the understanding of study objectives and research values, especially for people coming from service delivery professional role and with limited research experience and training.

Lesson 5. Project timing and recruitment strategies: time spent searching for and waiting for patients.

Study participants were recruited from outpatient clinics and hospital wards. In each case, the recruitment strategies needed to be adjusted to the setting (McGrath et al., 2013) and to patients physical and mental condition, therefore requiring different timing to carry out.

As the number of Indigenous cancer patients is relatively small, the IPN would have one single patient to ascertain. The procedure would start by the IPN going through the appointment list with the hospital's IHLO. They would then locate the clinic or ward where the patient was to be and then search for the patient.

At the outpatients' clinics, the first step was to confirm if the patient was checked into the system with the reception desk. If the patient had checked in, the IPN would then ask the receptionist if they could identify the patient. In a normal day, in the waiting area there would be approximately 30-40 patients attending appointments. If the reception could identify the

patient the IPN would approach the patient, confirm the person's identity and their Indigenous status and engage in conversation about the study. If the person at the reception desk could not identify the patient the IPN was looking for, the IPN then needed to search for the patient. Additionally, in the case of a patient who had not checked into the system, the IPN needed to wait for the patient to arrive. There were occasions that patients would not attend appointments or would be late. In either case, the IPN spent a significant time waiting for patients. The lesson drawn with regards the timing and recruitment is that it can take much longer than expected to recruit the estimated number of participants for the study. The research team must apply multiple strategies to recruit participants and be highly flexible in order to achieve the study recruitment target.

Discussion

This study describes and reflects upon the training experience of an IPN and implementation of the intervention in the Australian context with Indigenous cancer patients.

By systematically assessing and addressing patients' needs, IPNs can potentially fill an important gap in the supportive care needs of Indigenous cancer patients currently not covered by the hospital's IHLOs. IPNs could provide tailored support based on study protocols to assist patients beyond the current role of hospital-based IHLOs. For example, the IPN could contact patients after they have been discharged to assess if there are any issues the need assistance with. Based on our experience this assistance is possible but not without its challenges.

Culturally appropriate program/approaches are crucial in enhancing personal empowerment and as a result promote more effective service delivery for Indigenous people (Williams, 1999). The people most able or equipped to provide a culturally safe atmosphere are people

from the same culture (Williams, 1999). Evidence from previous research shows that Aboriginal and Torres Strait Islander cancer patients place high importance on the relationship within their culture and their relationships with staff can affect their engagement in treatment and follow-up (Shahid et al., 2009). While Indigenous people valued the personal interaction with the IPN they also treasured their privacy. The critical point is to recognize the collective bonds within community and find the balance between a personal assistance that is not perceived as intrusive.

With regards the study procedures and the IPN preference for informal assessment of patients, represented a clear conflict of approaches and measurement understanding. Studies involving interventions are designed to evaluate the effects of the interventions to provide evidence for policy and programs in the future implementation of these interventions. Therefore, study design must balance needs for internal validity - an accurate representation of whether an intervention works in a given setting - and external validity - the ability to generalize the results beyond a specific scenario, through careful evaluation designs (Godwin et al., 2003).

The relationships with the host institution, staff members and research team must be built and nurtured in a way to integrate the intervention into the routine of the service. These relationships take time to be developed and not necessarily occur during the study period.

Conclusion

RCT might provide the best available evaluation measure of an intervention but caution should be taken in the implementation process. Socio-cultural aspects and training can affect the conduct of an intervention study. We reported here five issues that need consideration prior to the implementation of IPN intervention. Specifically: (1) Recognition of the

collective bonds within Indigenous community and understanding by IPN of degree of personal assistance perceived as not intrusive by the patient; (2) Conduct of ongoing evaluation of the different role of an IPN involved in this intervention. That is, the difference between acting as IPN (care provider) and researcher (standardized data collection) within the intervention; (3) Acknowledgement that meaningful engagement develops from a trusting/collaborative relationship between research team and study site staff which may not occur in the study time frame; (4) Acknowledgement that existing skills as well as training provided may not translate in the IPN understanding and aligning with the study objectives/research values; (5) Recruitment of participants requires innovative and highly flexible strategies to be successful.

In considering our findings the reader should bear in mind this was a small pilot study, which impacts on the generalisability of our findings. Nevertheless, the study gave us a valuable insight of the various aspects that can affect the conduct of a research study in a hospital setting and will help inform the design of future RCT in this group. A refined intervention should be tested in a RCT with an adequately powered sample size.

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