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Engagement and accountability in your community
Guest Editors: Josée Lavoie and Lisa Schilling

241 Editorial

244 Civic engagement in the Indonesia health sector: the role of religiosity, empathy, and materialism attitude
Aluisius Hery Pratowo, Firman Rosjadi Djoenadi, Christina Avanti, Nur flora Nita Taruli Basa Sinaga and Asri Maharani

261 Lessons from the field for community engagement and accountability
Alex Berland

267 A content analysis of Arabic YouTube videos for cancer treatment
Ajayeb S. Abu Daabes and Faten F. Kharbat

274 Health service engagement with consumers and community in Australia for issue: engagement and accountability with your community
Shane Rendalls, Allan D. Spigelman, Catherine Goodwin and Nataliya Daniel

284 Power of partnerships: what makes a difference in reducing maternal mortality and how can Canadians contribute?
Farah Shroff, Jasmit S. Minhas and Christian Laugen

298 Equity analysis of health system accessibility from perspective of people with disability
Hussain Zandam and Muhamad Hanafiah Juri

310 Health delivery system for older adults in academic campus in India
Tulika Bhattacharyya, Chandrima Chatterjee and Suhita Chopra Chatterjee

323 It takes a community to care for the sick and disabled
Fiona MacVane Phipps


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Whose community is being benefitted?

Engagement and accountability with your community is the theme in this issue, and there is no denying that virtual communities are and will remain a significant political reality. Drawn together by common interests and philosophies, members of virtual communities share information and messages of support on web sites provided by companies that report tens of billions of dollars in annual profit. Since it has become evident that corporations like Facebook earn their profit from third parties, not from virtual community members themselves; have been unable or unwilling to prevent the spread of damaging deliberate misinformation content on their platforms; and in expanding their corporate value to third parties they have on several occasions violated the privacy of millions of their virtual community members; regulatory agencies in the European Union and the USA have started taking action through fines and proposed regulation. It is crucial to ask whose community is being benefitted by social media, and to what extent are communities being harmed. Case in point: vaccination advice.

Leading policy and law makers in the UK (Lomas, 2019; Pym, 2019), USA (Najera, 2019) and elsewhere are applying pressure to social media corporations so that false and misleading anti-vaccination information should not continue to receive prominence on these virtual community distribution channels. Good governance often requires making difficult and sometimes unpopular decisions in order to maintain a community’s health when the best available scientific evidence contradicts popular viewpoints. However, one consequence of the populist political movement has been a backlash against political leaders who oppose the anti-vaccination movement on scientific grounds (e.g. in Italy; Broder, 2019). In the USA, following widespread criticism by scientists, public health and medical professionals against President Trump’s proposal to form a commission on vaccine safety and scientific integrity chaired by a vaccine skeptic (Anon, 2017), then apparent lack of action to form that commission (Smith, 2018), anti-vaccine advocates launched an effort on Facebook to “Inundate the CDC ACIP Meetings” (Wadman, 2019). Accounts of the meeting exchanges are disheartening (https://respectfulinsolence.com/2019/02/28/antivaxers-inundate-the-advisory-committee-on-immunization-practices/). Andrew Wakefield, the disgraced former UK gastroenterologist who left the UK after his falsified research against vaccination was discredited, is quoted as stating while attending one of President Trump’s inaugural balls “What we need now is a huge shakeup at the Centers for Disease Control and Prevention (CDC) – a huge shakeup. We need that to change dramatically” (Boseley, 2018).

The World Health Organization has identified vaccination hesitancy as one of today’s top ten threats to global health (WHO, 2019). In this journal’s 2017 theme issue on “Vaccine-preventable diseases: organizational issues and challenges,” one of the articles (Attwell and Smith, 2017) made the case that members of a social identity group will selectively accept or reject information based upon whether that evidence is consistent with their identity-group beliefs or not. In short, those members value tribal identity to the extent that simply providing factual education to counter misinformation will not cause all of their vaccine-hesitant community members to change. Given the ease and effectiveness of reinforcing such communities through social media platforms, this raises the question of whose community is being benefitted by the platform products of the for-profit corporations. Several countries have experienced a decrease in immunization rates followed by an increase in outbreaks of vaccine-preventable diseases such as measles that threaten
the well-being of many who cannot be vaccinated due to infant age or medical contraindication. Unable to stop the promotion of misleading anti-vaccine information readily found on the internet, several jurisdictions subsequently introduced legislation to require either disclosure of mumps-measles-rubella vaccination status for school entry or initiated mandatory vaccination programs, measures that come with political costs. Understanding the levels and drivers of public support for these and other policy options in specific communities is beneficial (Bettinger et al., 2019).

Shareholders in the social media corporations, executives of the corporations, members of virtual communities, and affected societies as a whole are stakeholders in the question of whose community is being benefitted. An ethical construct should guide the governance of social media platforms and their corporate providers, and there is little in the broad categories of ethical theory (deontology, utilitarianism, rights and virtues) that would seem to support a minority holding any privileges to sow misinformation that harms many others. While foundational documents like the American Constitution and Bill of Rights protect freedom of speech, deliberate false statement of fact is not necessarily constitutionally protected free speech. A series of US Supreme Court cases establish that “False statements that are on matters of public concern and that defame public figures are unprotected if either the speaker has knowledge that his statements are false, there is a negligence in the statement, or there is ‘actual malice’ to inflict harm” (https://en.wikipedia.org/wiki/False_statements_of_fact). Thus, there may be a legal framework (slander, libel, fraud and criminal liability) to enforce an ethical construct in this matter. Those who espouse or distribute an injurious false statement of fact should not be the community benefitted by social media platforms, and governance of the corporations providing those platforms clearly has not been adequate.

David Birnbaum and Michael Decker

References


Civic engagement in the Indonesia health sector
The role of religiosity, empathy, and materialism attitude

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Abstract

Purpose – The purpose of this paper is to understand the impact of religiosity on civic engagement in the health sector through giving advocacy for people with AIDs, mental health, cancer and disability.

Design/methodology/approach – The authors achieve this aim by proposing a structural equation model, which was derived based on literature. The data collection involved an on-line purposive sampling survey, which targeted young people who intend to work in the health sector. The survey asked about the experience and perception of 610 respondents in Indonesia.

Findings – The results indicate that the respondents with high religiosity were identified to be more caring towards those who suffer from mental health, AIDs, cancer and disability. However, the highly religious were less motivated by empathy in conducting civic engagement in the health sector. In this study, the impact of religiosity on civic engagement was found to be stronger for those who identified with low materialism.

Originality/value – The study contributes to the discussion on altruistic theory by challenging the widespread assumption that feelings of empathy drive civic engagement. The results extend the discussion on how to promote civic engagement in the health sector for young people with high materialism attitude.

Keywords – Emerging health economies, Emerging healthcare delivery structures, Cancer, Quantitative research, Political strategy, Behavioural social or mental health issues, One health movement

Paper type – Research paper

Introduction

Community engagement is an essential element for the public health sector, especially in developing countries, where there is a need of remarkable resilience to deal with an issue of great complexity. The concept of community engagement in the health sector has been paved the way to a core strategy of the WHO framework since the Alma Ata Declaration in 1987 (World Health Organization, 2017). This action needs partnership, which calls for great socio-political empowerment and sense of community through encouraging social networks and communication (Ramey et al., 2018).

Many developing countries line up behind the ambitious agenda of sustainable development goals due to lack of human capital investment in the health, education, and nutrition of people. Among those countries, Indonesia attempts to end the communicable diseases by fostering community engagement (UNDP, 2017). The practices of civic engagement in health service challenges acceptability, adaptability, quality and non-discrimination in public health services (Pratono and Maharani, 2018). As the tradition proposition indicates that religiosity makes people more generous, another study suggests that Indonesian physicians keep religious practices when caring for patients (Lucchetti et al., 2016).
Religious beliefs may become the primary antecedent to the civic engagement in voluntary contribution in health movement (Charsetad, 2016). The studies supporting the proposition that being religious is associated with the generosity of the people may face the inequality of relationships, which take more than policy pronouncements (Sablosky, 2014). Hence, the partnership between development agencies and faith communities have also multiplied (Deneulin and Zampini-Davies, 2017). On the other hand, religiosity often results in a barrier to community engagement, especially when religiosity generates an exclusive community (Lowicki and Zajenkowski, 2017).

Research on responses to community engagement has described the struggles of citizens to deal with various health issues. Silke et al. (2018) highlight the needs to understand how and why adolescents’ empathy and prosocial responding in various social context with different social targets, including participation in the health sector. Previous studies discuss how the exchange theory examines the willingness to engage in community services (Jha and Bhalla, 2018). A study in Asian context argues that the social paradigm is related to the dimensions of materialism (Polonsky et al., 2014). Prosocial behaviour highlights the exposure to individual values (Silke et al., 2018), which may involve materialism attitude to improve their social class image (Khare, 2014).

This study seeks to examine the impact of religiosity on civic engagement in the health sector through giving advocacy for people with AIDs, mental health, cancer and disability. We achieve this aim by proposing a model, which explains the relationship between religiosity and community engagement under a various level of materialism behaviour. The model also identifies the mediating effect of empathy. The following sections discuss the literature review on civic engagement in the health sector, hypothesis development that mainly concerns on the relationship between religiosity and engagement in the health sector, the research method of the on-line survey, empirical results, and discussion on both theoretical and managerial contributions related to the theory of materialism.

**Literature review**

**Civic engagement in the health sector**

Civic engagement refers to a process of developing relationships that enable stakeholders to work together to address health issues and promote well-being to achieve positive health impact and outcomes (World Health Organization, 2017). Improving population health often requires policy changes that spring from complicated advocacy efforts. Information exchanges among researchers, advocates and policymakers are paramount to policy interventions to improve health outcomes (Tabak et al., 2015). The main reason for utilising community engagement in public services may come from the decreasing boundary critique from the population and especially preventing later conflict between stakeholders in the area (Konst-Laakso and Rantala, 2018). Incorporating research to support advocacy work in public health needs to understand the skills and resources required for advocacy (Smith and Stewart, 2017).

The materialism theory highlights the initiative to build a relationship under dynamic context by creating innovative action (Lupton, 2019). The excellent public awareness in health sector warrants advocacy on the part of health advocacy groups and healthcare professionals (Pearson et al., 2015). Information exchanges among the citizens may include evidence on what works well for whom and cost-effective strategies to improve outcomes of interest, but the information is not easily communicated (Tabak et al., 2015). Hence, the advocacy demonstrates not only increasing recognition of mental health people, cancer, and disability but also legitimation through strengthening the voice and legal advocacy (Newbingging and Ridley, 2018).

Civic engagement demonstrates not only personal involvement in activities but also motivation to promote participation as well as the efficacy of participation (Schulze et al., 2010).
The need of participatory governance and stakeholders is essential for the general public sector, where the stakeholders are shaping the implementation and influencing the relationship between the service providers and beneficiaries (Komendantova et al., 2018). Public health researchers, policymakers and advocates acknowledge the role of engagement in public health, which involves advocacy and lobbying activities (Smith and Stewart, 2017). Effective knowledge-driven advocacy demonstrates the capability of citizenship to access various conceptual resources through sharing group to make sense of their experience (Newbingging and Ridley, 2018) and adapting the diverse interests of targeted groups and stakeholders (Adonteng-Kissi and Adonteng-Kissi, 2017).

The cancer advocacy groups take substantial time to cultivate through community support and grassroots activism (Maxwell, 2015). Transnational advocacy networks play a pivotal role to deal with global HIV and AIDS governance by involving global governance with local articulations through routed systems (Marx et al., 2012). The initiative to promote civic engagement in their broader community and awareness-raising and advocacy efforts around sexual orientation has been emerging (Poteat et al., 2018). However, there have been few adaptations of effective interventions from high-income countries and few high-quality evaluation studies in low- and middle-income countries, beyond those in sexual and reproductive health (Patton et al., 2016). The barrier to support disabled people may spring from stigma, discrimination and the hidden nature of negative attitudes (King et al., 2019).

Hypothesis development
This study concerns with four constructs, i.e. religiosity, civic engagement in the health sector, empathy, and materialism. Hence, we propose four hypotheses:

**H1.** Religiosity positively affects the engagement in health care services.

Religion has been acknowledged as an alternative medicine technique or through a psychosocial coping mechanism (Goss and Bishop, 2018). Religious attendance positively correlates with volunteering, charitable giving, as well as informal activities such as helping and supporting friends, family and neighbours (Lewis et al., 2013). The religious beliefs of workers in the health sector affect the interaction with that demonstrates patient care (Bjarnason, 2007). The religious beliefs also become the primary antecedent to the attitude towards blood donation as considerable prosocial activities (Charsetad, 2016). Religious activities play a pivotal role to increase the acceptability of health services with support from local volunteers (Pratono and Maharani, 2018).

Religiosity refers to ritual and ceremony that show socially based beliefs and traditions, which may contribute to a value of belonging and acceptance (Dein et al., 2010). The initiatives in the health sector include matching community engagement with the age and stage of the family with modifiable recruitment and retention practices (Kulig et al., 2018). Religion may promote social change independently from the level of development and modernisation (Autiero, 2018). Since religiosity encourages empathy, some studies argue that there is no relationship between empathy and discrimination (Silke et al., 2018).

The engagement in the health sector needs support from the local religious leaders due to their role as opinion shapers, especially when protecting people’s health and caring for the environment become religious objectives or ways of honouring God (Deneulin and Zampini-Davies, 2017). Religious leaders see themselves as health promoters as their belief is translatable into a successful health programme, which could be part of the religious-based information materials (Lumpkins et al., 2013). The stigma of having a curse or punishment from God may spring from the religious people, who prejudice against the HIV/AIDS patients from a religious perspective (Muturi and An, 2010). Promoting religious tolerance is more about encouraging people to accept other religious beliefs and practices.
rather than discouraging them from having any objections towards things that contradict one's sacred beliefs (Verkuyten and Yogeeswaran, 2017):

**H2.** Religiosity positively affects empathy.

Religiosity has a strong relationship with empathy through enhancing the capability to attribute mind to another human being. Lack of empathy prevents not only social interaction but also religiosity (Lowicki and Zajenkowski, 2017). Integral emotions are elicited in response to a target stimulus and therefore offer the opportunity to shape the feelings evoked. Religious practice is related to the higher perceived threat and lower empathy, while the religious practice is essential to sensibilities (Bilali et al., 2018).

The initiative of praying with patients has been the subject of contentious debate. It will be helpful for some patients by strengthening the therapeutic alliance; the response may call for sensitivity (Dein et al., 2010). Empathy is essential for health care services, especially when patients consider the compassionate of healthcare providers for service delivery (Kemp et al., 2017). However, empathy may have severe limitations. Empathy may occur with ingroup bias, such as religious, race and attractiveness (Bloom, 2017). The lack of empathy may play in conferring risk for conduct problem. Socio-environmental processes empathy development is associated with cognitive and socio-environmental processes (Moul et al., 2018).

The religiosity is part of the service of self-enhancement, which demonstrates socially desirable responding (Sedikides and Gebauer, 2010). The prejudice in moralised entities and activities leads to avoidance rather than toleration (Verkuyten and Yogeeswaran, 2017). The intention to buy products of people with a health problem may demonstrate initiative of consumers with high religiosity (Kuo and Kalargyrou, 2014). A negative association between religiosity and AIDS is related stigma, which shows those who are affected by HIV/AIDS (Muturi and An, 2010):

**H3.** Empathy and community engagement in health care services.

Empathy refers to a natural socio-emotional need to understand the others who deal with an unfortunate situation (Bloom, 2017; Kemp et al., 2017). In the narrow sense, empathy becomes a positive force for good by motivating us to care about and help that person (Bloom, 2017). However, the transition from the agrarian societies to the industrial ones contributes to the shift from traditional values and orientation towards materialist, rational and secular values (Autiero, 2018).

There is a growing consensus that community development needs to cultivate not only a greater sense of empathy but also to realise the greater social well-being (Silke et al., 2018). Empathy and moral obligation contribute to the feasibility of starting a civic engagement, including voluntary in health service (Hockerts, 2015). Empathy is an emotional appeal, which influences the way people view their relationship with an unfortunate person, and thus help build stable relationships (Kemp et al., 2017).

Expression of empathy among young people is related to their exposure to critical environmental process as well as individual values (Silke et al., 2018). Community engagement may evoke an empathic response that plays in not only imparting traditional clinical skill-based knowledge but also facilitating the interpersonal skills (William et al., 2012). The empathic concern becomes predictive of prosocial behaviour (Decety et al., 2018). Working with community members encourage volunteers to confront unfamiliar issues and feel emotions, including greater empathy for others (Tremblay and Harris, 2018):

**H4.** Materialism moderate the relationship between religiosity and civic engagement in health care services.

Materialism is an essential element for those who lay their value to material goods in general, which distinguishes it from consumption itself (Polonsky et al., 2014). Silke et al. (2018)
identify that civic engagement is associated to the exposure of the adolescents to the key environmental processes (extra-curricular activities) as well as the individual values (self-efficacy). Both key environmental processes and individual values entail materialism attitude in which individuals become more susceptible to pronounce their performance by acquiring valuable brands to improve their social class (Khare, 2014; Pratono and Tjahjono, 2017). Consumers with materialism behaviour seek to fulfil through material possessions (Segev et al., 2015). Possession helps materialistic individuals in improving self-identity, which becomes central to happiness (Khare, 2014). Hence, religiosity with materialism attitude may lead to better outcomes in life satisfaction (VanderWeele, 2017).

A country in post-materialism experiences that religiosity foster altruistic and community engagement behaviour (Mostafa, 2016). They may consider that materialism is not seen as the road to individual well-being (Polonsky et al., 2014). Those who are materialistic and utilitarian orientation use religion as a means of achieving mundane goals, which show lack of sensitiveness to community engagement issues (Islam and Chandrasekaran, 2016). Materialism influence the relationship between credibility and intention to charity decreases (Pratono, 2019).

The citizen with strong religious believes that donation to international charities can help them to gain recognition from employers and co-workers (Teah et al., 2014). The religiosity and materialism were inversely related, whereby religious people tend to become less materialistic (Bakar et al., 2013). Value from financial success is different from the feminine value that is related with modesty, caring, harmony and a focus on improving the quality of life (Steel et al., 2018).

**Research method**

**Model**

This study puts forward a structural equation model to explore the complicated relationship between religiosity and civic engagement. The structural equation model involves four latent variables, engagement in the health sector, religiosity, empathy, and materialism attitude, which are related to each other. The model analysis of each construct and the relationship between them, which represent the hypotheses.

This study determines the hypotheses for the relationship between the constructs in the structural equation model following the concept. The model consists of two elements: the structural model and the measurement models. The structural model explores the relationship between religiosity and community engagement, while the measurement models explain the relationship between the latent variables and the indicators.

Introducing a mediating variable helps the study to explore the complicated process by which religiosity influences engagement in the health sector. The path model shows the direct effect and indirect effect. The direct impact explains the immediate impact of religiosity on community engagement. Hence, the indirect impact explains the relationship that entails a sequence of relationship with empathy as an intervening construct to clarify the relationship between religiosity and engagement in the health sector.

A moderating variable explains the interaction between the religiosity and engagement in various level of materialism attitude. With moderation, the construct of materialism attitude directly influences the relationship between the religiosity and engagement at a high level, moderate level and low level of materialism attitude. The distinction between moderating and mediating variables is that moderating variable does not depend on the predictor variable.

**The measures**

According to the measurement theory, the outer models involve the reliable or valid relationship between constructs and their corresponding indicator variables (Hair et al., 2014). This study uses questionnaires by adapting from previous studies. The measures of civic
engagement were adapted from Schulz et al. (2010). This study adopts the constructs of religiousness, which involves motivational constructs and religious cognitive-emotional systems (Joseph and Diduca, 2007). This study also adopts the measure of empathy from Hockerts (2015) and the measure of materialism from Khare (2014). Table AI provides detail measures.

Table I shows the measure of engagement represents in the four relative items, P04, P05, P06 and P7, which related to the following survey questions: “my social activities include involvement and advocacy for people with AIDs”, “involvement and advocacy for people with AIDs, “involvement and advocacy for people with cancer”, and “involvement and advocacy for people with disability”. Respondents are encouraged to express the level of agreement to each statement on a seven-point scale from 1 = entirely disagree to 7 fully agree.

Similarly, religiosity is operationalised by four items (R01, R02, R03, R04) that indicated the degree which they agree with each statement on the seven scales. The measures are related to the questions in the survey: “Religion is more important to me than what is happening in national politics”, “religion helps me to decide what is right”, “religious leaders should have more power in society”, and “religious should influence people’s behaviour toward others”.

**Data collection**

The data collection involves an on-line purposive sampling survey, that asked about the experience and perception of respondents with engagement in the health sector. Purposive online samples enhance the probability samples through participant observation of online discussion to access hidden population (Barratt et al., 2015), which is also called as non-random sample selection (Wojtys et al., 2018) The survey sent an invitation to the groups of young people in five cities in Indonesia: Medan, Jakarta, Bandung, Semarang, and Surabaya. We found the groups in social media that expose their community engagement in the health sector.

This study encouraged the respondent to be generous in answering the questionnaire by promising to cover their private information and profile of the organisations. The survey attempted to maintain respondent confidentiality. Privacy and confidentiality become the main reason for low response rates (Buchanan and Hvizdak, 2009). The internet survey is applicable to cluster sampling for targeted discussion groups in the health community and to sample users within the group (Fricker, 2011). By protecting the confidential information, the survey can avoid confidentiality dilemmas that might otherwise lead them not to tell the truth (Kaiser, 2009).

<table>
<thead>
<tr>
<th>Code</th>
<th>Items</th>
<th>VIF</th>
</tr>
</thead>
<tbody>
<tr>
<td>CP4</td>
<td>I intend to get involved in advocacy for people with mental health</td>
<td>1.895</td>
</tr>
<tr>
<td>CP5</td>
<td>I intend to get involved in advocacy for people with AIDs</td>
<td>2.092</td>
</tr>
<tr>
<td>CP6</td>
<td>I intend to get involved in advocacy for people with cancer</td>
<td>2.232</td>
</tr>
<tr>
<td>CP7</td>
<td>I intend to get involved in advocacy for people with disability</td>
<td>1.629</td>
</tr>
</tbody>
</table>

**Materialism**

| M2   | My dream in life is to be able to own expensive things               | 1.699 |
| M3   | People judge others by the things they own                          | 1.857 |
| M4   | I buy some things that I secretly hope will impress other people    | 1.532 |

**Religiosity**

| RE1  | Religion is more important to me than my national politics          | 1.709 |
| RE2  | Religion helps me to decide what is right                           | 2.202 |
| RE3  | Religious leaders should have more power in society                 | 1.499 |
| RE4  | Religious should influence people’s behaviour toward others         | 1.885 |

**Empathy**

| E1   | I don’t care how people feel who live on the margins of society (R) | 1.436 |
| E2   | Seeing socially disadvantaged people triggers an emotional response | 1.488 |
| E3   | I do not experience much emotion when thinking about social         | 1.681 |

| Table I | The measures |
Data collection was carried over six months in 2018 that results with 610 respondents or sample size. The respondents are young people with age between 18 and 25-year old, which 70 per cent of respondents aged 18 and 20. Based on the religious profile, the majority of respondents are Muslim with 60 per cent of the samples, followed by Christian (30 per cent) and others (10 per cent). The survey asked the respondents’ financial profile, only 33 per cent provided information about their daily expenditure. The monthly income of the respondents was US$6,000 on average, which represents the middle-class income in Indonesia.

Data analysis
This study uses partial least square to test the hypothesis by explaining the variance or the prediction of the construct. The SmartPLS 3.2.4 software is used to execute all the PLS-SEM analysis. The algorithm estimation involves path coefficients that explain the variance of the dependent constructs. The variables represent individuals with the measurements taken from the survey. The outer models explain how these variable constructs are measured. The reflective model has arrows pointing from the constructs to obtain validity and reliability of the constructs.

Results
The first model assessment focusses on the measurement models by evaluating the reliability and validity of the construct measures. Table II shows the traditional criteria for internal consistency relies on the coefficients of Cronbach’s $\alpha$, which indicate that all constructs are reliable with coefficients higher than 0.75. The coefficients of composite reliability also suggest that the observed constructs meet the standard for internal consistency reliability with values ranges from 0.851 to 0.882.

Table II provides convergent validity for measuring that correlation between alternative measures of the same construct. The coefficient of average variance extracted (AVE) are higher than 0.64, which indicates the construct explains more than half of the variance of its indicators. The convergent validity is also available at the Appendix, which shows the outer loadings on each construct is significant (Table AI). The results indicate that the coefficients of the outer loadings are higher than 0.708 (Table AII). Overall, the results show the high commonality of each construct.

Table II shows the discriminant validity with the Fornell-Larcker criterion to evaluate the reflective measurement models. The diagonal indicates the square root of each

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Cronbach’s $\alpha$</th>
<th>rho_A</th>
<th>Composite reliability</th>
<th>Average variance extracted (AVE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement in health service</td>
<td>0.829</td>
<td>0.871</td>
<td>0.882</td>
<td>0.652</td>
</tr>
<tr>
<td>Materialism attitude</td>
<td>0.789</td>
<td>0.976</td>
<td>0.862</td>
<td>0.678</td>
</tr>
<tr>
<td>Religiosity</td>
<td>0.816</td>
<td>0.867</td>
<td>0.877</td>
<td>0.642</td>
</tr>
<tr>
<td>Empathy</td>
<td>0.750</td>
<td>0.838</td>
<td>0.851</td>
<td>0.656</td>
</tr>
</tbody>
</table>

Table III shows the discriminant validity with the Fornell-Larcker criterion to evaluate the reflective measurement models. The diagonal indicates the square root of each

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Empathy</th>
<th>Engagement</th>
<th>Materialism attitude</th>
<th>Moderating effect</th>
<th>Religiosity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>0.810</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Engagement in health service</td>
<td>0.160</td>
<td>0.807</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Materialism attitude</td>
<td>0.468</td>
<td>−0.119</td>
<td>0.823</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderating effect</td>
<td>0.105</td>
<td>0.117</td>
<td>0.165</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Religiosity</td>
<td>0.146</td>
<td>0.392</td>
<td>−0.032</td>
<td>−0.046</td>
<td>0.801</td>
</tr>
</tbody>
</table>
construct’s AVE, while the non-diagonal elements show the correlation between the latent variables. The values of the square root of the AVE of each construct at the diagonal are more significant than 0.8, while the non-diagonal values are less than 0.4. The results show that the discriminant validity meets the Fornell-Larcker criterion, which indicates the high levels of convergent validity.

After examining the constructs’ reliability and validity, this analysis continues with the assessment of the structural equation model. This step requires to explore the model for collinearity since the estimation uses the OLS regressions that each endogenous latent variable relates to the predecessor constructs. Table I shows the outer VIF with the CP6 has the highest VIP value, while inner VIF values are less than 1.3. All of the VIF values are below the threshold value of 5.0 (see Table IV). The results indicate that the collinearity does not an issue for estimating the model.

For the goodness of fit, Table V shows that the standardised root means square (SRMS) is less than 1.0, which indicates no discrepancy between the implied model and the observed correlation. The results suggest that the model fits for the empirical data. The coefficient of determination or $R^2$ value shows that the three constructs explain 51 per cent of the variance of the endogenous construct. The values indicate the amount of variation in the endogenous constructs described by all exogenous constructs at a moderate level.

The PLS uses a bootstrapping approach to examine whether the path coefficients are significant or not. Table VI shows that all of the empirical $t$-values are larger than the critical value of 1.85 with a significant level of 5 per cent. The exogenous construct of religiosity significantly contributes to explain the endogenous variable of engagement with $t$-value 6.114 and probability of error is close to 1 per cent. This result indicates that $H1$ is...
acceptable, which support the argument that religiosity brings civic engagement in helping friends, family, and neighbours (Lewis et al., 2013). This result also confirms that supporting people’s health and caring for the environment become religious objectives or ways of honouring God (Deneulin and Zampini-Davies, 2017).

Figure 1 provides the results from the PLS-SEM algorithm, which represent the hypothesis relationship among the latent variables. The path coefficients have a positive relationship except for the moderating variable of materialism. The results also confirm that $H2$ and $H3$ are acceptable with positive and significant coefficients, which affirms that religiosity enhances the capability to understand the feeling of another (Lowicki and Zajenkowski, 2017; Bilali et al., 2018). The results also gain support from the previous study, which argues that compassionate encourages for voluntary (Kemp et al., 2017).

The impact of religion on engagement has the most substantial coefficient (0.591), while the weaker relationship occurs in the relationship between religion and empathy (0.159). Table VI also indicate the indirect effect between religiosity and engagement via the mediating construct of empathy. The indirect impact is the product of two effects $0.159 \times 0.186 = 0.029$. The total effect is 0.621, which springs from 0.591 + 0.159×0. When we removed the mediating variable, the direct effect of religiosity on civic engagement is 0.630.

Table VII also provides the coefficient of total effects, which combination of direct effect and indirect effect.

Table VIII shows that the size $f^2$, which indicates that religiosity provides a substantial effect on the civic engagement variable’s $R^2$ value. Besides, materialism and empathy have a smaller impact on engagement than religiosity. However, the effect of materialism is slightly higher than the effect of empathy. The result of blindfolding analysis shows that $Q^2$ is greater than 0, which indicates that the model provides relevance prediction (Table IX).

Figure 1 shows that the interaction between religiosity and materialism positively affects civic engagement with a coefficient value of 0.112, $t$-value of 1.89, and $p = 5$ per cent, which

**Note:** *Significant at alpha 5 per cent
confirms the $H_4$. Figure 2 shows that the slope of religiosity on civic engagement is slightly higher for respondents with high materialism than for respondent with low materialism. However, at the same level of religiosity, the respondents with weak materialism tend to have greater civic engagement than respondent with high materialism. The results support the $H_4$.

**Discussion**

*Theoretical implication*

This study challenges the altruistic theory by asking the effect of religiosity on civic engagement. The results indicate that religiosity is an essential element to civic engagement.

<table>
<thead>
<tr>
<th>Path</th>
<th>Original sample ($O$)</th>
<th>Sample mean ($M$)</th>
<th>SD</th>
<th>$t$-Statistics</th>
<th>$p$-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Materialism $\rightarrow$ Engagement</td>
<td>$-0.224$</td>
<td>$-0.212$</td>
<td>$0.099$</td>
<td>$2.251$</td>
<td>$0.025$</td>
</tr>
<tr>
<td>Moderating effect</td>
<td>$0.151$</td>
<td>$0.136$</td>
<td>$0.085$</td>
<td>$1.789$</td>
<td>$0.074$</td>
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<td>Religiosity $\rightarrow$ Engagement</td>
<td>$0.391$</td>
<td>$0.392$</td>
<td>$0.055$</td>
<td>$7.077$</td>
<td>$0.000$</td>
</tr>
<tr>
<td>Religiosity $\rightarrow$ empathy</td>
<td>$0.146$</td>
<td>$0.159$</td>
<td>$0.058$</td>
<td>$2.525$</td>
<td>$0.012$</td>
</tr>
<tr>
<td>Empathy $\rightarrow$ Engagement</td>
<td>$0.196$</td>
<td>$0.192$</td>
<td>$0.086$</td>
<td>$2.286$</td>
<td>$0.023$</td>
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Table VII. Total effect

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Empathy</th>
<th>Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>0.060</td>
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</tr>
<tr>
<td>Materialism</td>
<td>0.083</td>
<td></td>
</tr>
<tr>
<td>Moderating effect</td>
<td>0.027</td>
<td></td>
</tr>
<tr>
<td>Religiosity</td>
<td>0.026</td>
<td>0.643</td>
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</table>

Table VIII. $f^2$ matrix

<table>
<thead>
<tr>
<th>Constructs</th>
<th>SSO</th>
<th>SSE</th>
<th>$Q^2$ ($=1$−$\text{SSE}/\text{SSO}$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>813</td>
<td>805.546</td>
<td>0.009</td>
</tr>
<tr>
<td>Materialism</td>
<td>1,084.00</td>
<td>1,084.00</td>
<td></td>
</tr>
<tr>
<td>Moderating effect</td>
<td>271</td>
<td>271</td>
<td></td>
</tr>
<tr>
<td>Religiosity</td>
<td>813</td>
<td>813</td>
<td></td>
</tr>
<tr>
<td>Engagement</td>
<td>1,084.00</td>
<td>708.539</td>
<td>0.346</td>
</tr>
</tbody>
</table>

Table IX. Blindfolding analysis

Figure 2. Moderating effect of materialism attitude
in the health sector. The respondents with higher scores in religiosity tend to be more caring towards those who suffer from mental health, AIDS, cancer and disability. The results confirm previous studies, which argue that religiosity people are encouraged to support health sector through volunteering, charitable giving and other informal supporting activities (Lewis et al., 2013; Deneulin and Zampini-Davies, 2017; Goss and Bishop, 2018; Pratono and Maharani, 2018).

This study indicates that civic engagement in the health sector is less motivated by empathy than the findings at the previous studies. This results are different to previous studies, which argue that religious fuels empathy (William et al., 2012; Bilali et al., 2018) and young religious people who are altruistic tendencies tend to get involved at civic engagement (Decety et al., 2018). In comparison with materialism attitude, empathy and religion do not have a strong relationship, and the belief is partly responsible for the lack of empathy in Indonesia people. The results indicate that religiosity has a more significant effect on civic engagement than empathy and materialism. Religiosity influences on empathy do not account for more than 3 per cent of the variance.

Religiosity drives the materialism people to be more generous in supporting those who suffer from mental health, AIDS, cancer and disability. Understanding how materialism works in the positive outcome is essential to promote and encourage civic engagement, especially when materialists are less concerned with the environment (Segev et al., 2015). In this study, the relationship between religiosity and civic engagement was found to be higher for respondents who identified as low materialism than for those with high materialism. This study recognises that for high materialism people, the religiosity is critical to whether they will support those who suffer from the health problem. The results challenge the widespread assumption that empathy is a driving force to civic engagement (Bloom, 2017; Pratono, 2018).

Practical implication
Our findings provide essential inputs for the health sector governance, especially in the low- and middle-income countries with a democratic system. Civic engagement is crucial for establishing good governance as it allows people to deliver their voice and to contribute to the policy-making of their society (Bhargava et al., 2015). In a country with a democratic system, civic engagement shapes the institutions that govern people’s lives. Beyond the formal health system, health sector governance collaborates with other sectors, including civil society, to promote and maintain population health (World Health Organization, 2015).

This study encourages that civic engagement needs to be careful when an attempt to gain from networks of participation. Receiving inattention from the community, AIDS, mental health, and diffable issue may become a continuous problem in the community. O’mara-Eves et al. (2015) show that interventions using community engagement in the field of public health help the community gain greater health outcomes. Networks of participation deepen involvement within the community because someone they trust suggests it (Pratono and Ratih, 2019).

Indonesia is a multicultural country with more than 300 ethnic groups, 750 languages and dialects, and numerous religions. Hence, policy to improve health status among Indonesians should be sensitive to religious and cultural norms. Different religious groups have diverse forms and norms about healthcare and medicine, including maternal and child health. For example, mothers in Nanggroe Aceh Darussalam province, which have a strong Islamic background, believe that death due to childbirth is a “fate” and part of life destiny (Susanti, 2013).

Research limitation
The empirical evidence indicates that religiosity plays a pivotal role in civic engagement. Empathy and prosocial behaviour become valuable resources for a developmental
perspective at young ages. The conclusion needs to consider some limitations. First of all, research indicates that on-line interviews target only specific types of individuals who spend time on the internet. This study may not be able to get responses from a cross-sectional mix of respondents. Second, the PLS-SEM allows the study to examine the mediating role of empathy and the moderating part of materialism attitude. The PLS SEM algorithm requires a recursive model and cannot handle the circular relationships between the latent variables (Hair et al., 2014).

This study adopts the concept of civic engagement from Schulz et al. (2010), which mainly concern the intention to support people with mental health, AIDs, cancer and disability. Future studies are encouraged to explore more cases, which may have different support from the communities. The initiative to develop a new construct should meet the principle of the reliability and validity from the measurement theory, which examines the relationship between constructs and the corresponding indicator variables (Hair et al., 2014).

Last, this study focussed on a cross-section survey to understand the attitudes and beliefs of young people in the Indonesia context regarding participatory in the health sector. The data collection involves an on-line interview, which may ignore the young people who have no access to the internet. Also, peer relationships and institutional context were not examined in this particular study, which may bring an additional limitation which needs to be addressed in future studies. We suggest the future studies adopt various data collection, such as face-to-face interview, offline survey, and telephone interview for civic engagement in the health sector. Different survey methods need to be tested, which may provide different results.

Conclusion
This paper contributes to the discussion on altruistic theory by challenging a widespread assumption that the feeling of empathy drives civic engagement. The effect of religiosity on generosity become weak for those who have high materialism. The results are different from the tradition proposition, which argues that religion makes people more generous. This study recognises that for top materialism people, the religiosity is critical to whether they will support those who suffer from the health problem.

References


Appendix

<table>
<thead>
<tr>
<th>Construct</th>
<th>Empathy</th>
<th>Engagement</th>
<th>p-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td></td>
<td>-0.032</td>
<td></td>
</tr>
<tr>
<td>Materialism</td>
<td></td>
<td>-0.130</td>
<td></td>
</tr>
<tr>
<td>Moderating effect</td>
<td></td>
<td>0.118</td>
<td></td>
</tr>
<tr>
<td>Religiosity</td>
<td>0.397</td>
<td>0.963</td>
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Table AI. Finite mixture (FIMIX) segmentation

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<tr>
<th>Path</th>
<th>Original sample (O)</th>
<th>Sample mean (M)</th>
<th>SD (STDEV)</th>
<th>t-Statistics (O/STDEV)</th>
<th>p-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>C01 ← engagement</td>
<td>0.865</td>
<td>0.863</td>
<td>0.021</td>
<td>40.331</td>
<td>0.000</td>
</tr>
<tr>
<td>C03 ← engagement</td>
<td>0.901</td>
<td>0.900</td>
<td>0.015</td>
<td>61.549</td>
<td>0.000</td>
</tr>
<tr>
<td>C04 ← engagement</td>
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<td>0.872</td>
<td>0.020</td>
<td>44.080</td>
<td>0.000</td>
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<tr>
<td>C05 ← engagement</td>
<td>0.845</td>
<td>0.843</td>
<td>0.027</td>
<td>31.080</td>
<td>0.000</td>
</tr>
<tr>
<td>E02 ← Empathy</td>
<td>0.862</td>
<td>0.854</td>
<td>0.084</td>
<td>10.250</td>
<td>0.000</td>
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<tr>
<td>E08 ← Empathy</td>
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<td>0.717</td>
<td>0.107</td>
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<tr>
<td>E10 ← Empathy</td>
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<td>0.782</td>
<td>0.085</td>
<td>9.455</td>
<td>0.000</td>
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<tr>
<td>IR03 ← Religiosity</td>
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<td>0.911</td>
<td>0.014</td>
<td>64.078</td>
<td>0.000</td>
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<tr>
<td>IR04 ← Religiosity</td>
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<td>0.894</td>
<td>0.021</td>
<td>42.311</td>
<td>0.000</td>
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<tr>
<td>IR05 ← Religiosity</td>
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<td>0.825</td>
<td>0.035</td>
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<td>0.000</td>
</tr>
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<td>M02 ← Materialism</td>
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<td>0.783</td>
<td>0.062</td>
<td>12.778</td>
<td>0.000</td>
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<td>0.000</td>
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<td>M06 ← Materialism</td>
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<td>0.000</td>
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<td>1.059</td>
<td>0.087</td>
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Table AII. Outer loading with bootstrap approach
### Table AIII.

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<th>Materialism attitude</th>
<th>Engagement</th>
<th>Religiosity</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E02</td>
<td>0.881</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E03</td>
<td>0.788</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M02</td>
<td></td>
<td>0.723</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M03</td>
<td></td>
<td>0.826</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M04</td>
<td></td>
<td>0.911</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P04</td>
<td></td>
<td></td>
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<tr>
<td>P05</td>
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<td>P06</td>
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<td>P07</td>
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<td></td>
</tr>
<tr>
<td>R01</td>
<td></td>
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<tr>
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Lessons from the field for community engagement and accountability

Alex Berland
A. Berland Inc., Vancouver, Canada

Abstract

Purpose – In Canada, community engagement and accountability are a political imperative, resulting in an omnipresent program with varied opportunities for public participation. The purpose of this paper is to promote leadership and commitment for health system transformation that truly benefits communities.

Design/methodology/approach – This paper is based on the author’s experience with many engagement and accountability activities, applied in varied settings, for purposes such as evaluation, planning, policy making and system transformation. The specific context is generalized with international experiences and references.

Findings – The “lessons learned” are based on practical considerations with relevance for both novice and experienced practitioners: clarifying principles, processes and purposes at the outset; using effective leadership to achieve the desired impact; using a variety of methods to engage communities; clarifying engagement and accountability roles precisely; measuring things that are meaningful; and consulting with internal as well as external communities. Also, community leaders should recognize effort as well as results.

Research limitations/implications – Commitment to engagement and accountability is commendable – but is it enough? The paper concludes by looking beyond health system impacts to propose a broader systems perspective. If clinical governors want to use engagement and accountability to achieve “total value” for their communities, they will need to demonstrate as leaders that they are committed to long-term thinking and broad social goals.

Originality/value – Too much focus on the process of care may mask accountability for reporting outcomes or systemic impact. The sustainable development goals highlight the need for systems thinking and public expectations include corporate social responsibility. As shown in the examples cited, a deeper commitment to engagement and accountability requires looking beyond care delivery to social determinants and to systemic impacts of the health care industry itself.

Keywords User involvement, Leadership, Process mapping, Governance structures, Organizational development for effective clinical governance, First Nations/Indigenous peoples health

Paper type Viewpoint

For several decades, governments throughout Canada have required service providers to engage with and be accountable to their communities. This is a reasonable expectation because most health care in this country is funded by citizens through a tax-based universal health care system. Over time, the consultation imperative has been sustained through changing political regimes; it is today an omnipresent program with varied opportunities for public participation in co-designing care. The following recommendations are based on the author’s experience with engagement and accountability activities, applied in settings such as community agencies, hospitals and mental health services, for purposes ranging from service evaluation to strategic planning, policy making and even radical system transformation. As “lessons from the field” are valid for a specific context, they are accompanied here by relevant references from other jurisdictions.

1. Clarify principles, processes and purposes at the outset

Government agencies or health care providers often wish to consult communities for their input or reaction to a strategic objective or plan. However, stakeholders and community groups, if they have any experience, may view these efforts with suspicion. Therefore, providers should state at
the outset clearly defined principles to which they will commit themselves. These principles could include for example, mutual trust building, transparency, respect for diversity and inclusiveness, and goals of social justice and equity. “The engagement process itself, and how it feels, is what engages people with the mission or needs of the organization” (Ockenden, 2019).

Providers should also explain thoroughly how their consultation will proceed and how the results will be used. The International Association of Public Participation (IAP2) is an NGO that describes a spectrum of public participation framed within specific values and ethical principles. The IAP2 continuum defines specific purposes of participation such as inform, consult, involve, collaborate and empower, with a goal and “promise to the public” for each level of participation (International Association of Public Participation, 2019). By clarifying the expected process and outcomes of the engagement, providers can demonstrate trustworthiness as well as competence.

The concept of “reciprocal accountability” has been introduced in British Columbia (BC) Canada by a relatively new entity, the First Nations Health Authority (FNHA), which has assumed responsibility for many services to Aboriginal communities that were previously delivered by other levels of government. An early task for the new organization was to engage with dozens of First Nations communities and pre-existing service providers. In response, FNHA developed an iterative “Engagement and Approvals Pathway” to elicit guidance and build consensus, based on principles for reciprocal accountability such as “Balanced expectations based on capacities” and “Clear roles and responsibilities for the partners.” These accountability principles are further detailed for community, regional and national or provincial level responsibilities (First Nations Health Council, 2011).

2. Use effective leadership to achieve the desired impact

Although the products of an engagement may be reactive, leadership must be an active process based on commitment to the principles. Consultation leaders must demonstrate that they can be trusted by, for example, showing that they will always listen, if not necessarily agree. Where disagreement occurs, engagement may include intensive dialogue and negotiation, even confrontation, not necessarily in a public forum. The accountability around such disagreements should follow ethical and practical principles such as focusing on issues not personalities, respecting confidentiality, bargaining in good faith and truth-telling.

Sometime communities may resist attempts at engagement, especially if they feel manipulated by consultation processes that avoid important issues. For example, focusing on patients’ experience only during the hospital phase of surgery omits the politically sensitive topic of barriers to access such as travel distance, cost and delays, as well as the professionally complex topic of after-care and follow-up in community settings. In such cases, leadership requires asymmetric openness, namely significant effort by providers to demonstrate accountability. An example of this openness is the Independent Reconfiguration Panel approach used by England’s National Health Service (NHS), which reviews service changes contested by affected communities and requires documented evidence of consultation that follows detailed statutory guidelines (National Health Service, England, 2017).

Leadership also implies sharing as much strategic and operational information as is feasible and relevant. The benefit is that leadership is usually present at all levels in groups. This means that learning can truly be a two-way exchange: varied perspectives on a problem may yield novel insights and suggestions. In order to engage many voices, however, leaders should manage common engagement problems such as consultation fatigue among vulnerable groups, domination or opposition by powerful stakeholders and insufficient information. In such situations, leaders can apply emotional intelligence, responding appropriately to specific concerns in order to help the entire group engage effectively. Where resistance is greater, consider using outside facilitators who can be seen as neutral parties and are likely to have greater expertise in managing group dynamics.
3. **Use a variety of methods to engage communities**

For episodic consultation, relatively superficial engagement options include online surveys, larger public forums and specialized focus groups. For these methods, it is important to avoid problems such as representation bias and top-down definition of issues. A good example of a more in-depth episodic activity is “patient journey mapping,” which examines care processes for the purpose of improving quality, efficiency and service coordination (Treble *et al.*, 2010). The BC Patient Safety and Quality Council (2018) conducted such an exercise for people who use drugs (i.e. opioids) to better understand their perspectives and experience when accessing treatment in primary care settings. In addition to primary care clinicians and health authority managers, the organizers invited people who use drugs, including Aboriginal representatives due to the disproportionate impact on their communities. One participant commented, “Building engagement is as important as anything else providers do.”

Regular, ongoing engagement processes are more appropriate than episodic efforts for deeper relationships with communities. These might include for example an independent Patient Advocacy Service that could review provider services, steer patients toward formal complaints processes, or act as an independent facilitator. Another example would be independent Citizens’ Forums in each community that could provide ongoing input to providers about how well local services operate. Similarly, non-executive directors can be appointed to governing bodies to increase representativeness and to help ensure openness and due process. As discussed below, whatever the method of engagement, lay community members need training and dedicated support to learn about the complexities of service planning and delivery. A special concern for minority or vulnerable populations is to ensure they are both supported and sufficiently numerous not to be isolated as “token” representatives. Support in this instance includes creating a safe environment for all participants and removing barriers such as costs, transport problems, language and literacy (Ockenden, 2019).

4. **Clarify engagement and accountability roles precisely**

In all these examples, it is critical to specify “who does what for whom.” In the case of engagement around clinical issues, BC’s Patient Voices Network (2019) uses a variety of methods to help community members engage productively. Resources for the Network’s member-participants include webinars on understanding the health care system, and skill-building for facilitation and presentation. Resources for providers include guidance on conducting open-ended discussions with communities about their priorities for care.

Terms of reference for any larger-scale engagement process should detail roles and responsibilities, such as who appoints and authorizes the process and to whom those leading the process are accountable; who will be deciding the process and the communities to be engaged; and how much information must be shared during the engagement process. The key issue for governing bodies is to decide the degree of independence or powers for those leading any engagement or accountability process. These powers may include, for example, whether the scope of work is restricted to service delivery or if it can look at systemic issues; who will review, approve, or receive any reports; whether any advocacy function is allowed; the depth and scope of interaction with stakeholders and the public; any authority to monitor, audit, inspect, or conduct research, and any requirement for service provider co-operation.

5. **Measure things that are meaningful**

Any accountability process that wants to involve a community needs to measure things that are significant for that group. Being accountable should include reporting relevant outcomes in accessible ways. As in the old maxim, “Systems learn from data, but people learn from stories.” For expert audiences, accreditation results, both positive and negative, can be supplied unedited. The general public needs translation: an NHS regulator’s website
offers resources that explain “What to expect from good care – whether it’s from a hospital, care home, home care service, GP or dentist” (Care Quality Commission, 2019).

The quantitative indicators cherished by government officials may not be as important for patients and families as an apt narrative illustrating subjective factors or complexities (Berland, 2016). For instance, while director of a psychiatric hospital, the author met over many months with families of patients, adults with severe mental illness. During one meeting, a woman whose son suffered frequent relapses requiring readmission, stated, “You view his care as a failure when he has to return to hospital. I see the care as a success because he is able to cope with living in community for longer periods.” The consequence of that family member’s comment was our increased focus on understanding patients’ experiences of transitions – how well the delivery model articulates with other parts of the patient care journey to and from a home community. These transitions and service transfers can be hazardous, especially for people with recurrent mental health problems and other chronic illnesses.

It is important also to recognize the kind of expertise community members can and cannot contribute: for instance, the quality of patient and family experience – yes; the number and type of human resources required to meet clinical standards – no.

6. Consult with internal as well as external communities

“People support those things that they help to build […] and tend to resist those things that others build for them” (Ockenden, 2019). Therefore, engagement should also apply to clinical and non-clinical staff, managers and even volunteers. The organizational behavior theorist Peter Drucker wrote, “What motivates knowledge workers is […] to know the organization’s mission and to believe in it” (quoted in Wartzman, 2014). Those framing that mission must understand at a deep level what services those knowledge workers actually perform.

A health system, or even its smaller units, may have multiple internal “communities” made up of staff groupings constituted according to professional interests (e.g. pharmacists) or worksite location (e.g. all clinicians and managers working in a particular setting) or social status (e.g. senior doctors with governing board members), or other affiliations based on ethnicity, gender or labor union. In addition, there may be “external plus internal” stakeholders, such as suppliers, including contracted NGOs that provide non-core health services or research funders. Adding to the engagement challenge, these communities may be dynamic: on some occasions acting separately in “silos,” on other occasions forming coalitions across boundaries around specific issues (Glouberman and Mintzberg, 2001).

A systems level example would be internal engagement to anticipate and prepare for changes in health service delivery. Reciprocal accountability could be demonstrated by committing in advance to share the results of analysis and to make a priority of mitigating negative effects for stakeholders. Sharing hard data is important since so many providers have an evidence-based orientation grounded in their scientific training. Moreover, clinicians are often less interested in system level impact, concerned more with results for their individual patients. They may be motivated to engage when accountability is specified with targets for improved patient outcomes to be achieved in a proposed initiative. Unfortunately, in our experience, it has been easier to engage and elicit responses when there is a “burning platform” such as financial pressure, rather than a hypothetical improvement in quality. This is where skilled engagement elicits multiple voices so that necessary but unpopular changes are not just supported from the top but also from other stakeholders in the clinicians’ wider network.

More positively, it is important to engage internally so as to understand what staff experience at the patient care interface, as evidence of the need for improvements in training, resources or policy. In this, the patient journey mapping exercise previously described can be very useful. Due in part to the specialized nature of their work, clinicians may have a narrow view of internal processes related to an individual’s care. A common response to a journey map is, “I had no idea it was so complicated. No wonder we have communication problems at the transition points.”
7. Community leaders should recognize effort as well as results

This final recommendation is about respect for those who seek to engage with their communities. Providers work in a demanding environment, facing both stubborn constraints and unpredictable forces. Politicians may commit to impossible, altruistic goals that must be delivered with limited resources. Unsurprisingly, success is mixed. Community members may also be critical due to historic experience of service failings or residual effects of colonization or other injustices. Although understandable on an intellectual level, hearing directly the anger from disadvantaged communities can be stressful for those trying to engage and to be accountable.

Engagement leaders should be prepared to hear disillusionment around consultation processes. Patient and family groups may have been asked repeatedly for their opinion, yet receive no follow-up about how their voices have influenced decisions. Managers may report that their efforts to respond to feedback are thwarted by institutional factors such as inertia or clinician resistance. Clinicians may believe lack of resources indicates that decision makers have not listened to previous advice. As a result, both internal and external stakeholders may come to believe that consultation is a waste of time with no impact on services or outcomes. As one family group member stated, “You keep asking our opinion. We keep saying the same things. Nothing changes, yet you come back and ask us again. Why do you bother?” The only plausible response to this reasonable challenge is gratitude, sincere communication, sustained effort and demonstration of how public feedback is being used.

Capable leadership is required to sustain an organization’s commitment to engagement and accountability. The critical leadership contribution for any engagement process is meticulous planning to achieve the right scope and balance of participation. True accountability requires leadership in communicating complex results using appropriate methods for varied audiences. From the provider side, leadership is about framing expectations; candidly explaining purposes, causes and effects; and sincerely investigating stakeholder recommendations. On the community side, leadership is about recognition of intentions as well as outcomes; persistence during the long periods required for deep change; and support for those providers who are sincerely committed to engaging with and being accountable to their communities.

8. Conclusion

Commitment to engagement and accountability is commendable – but is it enough? Although focusing on the patient experience is critical for designing service improvements, too much attention to the process of care can mask accountability for reporting outcomes or the systemic impact of providers’ work. Generalities about “saving lives” are no longer enough – among other trends, the sustainable development goals highlight the need for systems thinking. Service providers, whether for profit or not-for-profit, should behave like responsible corporate citizens of their society. A deeper commitment to population health requires looking outside the providers’ delivery models to social determinants of health and to systemic impacts of the health care industry itself. This means that engagement efforts should reach beyond narrow definitions of roles and social contributions. In the corporate world, emerging concepts like “radical transparency” and “integrated reporting” reflect evolving public expectations for accountability. As King (2016) comments, “The concept of value has changed completely. We look at the company’s impact on these three critical aspects: the economy, society, and the environment. What are the positive impacts? What are the negative impacts? And we start getting to the concept of total value.”

As a final example, an integrated model of commitment to engagement and accountability can be seen in a non-profit care provider serving Aboriginal communities in Alaska USA, which has built its organizational structures and practices on clearly stated principles of community ownership and strong relationships (Gottlieb, 2013). The organization defines its patients and their communities as “customer-owners,” who make up the governing board and
various advisory panels. Corporate goals such as “achieve excellence in customer-owner satisfaction” are evaluated in measures that are meaningful to patients, such as waiting times. A major focus for the organization is building and maintaining relationships among their own staff, the customer-owners, and outside service providers such as referral centers. Looking beyond treatment and health education, the organization defines mission success as, “Whether the population served is able to truly experience multidimensional wellness, and if improvements in wellness are experienced from one generation to the next” (Gottlieb, 2013). If their aim is to use engagement and accountability to produce total value for their communities, other care providers will need to develop leaders among both providers and community stakeholders who are committed to this type of long-term thinking.

References


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A content analysis of Arabic YouTube videos for cancer treatment

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Abstract

Purpose – The purpose of this paper is to describe and assess Arabic videos related to cancer treatment to gain insights about the nature of health information as it is shared on YouTube. Accordingly, future strategies for different bodies are suggested to promote effective communication.

Design/methodology/approach – The approach is to select a representative sample of YouTube videos for certain search terms related to cancer treatment in the Arabic language. In order to identify the search terms, Google Trends is utilized. To retrieve the most relevant videos, a simple python tool is developed using YouTube API V3. For this study, the first 150 relevant videos are quantitatively and qualitatively analyzed. Objective data and subjective data are collected for each video and analyzed. Objective data include video title, URL, length, view count, like count, dislike count, comment count and the associated tags. For content analysis, coding themes are defined for the subjective data as follows: video format, video authorship and video content. Video content includes three categories: types of treatments, targeted part and evidence-based indicators.

Findings – The study included 150 videos, from which 30 videos were not content related; therefore, 120 videos remain in the analysis. Using rounding values, it can be observed that the average video lasted 10 min, had 184,966 views, was commented on 263 times, was liked by 2,295 users and disliked by 148 users. Non-professional individuals (46 percent) posted less than half of the videos, whereas public institutions posted only 18 percent of videos. More than half of videos (56 percent) promoted using herbal, botanical, and other natural products for cancer treatment. The majority of YouTube video formats were videos (52 percent), followed by audio with captions (30 percent). News and stories were the dominant videos, with (16 percent), and other types of videos were mostly testimonials and private centers promotions. Only 6 and 9 percent of videos targeted the genetic and immune systems, respectively. Out of the 120 analyzed videos, 86 percent did not mention any risk factor for the recommended treatment, and 73 percent did not offer the details of their usage direction.

Research limitations/implications – Researchers need to understand the information that is currently available on social media platforms related to the high-risk diseases in order to design initiatives, tools, and actions to allow an easy effective transfer of knowledge.

Practical implications – Recounting in-depth knowledge of YouTube cancer treatment contents will allow policy makers, YouTube management, medical organizations, and government agencies to understand the viewers’ behavior of YouTube and their needs to provide accurate and trustworthy information to adopt evidence-based resources.

Social implications – Creating the suitable content, in terms of health promotion strategies, associated with the appropriate format and understandable language that people need will be one of the major responsibilities of YouTube management, government and professional bodies. The well-designed health messages will enhance users’ engagement and attention to health issues from trusted sources.

Originality/value – There is very less information about Arabic messages in social media, YouTube in particular, specifically regarding cancer treatment. Thus, this study is one of the first studies to explore how Arabic messages are presented on YouTube. The aim of the assessment is to extract the current status and suggest future strategies for different bodies to have effective communication toward the Arabic communities.

Keywords Culture, Research methods, Patient perspectives, Informatics, Medical education, Cancer

Paper type Research paper

1. Introduction

According to Cancer statistics 2018 (Bray et al., 2018), cancer is expected to be the leading cause of deaths in the world in the twenty-first century. It is also considered “the single most important barrier to increasing life expectancy” (Bray et al., 2018). Cancer treatment is still a
debate among scientists. In order to have better information about different kinds of treatments, users tend to have different sources; the internet is considered as the main source (Sahin et al., 2018). In fact, Sahin et al. (2018) reported that 80 percent of internet users consult the Web for health information. One potential way of educating the public about cancer treatment is through social media platforms such as the widely used YouTube (Goobie et al., 2019). YouTube is the second most visited website globally (Sahin et al., 2018) used to share videos that encourage the user to share knowledge including health information (Youtube.com, 2019). According to the statistics of 2017, it was found that the Middle East and North Africa (MENA) area is ranked second in terms of the number of views of YouTube videos, with more than 300m views (GO-GULF, 2017). YouTube statistics showed that the number of channels in the MENA region has risen 160 percent since 2015 (ArabianBusiness.com, 2018). It was also revealed that each minute, two hours are uploaded in the region, which leads us to the fact that four out of ten viewers watch online videos on a daily basis (GO-GULF, 2017).

Different research works addressed the importance of social media platforms, including YouTube, regarding health-related information (Lloyd et al., 2019). YouTube has been proved to affect the patient decision-making process (Goobie et al., 2019; Sahin et al., 2018; Basch and MacLean, 2019). It is a matter of concern that health-related videos posted on YouTube might contain inaccurate and harmful health information (Esen et al., 2018; Knight et al., 2015; Azer et al., 2013).

Content analysis for YouTube videos has been conducted for several reasons in the past. For example, Hillyer et al. (2019) analyzed the first top viewed videos related to breast cancer treatment. They pointed out that the majority of the videos did not discuss indications for mastectomy, which affect the decision of a patient. Sahin et al. (2018) evaluated YouTube videos related to colorectal cancer. They addressed many issues; the video popularity does not indicate the comprehensive material included within the video, very few videos addressed the risk or protective factors, and many videos offered misleading (non-evidence-based) information. Aydin and Akyol (2019) addressed the same warning signals after assessing the quality of videos related to thyroid cancer. In addition, Esen et al. (2018) focused on YouTube videos related to breast self-examination. They found that many of the offered videos were misleading and need to be authorized. Other platforms were addressed as well; for example, Basch and MacLean (2019) described the posts related to HPV and vaccinations on Instagram. They noticed that posts that were anti-vaccine had a higher average of likes than other posts. In fact, users sometimes prefer videos that support the use of non-recommended therapies (Goobie et al., 2019). The more critical issue is that patients seem to prefer commercial media more than professional medical societies or governmental agencies (Carneiro and Dizon, 2019). Knight et al. (2015) explored the features of the content regarding sedentary behavior on YouTube. They described the content to be an education-related content with low views and underutilized tool.

Having visited the previous literature, it is clear that social media, including YouTube, has the attention of the researchers and practitioners. However, it seems that the main focus is on the English content, which is not rational. Arabic language is one of the main languages in the United Nation (Un.org, 2019) where around 4.23 percent of world population speaks it, compared to English, which is spoken by 5.52 percent. There is very less information about Arabic messages in social media, YouTube in particular, specifically regarding cancer treatment. Thus, we need to explore how Arabic messages are presented on YouTube. Actually, there is a value in identifying Arabic content related to cancer treatment in YouTube and understanding if the information available is evidence based. The aim of this study is to describe and assess Arabic videos related to cancer treatment to gain insights about the nature of health information as it is shared on YouTube. We do this by not only analyzing a systematic sample of cancer treatment videos in terms of video
analytics (quantitative) but also by deep content analysis (qualitative). The goal of this assessment is to extract the current status and suggest future strategies for different bodies to have effective communication.

The paper is organized as follows: Section 2 will introduce the method of the research including the search strategy and data management and analysis. Section 3 presents the results in detail. Section 4 discusses the results and the conclusion is presented in Section 5.

2. Methods

Search strategy

To conduct this research, the approach in Yiannakoulias et al. (2019) is adopted. First, a sample of YouTube videos is collected for analysis. As it was mentioned in Yiannakoulias et al. (2019), it is very challenging, to the extent of being impossible, to compile a complete list of YouTube videos to select a true random sample. Therefore, we follow the strategy to collect a sample of most relevant videos. In detail, the process of selection is described below.

Our approach is to select a representative sample for certain search terms related to cancer treatment in the Arabic language. In order to identify the search terms that should be used, Google Trends (Google Trends, 2019) is utilized to identify the relative potential search terms. Google Trends is considered a highly trusted tool in research, health, politics and other areas that determine variations in online interest (Mavragani and Tsagarakis, 2019). Data from Google Trends are normalized over a selected period and can be downloaded online along with the associated region and related search terms. According to Google Trends in April 2019, the search for “علاج السرطان” (cancer treatment) was considerably more frequent and broad than other search terms. However, another term popped up, that is “علاج السرطان بالاعشاب” (cancer treatment using herbs). The latter search term overlaps with the first term but is more specific; therefore, we choose to select the first term for this study.

To search YouTube, a simple python tool is developed using YouTube API V3 (Google Developers, 2019) to retrieve the most relevant videos for a search term. The developed tool produces an excel file that contains the metadata for the resulting video list. The extracted metadata include video title, URL, duration, view count, like count, dislike count, comment count, and the associated tags. As discussed in Mavragani and Tsagarakis (2019), the more pages we dig in, the less quality and relevance we obtain. In fact, it is noticeable that users are not likely to explore the advance pages since the saturation of the topic becomes very low by the end of the first 50 results (Knight et al., 2015). The original list for the search term contains more than 11,000 videos with 220 pages containing 50 videos each. For this analysis, the first 150 relevant videos are quantitatively and qualitatively analyzed, studied and evaluated.

Data management and analysis

Prior to coding, the suitability of the videos was determined as per their language and content. The selected videos should be in the Arabic language and should pertain to cancer treatment. Thus, 30 videos were excluded to match the requirements, which ended up with 120 Arabic videos related to cancer treatment.

Content analysis is a well-known method that can be used with qualitative and quantitative data to describe and analyze a phenomenon in a conceptual form (Elo and Kyngas, 2008). In this study, objective data and subjective data are collected for each video. Objective data include video title, URL, length, view count, like count, dislike count, comment count and the associated tags. Descriptive statistics are performed to understand the context of YouTube results.

Regarding the subjective data, two researchers viewed all the videos in the sample and independently defined coding themes to be used for subjective data as follows: video format, video authorship and video content. This classification was done by observing the videos and visiting the uploaded channel pages. Video format was classified as audio with
captions, captions alone, informal interviews, informal presentations, news and stories, and others such as testimonials or formal presentations. Video authorship was classified as non-professional individuals, professionals, traditional media and public institutions. Video content includes three categories: types of treatments that are classified into herbal, botanical, and other natural products, dietary products, chemical drugs, spiritual treatment, and others (cryoablation, etc.); the targeted part is classified into specific body part, genetics, immune system, the whole body, and others; indicators that include usage direction, effective ingredients and the risk factors.

To ensure consistency in coding, three videos were coded collaboratively until an agreement was reached.

3. Results
Our study included 150 videos, from which 30 videos were not content related; therefore, 120 videos remain in the analysis. Table I summarized the descriptive statistics measures on the videos. Using rounding values, it can be observed that the average video lasted 10 minutes, had 184,966 views, was commented on 263 times, was liked by 2,295 users and disliked by 148 users.

**Audience engagement**
For most of the videos, the number of likes was less than 1.2 percent of the total number of views (2,295/184,966). Over 25 percent of the videos did not have any likes and around 25 percent of the videos did not have any comments. In an *ad hoc* analysis, there were 22,950 comments left by users for the 120 videos (range = 0–3,333, mean = 263). All videos failed to include a physical address, a website URL or phone number for viewers to locate additional information if needed.

Table II presents the proportion of videos satisfying each variable in the coding theme specifically.

**Videos characteristics**
The majority of YouTube video formats were videos (52 percent), followed by audio with captions (30 percent). News and stories were the dominant videos with (16 percent), and other types of videos were mostly testimonials and private centers promotions. Non-professionals individuals (46 percent) posted less than half of the videos, whereas public institutions posted only 18 percent of videos. By analyzing the videos, we found that more than half of videos (56 percent) promoted using herbal, botanical and other natural products for cancer treatment. Only 6 and 9 percent of videos targeted the genetic and immune systems, respectively. Out of the 120 analyzed videos, 86 percent did not mention any risk factor for the recommended treatment and 73 percent did not offer the details of their usage direction.

4. Discussion
The current study examined the characteristics and content of messages about cancer treatment delivered through social media based on 120 videos uploaded on YouTube.

<table>
<thead>
<tr>
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<th>Min.</th>
<th>Max.</th>
<th>Range</th>
<th>Sum</th>
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<td>Number of views</td>
<td>184,966</td>
<td>41</td>
<td>1,591,617</td>
<td>1,591,576</td>
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<tr>
<td>Number of likes</td>
<td>2,295</td>
<td>6</td>
<td>27,333</td>
<td>27,327</td>
</tr>
<tr>
<td>Number of dislikes</td>
<td>148</td>
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<td>1,192</td>
<td>1,192</td>
</tr>
<tr>
<td>Number of comments</td>
<td>263</td>
<td>0</td>
<td>3,333</td>
<td>3,333</td>
</tr>
<tr>
<td>Length (hours)</td>
<td>0.17</td>
<td>0.01</td>
<td>1.11</td>
<td>1.0</td>
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</tbody>
</table>

*Table I. Descriptive statistics measures of the Arabic videos*
The findings of this study indicate that content related to cancer treatment on YouTube is varied in nature and contains a variety of important messages for the public, professionals and government agencies.

Similar to most online content, the videos on YouTube are not peer reviewed; therefore, any user can upload any content. In our analysis, videos presented by non-professionals received the most number of views and likes. This finding is consistent with previous studies on the preference of the users toward commercial media (Carneiro and Dizon, 2019). From the comments associated with each video, it is noticeable that the viewers, in general, do not have the needed ability to distinguish between evidence-based information and misleading piece of material. It is clear that users need to be educated and they need to have a reference point from doctors or physicians.

The findings of this study demonstrated that the primary focus of the videos was to use herbals, botanicals, and other natural products for cancer treatment. Fewer videos focused on dietary systems. This result also indicates that using natural products in cancer treatment is common among cancer patients. In fact, 7 percent of cancer patients are reported to take herbal medicine (Paek et al., 2010). Using herbal treatment becomes central topic because of its significance as a public health concern. Abu Daabes (2018) stated that this kind of medicine contains substances that could be harmful to some people with cancer. None of the explored videos included a website or physical address, which means that users are not able to connect for additional resources.

<table>
<thead>
<tr>
<th>Coding theme/variables</th>
<th>$n = 120$ (%)</th>
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</thead>
<tbody>
<tr>
<td><strong>Video format</strong></td>
<td></td>
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<tr>
<td>Audio with captions</td>
<td>30</td>
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<td>Captions alone</td>
<td>18</td>
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<tr>
<td>Video</td>
<td></td>
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<tr>
<td>Informal interview</td>
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<tr>
<td>Informal presentation</td>
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<tr>
<td>News and stories</td>
<td>16</td>
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<tr>
<td>Others</td>
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<tr>
<td><strong>Video authorship</strong></td>
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<tr>
<td>Individuals</td>
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<tr>
<td>Professional</td>
<td>11</td>
</tr>
<tr>
<td>Non-professional</td>
<td>46</td>
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<tr>
<td>Traditional Media</td>
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<td>Public institution</td>
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<tr>
<td><strong>Video content</strong></td>
<td></td>
</tr>
<tr>
<td>Type of treatment</td>
<td></td>
</tr>
<tr>
<td>Herbal, botanical, and other natural products</td>
<td>56</td>
</tr>
<tr>
<td>Dietary products</td>
<td>14</td>
</tr>
<tr>
<td>Chemical drugs</td>
<td>30</td>
</tr>
<tr>
<td>Spiritual treatment</td>
<td>12</td>
</tr>
<tr>
<td>Others (Cryoablation, etc.)</td>
<td>8</td>
</tr>
<tr>
<td>Targeted part</td>
<td></td>
</tr>
<tr>
<td>Specific body part</td>
<td>63</td>
</tr>
<tr>
<td>Genetics</td>
<td>6</td>
</tr>
<tr>
<td>Immune systems</td>
<td>9</td>
</tr>
<tr>
<td>The whole body</td>
<td>12</td>
</tr>
<tr>
<td>Others</td>
<td>10</td>
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<tr>
<td><strong>Indicators</strong></td>
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<tr>
<td>Usage direction (not mentioned)</td>
<td>73</td>
</tr>
<tr>
<td>Effective ingredients (not mentioned)</td>
<td>34</td>
</tr>
<tr>
<td>Risk factors (not mentioned)</td>
<td>86</td>
</tr>
</tbody>
</table>

The findings of this study indicate that content related to cancer treatment on YouTube is varied in nature and contains a variety of important messages for the public, professionals and government agencies.

Similar to most online content, the videos on YouTube are not peer reviewed; therefore, any user can upload any content. In our analysis, videos presented by non-professionals received the most number of views and likes. This finding is consistent with previous studies on the preference of the users toward commercial media (Carneiro and Dizon, 2019). From the comments associated with each video, it is noticeable that the viewers, in general, do not have the needed ability to distinguish between evidence-based information and misleading piece of material. It is clear that users need to be educated and they need to have a reference point from doctors or physicians.

The findings of this study demonstrated that the primary focus of the videos was to use herbals, botanicals, and other natural products for cancer treatment. Fewer videos focused on dietary systems. This result also indicates that using natural products in cancer treatment is common among cancer patients. In fact, 7 percent of cancer patients are reported to take herbal medicine (Paek et al., 2010). Using herbal treatment becomes central topic because of its significance as a public health concern. Abu Daabes (2018) stated that this kind of medicine contains substances that could be harmful to some people with cancer. None of the explored videos included a website or physical address, which means that users are not able to connect for additional resources.
It is important to disseminate evidence-based messages about different indicators including usage directions, effective ingredients, and risk factors. Although we did not have the tools to assess the accuracy of the information provided by the cancer treatment YouTube videos, we noticed in an ad hoc analysis that 73 percent videos did not mention any usage directions or risk factors of using the recommended treatment. This presented deceptive or misleading information, which was mentioned in many previous studies as well (Esen et al., 2018; Sahin et al., 2018).

5. Conclusion and recommendations
This is one of the initiative studies addressing Arabic YouTube videos related to cancer treatment. The findings of this study confirmed that Arab users are concerned about the internet as a source of medical information, regardless of the qualifications of people making claims and their level of reliability. Thus, it is crucial for organizations, researchers and government agencies to understand the viewers and their needs to provide accurate and trustworthy information and resources on YouTube or other platforms. Basch and MacLean (2019) stated that the public would likely have trouble understanding the written information about disease treatment; they would rather depend on audio and video messages to build the needed awareness, thus making decisions accordingly. Creating the suitable content, in terms of health promotion strategies, associated with the appropriate format and understandable language that people need will be one of the major responsibilities of YouTube management, government and professional bodies. The well-designed health messages will enhance users’ engagement and attention in health issues.

YouTube and other social media need to develop governance evidence-based measures that control the users from uploading untrusted material and that can help audiences evaluate the information presented on their platforms. In addition, regarding health professionals, it is essential to monitor popular internet and social media platforms to stay informed about the messages presented to their patients. This is one of the missions for health professionals, which entitled them to build solid health care management strategies in order to empower and educate the users, in general, and their patients, in particular.

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Health service engagement with consumers and community in Australia for issue

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Abstract

Purpose – The purpose of this paper is to provide an overview of consumer and community engagement in health service planning, quality improvement and programme evaluation in Australia, and key components and importance of a strong suite of tools for achieving effective outcomes.

Design/methodology/approach – This paper is a non-systematic review of Australian national, state and territory websites in relation to policy commitment to consumer engagement, best practice framework for consumer engagement and recent project example.

Findings – Consumer engagement is a recognised component of the Australian health system. It is reflected in the national and state health policy and is a mandatory requirement of hospital accreditation. The application of co-design principles is gaining increasing popularity in health service planning and programme evaluation. Co-design is an important enabler of patient/community-centred service planning and evaluation; however, on its own it may lead to poorer outcomes. Co-design must occur within a broader systemic framework.

Practical implications – The research identifies a conceptual framework, approaches and tools of value to health service management and planners.

Originality/value – Consumer and community engagements are critical to the development of consumer-centric services. However, this should complement and add value to, not divert attention away from established principles of service planning, continuous quality improvement and programme evaluation. To do so may result in poorer quality health and well-being outcomes, reduced efficiency and ultimately reduced consumer and community satisfaction with services. This paper examines consumer and community engagement within the broader planning and quality improvement framework and practical implications for keeping planning, research and evaluation on track.

Keywords Continuous quality improvement, Health policy, Patient perspectives, Qualitative research, Quantitative research, Process mapping, First nations/Indigenous peoples health, Healthcare commissioning

Paper type Conceptual paper

1. Introduction

The Australian Department of Health and all States and Territories in Australia mandate consumer[1] engagement for health service planning, programme evaluation and research (COTA, 2016; EIH, 2015; NTDCM, 2017; SAHealth, 2019a; VicHealth, 2017; WAGovt, 2018a). The First Nation people in Australia continue to experience reduced life expectancy and poorer health outcomes than other Australians (AIHW, 2009) engagement with Aboriginal and Torres Strait Islander communities in service planning and research is critical to ensure that health services are responsive to and address the health priorities of these communities. The Australian National Health and Medical Research Council (NHMRC) has provided clear

The authors thank Central and Eastern Sydney Primary Health Network for the approval to use the case example.
and detailed guidelines as to how to engage with Aboriginal and Torres Strait Islander people in planning and undertaking health research. These guidelines provide a valuable template for engagement with the broader community in research, programme evaluation and service planning (NHMRC, 2007, 2018).

This paper explores the current status of consumer and community engagement in health service planning, research and delivery, and discusses some of the strengths and limitations of current approaches. This is highlighted through a recent project example.

2. Purpose
This paper is to provide an overview of consumer and community engagement in health service planning, quality improvement and programme evaluation in Australia, and key components and importance of a strong suite of tools for achieving effective outcomes.

3. Design/methodology/approach
This paper is a non-systematic review of Australian national, state and territory websites in relation to policy commitment to consumer engagement, best practice framework for consumer engagement and recent project example.

4. Consumer engagement
4.1 Who is consumer and who is community?
Consumers tend to be regarded as people who are receiving services – in some instances this may include people with “lived experience” – and people who have accessed similar services, rather than users of a service. Consumers may include people having experienced specific types of healthcare (e.g. mental health, chronic disease, antenatal and obstetric care (Carswell et al., 2017; WAGovt, 2018b; ACI, 2019; MSHHS, 2016) or particular communities, as in the case of culturally and linguistically diverse (QldHealth, 2017) or Aboriginal and Torres Strait Islander communities (NHMRC, 2007, 2018). The focus of co-design is to obtain consumer perceptions of service for input to service planning, ongoing quality improvement or programme evaluation (Figure 1).

In other instances, engagement may be with consumers who also represent the “general community” in which health services operate. This is more common at a local health district, primary health network (PHN) or hospital level. In this instance, individuals are identified as...
community representatives. In the case of capital (NSWHI, 2019) or public health service planning, community representatives will also bring to consideration the wider community impact of the service on other health and community service providers, transport, employment, local community amenity, etc.

4.2 Consumer feedback or consumer engagement
Consumer engagement has gone beyond best practice to become a standard requirement for health service delivery. Accreditation standards for hospitals and health services in Australia require all services to have consumer engagement processes in place and mechanisms to receive consumer feedback (ACSQHC, 2019). While not always published at a hospital level, consumer experience is measured and reported at the jurisdictional level and across a range of programme areas (QldHealth, 2019; VicHealth, 2016). In some programme areas such as mental health, standardised consumer experience measures have been developed for application across jurisdictional boundaries (NSWHealth, 2017; VicHealth, 2013).

There has been an increasing focus on engagement moving beyond consultation and consumer experience to bring consumers to the table to actively engage in key decision making. Health services actively highlight to the community the importance of the consumer voice in clinical decision making, including in advanced care directives, family case conferencing and encouragement to speak up. At a governance level, consumer experience is increasingly sought for positions on Health Service Boards, quality and safety and clinical governance committees (VicHealth, 2014b).

4.3 Community and key stakeholder engagement
As with consumer engagement, there has been a long history of community and other key stakeholder engagement in health service planning and quality improvement. This includes engagement with health service staff, teaching and research institutions, public and private health services, government agencies and community services working with the patient cohort or local community. This has been most marked in large scale capital planning and development (ACI, 2019; NSWHI, 2019) health service planning (Burkett, 2012; CommunityInsights, 2018; Donott et al., 2014; EIH, 2015; VicHealth, 2017; WAGovt, 2018a), programme reviews (Finlayson, 2017; SAHealth, 2019b) and enquiries into health system failure (e.g. Institutional Responses to Child Sexual Abuse, Royal Commission, 2016; Garling, 2008).

4.4 A best practice approach
The NHMRC lays out clear guidelines for engagement with Aboriginal and Torres Strait Islander people. The challenges and techniques for engaging with disadvantaged and marginalised populations are well articulated and relevant to all community groups. While the key principles are summarised below, it is strongly recommended that the reader access the NHMRC documents directly:

(1) Building relationships between researchers and the community and maintaining this throughout the project.

(2) Conceptualisation, exploring with communities how the research can support their wellness journey:
   • possibilities and opportunities to shape the research to best meet their needs;
   • involvement in project management and opportunities to build research skills in the community; and
   • levels of participation and project outcomes.
Development and approval of a research agreement detailing engagement with, and support from, the local community.

Data collection processes that are culturally appropriate, meaningful to the community and ensure consent from all individuals participating in the research.

Analysis process that involves discussions where the researchers, community and organisations talk about what the research means for each of them and what it means for the community.

Report writing with the input of communities to ensure information is presented in a culturally appropriate way. Acknowledgement of community contribution, authorship and intellectual property, as stated in the research agreement.

Disseminating results with communities involved in the research.

Learning from the experience and evaluating the research process with the community to support and build capacity.

4.5 Co-design

The term co-design is frequently appearing in the literature surrounding health service planning and evaluation and is shifting into mainstream conversation. Co-design reflects the processes by which consumers and end users of services are involved in the planning, development and evaluation of services. It builds upon the identified needs, commitment and objectives of participants (NCOSS, 2017). A key determinant of outcomes will be the wider context in which co-design takes place and whose voice is being listened to.

Within a wider conceptual framework co-design is a natural extension, or reification, of what has long been accepted as best practice in health service planning, quality improvement and evaluation. It highlights the importance of placing the patient (and patient cohort and wider community) at the centre of planning and delivery of patient-centred care. This leads naturally to the development of consumer and community engagement processes. The principles of co-design articulate the importance of consumer and community engagement and provide a "recipe" for how to bring this about.

While co-design is an important component of health service planning, quality improvement and programme evaluation, it is an enabling function, it is not the defining process. While refining the recipe to produce one dish, we should not forget the whole meal and how each course fits together. There is a danger that co-design can become the "flavour of the month" and the key underlying principles of responsive, effective and efficient consumer- and community-centric service delivery are lost. There is also the risk that without a structured approach to determining the wider process, co-design in itself may lead to mediocre or poorer outcomes.

Co-design has been a springboard for a range of consultancy and management advisory offerings within Australia and internationally, the key question is the degree to which proponents of co-design bring a broader service offering.

The principles of ongoing quality improvement and the quality cycle stretch back to Deming in the 1950s (NSWCEC, 2018; VicHealth, 2010; Moen, 2009).

The process of Plan-Do-Study-Act (PDSA) has been a foundation of service planning and programme review across all states and jurisdictions in Australia (ASQ, 2019; VicHealth, 2010; WAGovt, 2018a; Hughes, 2008; NSWCEC, 2018; DOH, 2012). It is an ongoing process which involves analysing and defining a problem, developing a solution, implementing solutions, testing the solutions and refining the next stages of improvement. PDSA provides a structured framework for ongoing quality improvement. Within a co-design framework PDSA entails:

- Planning who you are going to talk to, what you are going to talk about and how this dialogue will take place.
Dialogue with consumers and stakeholders through a range of consultative strategies. Information sharing and knowledge building may be required to optimise the communication process and outcomes.

- Studying and testing what has been said, and confirming key findings with participants to ensure clarity of meaning.
- Acting on the issues and recommendations identified.

While co-design is an enabling process, the key components of high quality and effective service planning require a broader and robust planning and evaluation toolkit, including:

- collective impact (SAHeath, 2019b; Finlayson, 2017; CFCA, 2017) which considers the issue from the perspective of all stakeholders, both in planning and evaluation;
- programme logic (DOHA, 2013; NSWHealth, 2015; Holt, 2009; Department of Health, 2013) through which objectives and outcomes are clearly linked with resourcing and activity;
- SMART goals (HealthDirect, 2019; VicHealth, 2019; ACI, 2015) providing specific, measurable, achievable, realistic and time-related goals;
- process improvement (Stanton et al., 2014; Inozu, 2012; Mason et al., 2015; Ramori et al., 2019) focusing on efficient service delivery using a range of methodologies, including six sigma and lean;
- translational research (Woolf, 2008; Morris et al., 2011; NHMRC, 2019) and strategies to bring findings from research into improvements in service delivery; and
- capacity building (VicHealth, 2006, 2014a) to foster skills development at an individual, organisational and community level, to build sustainability and drive ongoing improvement.

5. A practical example
PHNs are an Australian Government initiative to increase the effectiveness and efficiency of medical services for patients in the community. PHNs act as budget holders commissioning a range of primary care services.

In 2017, a metropolitan PHN engaged an external consultant to undertake co-design workshops with people with lived experience (consumers) and local service providers to develop a recovery orientated and stepped care approach to support people experiencing severe mental illness in the community.

The co-design process entailed two workshops with key stakeholders including people with lived experience and local service providers. The key themes identified in the workshops provided the foundation for the service specifications. The contract for service provision was awarded to a community-based service provider.

One-year post implementation the PHN engaged consultants to review the progress of the project. The evaluation team included experienced mental health service providers, consumers and carers with lived experience of severe mental illness. The team worked with the PHN, service providers and staff in designing the evaluation method. Importantly, the team utilised the programme logic underlying the service to define activity, output and outcome measures for the review (Figure 2).

The review method entailed detailed data analysis; policy and document review; process mapping; consultations with consumers, direct service providers, service management and external clinical supervisors; and a clinical and operational risk assessment. The review found that while comprehensive activity measures were in place, there was limited information collected on service outputs or outcomes, as well as issues with consistency in
the client information system. From the activity analysis and process mapping with consumers and staff, the review was able to make practical recommendations for service improvement, reveal positive service experiences, identify operational and clinical risks and develop a risk mitigation plan.

As an outcome of the first-year evaluation, the PHN is engaging in a co-design process with the contracted service provider, staff, consumers and other key stakeholders including local hospital services and other community service providers. Based on the programme logic, the assessment and triage criteria, SMART activity output and outcome measures will be defined. The inclusion of external stakeholders in the co-design process will facilitate the development of measures to assess the cross-agency collective impact of the programme on the demand for other services.

The co-design process will also apply process improvement methods (lean methodology) to address challenges identified in current consumer pathways and internal service systems and processes. This will improve the consumer experience, service outcomes and deliver efficiencies for both the programme and other service providers. The co-design process will extend to implementation planning, risk assessment and preparation of reports and presentation of findings.

Lean methodology highlights the importance of local service champions in redesign. Identifying champions and partnering with them in the co-design process strengthens service capability through skills transfers and builds sustainability of solutions.

The above example indicates the value of co-design as an enabler for service improvement while highlighting the importance of this taking place within a broader methodological framework.

**Note**
1. This paper uses the terms patient and consumer interchangeably reflecting the contextual differences in which it occurs.


WAGovt (2018a), “Delivering community services in partnership policy: a policy to achieve better outcomes for western Australians through the procurement of community services”, Department of Finance, Perth.


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Power of partnerships
What makes a difference in reducing maternal mortality and how can Canadians contribute?

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Abstract

Purpose – Many low- and middle-income countries (LMICs) are struggling to reduce maternal mortality rates, despite increased efforts by the United Nations through the implementation of their Millennium Development Goals program. Industrialized nations, such as Canada, have a collaborative role to play in raising the global maternal health standards. The purpose of this paper is to propose policy approaches for Canadians and other Organization of Economic Cooperation and Development (OECD) nations who wish to assist in reducing maternal mortality rates.

Design/methodology/approach – Ten Canadian health experts with experience in global maternal health were interviewed. Using qualitative analytical methods, the authors coded and themed their responses and paired them with peer-reviewed literature in this area to establish a model for improving global maternal health and survival rates.

Findings – Findings from this study indicated that maternal health may be improved by establishing a collaborative approach between interdisciplinary teams of health professionals (e.g. midwives, family physicians, OB/GYNs and nurses), literacy teachers, agriculturalists and community development professionals (e.g. humanitarians with diverse linguistic and cultural backgrounds). From this, a conceptual approach was devised for elevating the standard of maternal health. This approach includes specifications by which maternal health may be improved, such as gender justice, women’s literacy, freedom from violence against women, food and water security and healthcare accessibility. This model is based on community health center (CHC) models that integrate upstream changes with downstream services may be utilized by Canada and other OECD nations in efforts to enhance maternal health at home and abroad.

Research limitations/implications – Maternal mortality may be reduced by the adoption of a CHC model, an approach well suited for all nations regardless of economic status. Establishing such a model in LMICs would ideally establish long-term relationships between countries, such as Canada and the LMICs, where teams from supporting nations would collaborate with local Ministries of Health, non-government organizations as well as traditional birth attendants and healthcare professionals to reduce maternal mortality.

Practical implications – All OECD Nations ought to donate 0.7 percent of their GDP toward international community development. These funds should break the tradition of “tied aid”, thereby removing profit motives, and genuinely contribute to the wellbeing of people in LMICs, particularly women, children and others who are vulnerable. The power of partnerships between people whose aims are genuinely focused on caring is truly transformative.

The authors would like to thank the participants of the study for sharing their thoughts and wisdom. Stephanie Stresing, Research Assistant, helped with citations and literature search and the authors also extend the thanks to her. Finally, this paper served as the impetus for the creation of Maternal and Infant Health Canada (maa.med.ubc.ca), which is dedicated to improving the lives of women and children in Canada and abroad, through education, research and innovation.
Social implications – Canada is not a driver of global maternal mortality reduction work but has a responsibility to work in partnership with countries or regions in a humble and supportive role. Applying a comprehensive and interdisciplinary approach to reducing maternal mortality in the Global South includes adopting a CHC model: a community development approach to address social determinants of health and integrating various systems of evidence-informed healthcare with a commitment to social justice. Interdisciplinary teams would include literacy professionals, researchers, midwives, nurses, family physicians, OB/GYNs and community development professionals who specialize in anti-poverty work, mediation/dialogue and education campaigns that emphasize the value of all people regardless of their gender, ethnicity, religion and income. Diasporic Canadians are invaluable members of these teams due to their linguistic and cultural knowledge as well as their enthusiasm for working with their countries of origin. Establishment of long-term partnerships of 5–10 years between a Canadian team and a region or nation in the Global South that is dedicated to reducing maternal mortality and improving women’s health are valuable. Canada’s midwifery education programs are rated as world leaders so connecting midwives from Canada with those of the Global South will facilitate essential transfer of knowledge such as using birth plans and other evidence-based practices. Skilled attendants at the birth place will save women’s lives; in most cases, trained midwives are the most appropriate attendants. Video link to a primer about this paper by Dr Farah Shroff: https://maa.med.ubc.ca/videos-and-media/.

Originality/value – There are virtually no retrievable articles that document why OECD nations ought to work with nations in the LMICs to improve maternal health. This paper outlines the reasons why it is important and explains how to do it well.

Keywords Training, Teamwork, Governance structures, Population health, Family medicine, Midwifery, Obstetrics, Maternal child health, Behavioural social or mental health issues, Gynecology

Paper type Research paper

1. Introduction

Complications from pregnancy and childbirth are one of the leading causes of death and disability among women in lower- and middle-income countries (LMICs), second to HIV/AIDS (World Health Organization, 2009). Between 2014 and 2015, 90 percent of worldwide maternal deaths occurred in LMICs (Alkema et al., 2015), which demonstrates the severity of this timely issue. In 1990, the United Nations (UN) proposed eight Millennium Development Goals (MDGs), all aimed at improving the quality of life by 2015. Among these eight MDGs, Goal 4 targeted the reduction of child mortality by two-thirds, while Goal 5 aimed to reduce the maternal mortality ratio by three-quarters (Hogan et al., 2010). To date, these two goals still have not been met in several LMICs. Critical gaps in maternal health strategies, such as human right challenges and availability and quality of healthcare for pregnant women and neonates, continue to exist past 2015 (Kendall and Langer, 2015). Although maternal mortality rates have decreased from their 1990 level, this decrease has been slower than anticipated, which further complicated achievement of Goal 5. One of the intentions of this paper is to assist with the reduction of maternal mortality in LMICs that have not met the UN MDG goals. Many of the Sustainable Development Goals (SDGs) address the social determiner of maternal health such as clean water, gender equality, peace, justice and ending hunger and poverty.

Specific SDGs about maternal health include (Kendall and Langer, 2015):

- by 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births; and
- by 2030, ensure universal access to sexual and reproductive healthcare services, including: family planning, information and education, and the integration of reproductive health into national strategies and programs.

Maternal and child health are intimately connected. However, due to space limitations, this paper focuses only on maternal health. The motivation behind this study draws from the need to control the high number of maternal deaths in LMICs, most of which are preventable, by addressing the social determinants of health and an effective healthcare system (De Brouwere et al., 2010).
This study attempts to answer the following question:

RQ1. What role could Canada and other Organization of Economic Cooperation and Development nations play in reducing global maternal mortality?

To answer this question, resources targeted toward reducing maternal mortality post 2015 are highlighted. Global maternal health experts were interviewed to discuss the ideal partnership role Canadians could undertake with LMICs to address the problem of persistently high rates of maternal mortality. Several evidence-based approaches are proposed, including equity-focused approaches – addressing poverty and gender justice issues – coupled with clinical approaches. These recommendations address both the socio-economic and medical aspects of this severe problem.

2. Methods

Literature relating to maternal health and mortality in LMIC nations was retrieved and reviewed, coupled with a summary of currently existing support programs administered by Canada and other developed nations to LMICs. Relevant literature was searched through PubMed, Medline, OVID, Web of Science, CINAHL using these search terms: “midwives,” “global maternal mortality,” “maternal death,” “neonatal death,” “millennium development goal 4 & 5,” “obstetrical complications,” “postpartum haemorrhage,” “Misoprostol,” “gender inequality,” “traditional birth attendants,” “TBAs,” “Canada,” “partnership for reducing maternal death,” “SDGs” and “post 2015.” A compilation of these articles was created. From this initial literature search, we realized that minimal scholarly work on the topic of Canada’s role in improving global maternal health existed.

The second phase of the project consisted of interviewing Canadian experts on global maternal health. The interviews’ objective was to gain an understanding of their perspective on how Canada can best contribute to improving maternal health in LMICs. Participants included maternal health experts (e.g. obstetricians and gynecologists, family physicians and midwives), who were Canadian healthcare providers or researchers with vast practical experience dealing with maternal health in LMICs. The interviews were centered on social determinants of maternal health, host country-led inter-professional collaborative care, training, traditional medicine, diasporas and caring across borders. All participants signed a consent form, and the study received a certificate of approval from the University of British Columbia’s Behavioural Research Ethics Board. Additionally, all of the interviews were audio-recorded and transcribed.

The framework method of analysis was utilized to process the data collected for this project. The method involved transcribing and reviewing the interviews, coding, developing an analytical framework, applying this framework, charting data into a framework matrix and interpreting the data. This type of methodology has been successfully applied by multidisciplinary teams in previous studies (Gale et al., 2013). Themes extracted from the interviews were combined with prominent themes from the literature to construct an empirically based plan of action for reducing maternal mortality in LMICs.

3. Findings and discussion

The insights offered from experts in maternal mortality will be discussed in more detail in response to the following four questions: what are some equity issues implicated in maternal mortality? What clinical initiatives have been shown to work? What offerings can Canadians make to reduce maternal mortality? What is the potential role of holistic healthcare and traditional medicine in reducing maternal mortality? This section of the paper includes considerations for keeping up the momentum for global maternal mortality reduction efforts.

The ideas from the interview provided insights into our research questions, which are discussed below.
3.1 What are some equity issues implicated in maternal mortality?

Poor socio-economic conditions are found to be associated with key maternity-related complications such as hemorrhage, sepsis, hypertensive disorders, unsafe abortion, obstructed labor, etc., which leads to an increase in maternal death worldwide (Nour, 2008; De Brouwere et al., 2010; D’Souza et al., 2013; Smith et al., 2013). Properly addressing several socio-political issues – such as poverty, the prevention and mitigation of military conflicts, violence against women and social status inequalities – leads to general improvement in the maternal health of women.

Maternal deaths resulting, either directly or indirectly, from violence are sizeable. Official maternal death statistics, however, do not include the number of maternal deaths due to violence such as acts of war, social unrest, etc., making the number of maternal deaths from such incidences unknown, but considerable (Espinoza and Camacho, 2005). Violence and social unrest resulting in maternal death can occur in a variety of ways. First, direct exposure to violence causes deaths in all groups of people, including pregnant women. Second, pregnant women suffer indirectly as a result of poor nutritional and sanitation standards, inaccessible healthcare facilities, and emotional turmoil during periods of war. Third, war also has a negative impact on the reproductive health of women, a phenomenon identified through research that involved women from war-affected areas of Ethiopia, Belize and camps of Khmer refugees in Thailand (McGinn, 2000). Women are often forced to give birth at home due to fear of violence and limited access to adequate healthcare professionals and facilities (Interview Participant 1).

Another major obstacle in achieving improved maternal health status is poverty and the associated social barriers that accompany it. Individuals with lower incomes encounter risks and issues in daily life that are rare among those with middle and higher incomes. These problems include inaccessible clean drinking water and sanitation facilities, inadequate calories and nutrition, poor housing conditions, illiteracy, precarious working conditions and a lack of transportation to access life-saving healthcare facilities, not to mention their places of work and other locations. Lack of adequate income results in unhealthy lifestyles choices, which further leads to poor health. Moreover, inability to pay for clinical care is an important cause of maternal death in many LMICs where universal healthcare systems are not established (Arsenault et al., 2013). Women who are unable to pay the fees required for receiving healthcare services during the prenatal period and the delivery process may therefore not seek care. Hence, poverty contributes to a delayed decision to seek medical care, increased time to reach healthcare facilities, and impediments in receiving appropriate care (Sorensen et al., 2011). Strategies thus ought to be aimed at eliminating poverty and increasing literacy of women in LMICs, which will further result in improved maternal health status.

Raising the social status of women also contributes to achieving better general and maternal health. Women’s social status, when correlated with level of education relative to men, age at first marriage, reproductive autonomy, etc., reveals that an increase in the social and economic status of women has a profound effect in decreasing maternal mortality rates in LMICs (Shen and Williamson, 1999). One measure of women’s social status is their autonomy and freedom to make decisions related to their lives. Women who have higher levels of relative freedoms access greater levels of antenatal care and opt for safe delivery care, which, in turn, leads to a decrease in maternal mortality rate (Bloom et al., 2001). The disadvantageous social position of women also impacts maternal mortality rates by limiting healthcare choices. Women with socially disadvantaged conditions cannot avail better healthcare facilities due to the lack of choices and denial of the right to choose freely (Defo, 1997). An improvement in the social status of women would surely contribute to a decrease in maternal death by empowering women to choose the best healthcare for themselves and not depend on others to choose for them.
These choices and increased autonomy do not automatically accompany an increase in the social status of women or development of a nation. Some choices are constrained due to strict laws enforced in their country. Providing universal access to abortion facilities, for instance, proves to be an effective choice for decreasing maternal mortality; however, legalizing abortion has to be carried out in a way that is acceptable to local people. In total, 49 percent of abortions are unsafe worldwide (Sedgh et al., 2012); this huge number of unsafe abortions leads to increased maternal death. Safe abortions, provided free of charge, are considered an important facet of maternity care.

Literacy is another critical issue that has proven to improve women’s health and by extension, community health. Low literacy levels among women are correlated with precarious working conditions. For example, one study demonstrated that women with low literacy rates who were working in Indian mining communities among other things struggled with limited choices related to sexuality and reproduction (D’Souza et al., 2013). Higher literacy among women may result in a decrease in income-related inequalities, such as increasing the number of females in the workforce; giving them a higher overall status in society (McTavish et al., 2010). A study in Kenya found that pregnant women with a university education were more likely to use the services of a skilled birth attendant (Gitimu et al., 2015). The role of education in seeking skilled help during delivery emanates from an increased awareness concerning the importance of a skilled attendant during delivery. Education also increases the chances of acquiring employment opportunities and thereby improves financial status and standard of living, leading to better access to healthcare services overall (Govindasamy and Ramesh, 1997; Harrison, 1997). Greater employment opportunities for women, gained through education and literacy, not only directly improve health by making healthcare more affordable and also lead to improved standards of living and working conditions. Loan programs, vouchers and other means of financial security have also been proven to increasing utilization of maternity services (Bhutta et al., 2013). These initiatives lead to healthier populations.

Poverty, however, contributes to maternal deaths in more ways than just the problem of unaffordable healthcare (Jehan et al., 2012). Implementing cash transfers promotes healthcare access and leads to improved nutrition (Owusu-Addo et al., 2018). Healthy food, housing, transportation and other determinants of health all cost money. With means to afford a better life, women’s pregnancies are healthier, and their chances of safe delivery are substantially greater (Filippi et al., 2006).

Implementing Canada’s commitment to the allocation of 0.7 percent of the country’s GDP to international development would help reduce maternal deaths in the LMICs. At the root of many maternal deaths is the low social standing of women, particularly working-class women who belong to marginalized communities. Canada’s Feminist International Policy aims to improve the overall social status of women, which is also a long-term strategy to decrease maternal death rates (Banda et al., 2016). Social change, therefore, aimed at altering social structures and perceptions about women’s value and worth hold great promise.

3.2 What health system initiatives have been shown to work?

Central to appropriate clinical services are adequate facilities and skilled personnel. Skilled attendants during pregnancy and labor are vital components of maternal and neonatal risk reduction (Hazarika, 2011; Kendall and Langer, 2015). It is also important to factor in prevalent social norms, such as the preference for female midwives, since adhering to these norms often leads to success. Well-trained midwives save women’s lives around the world and are a key component in the reduction of maternal death rates (Smith et al., 2013). Countries such as Iran, Sri Lanka and Egypt substantially reduced their maternal mortality rates by introducing skilled birth attendants and providing government-funded access to childbirth facilities
(Senanayake et al., 2011; Moazzeni, 2013). High quality public education starting from primary school is a vital element for training more midwives, nurses and physicians.

Transportation. Another critical component of maternal health services is accessible transportation to clinics and hospitals. Providing transportation from rural and remote areas to healthcare facilities assisted Egypt, Honduras and Malaysia in reducing maternal mortality (McGinn, 2000; PMNCH et al., 2014). Engineering, construction and other sectors are thus critical to effective and comprehensive maternal healthcare programs. One of the participants, who had worked in Nepal for a long period, noted: “When I first went, I saw many more ruptured uteruses because there was such poor transport that it was days until people got from some remote place to my hospital to get checked out for why her labour was going on for so long” (Interview Participant 9). This participant also suggested that it would be critical if countries like Canada could assist in the road-building process as part of efforts to quell maternal deaths.

Comprehensive and integrated approaches. Best practices in maternal health promotion and mortality prevention include a comprehensive and integrated approach. Another interview participant suggested that, “[i]t all starts with family planning and decreasing unwanted pregnancies. Then it comes to quality and proper care during maternity and childbirth and afterwards, and then it is ongoing psychosocial support. It is really quite comprehensive and not just getting drugs or blood products or obstetricians with head knowledge out to the villages [...] it needs to be looking at the whole person, in this case, it is the mother” (Interview Participant 10). This participant highlighted the importance of care throughout the prenatal and postnatal stages of pregnancy.

Promoting maternal health through nutrition and rest has proven to produce positive outcomes (Banda et al., 2016). Folate and iron supplementation are key factors in the prevention of neural tube defects and pregnancy-induced anemia (Peña-Rosas and Viteri, 2006). Prenatal care helps to detect gestational diabetes, hypertension, anemia, multiple pregnancies, the positioning of the fetus, and can diagnose complications such as pre-eclampsia or HIV/AIDS. Affordable and accessible prenatal care, in concert with other healthcare services, leads to increased delivery safety. Access to EOC is essential to treatment of the most prevalent life-threatening conditions, such as postpartum hemorrhage, sepsis, obstructed labor and pre-eclampsia. Lesotho improved maternal health through both community and comprehensive service improvements, including referral for obstetric emergencies (Satti et al., 2012).

Comprehensive reproductive healthcare includes access to family planning. Globally, affordable and accessible contraception for women is associated with a 29 percent reduction in maternal deaths (Campbell and Graham, 2006). Various contraception methods assist women in planning births, which, in turn, leads to planned healthcare and anticipated financial obligations. This study’s participants recommended the IUD as a safe, affordable and reliable form of birth control. Birth intervals of at least two years support improved maternal and child health (Campbell and Graham, 2006), and family planning also helps to reduce the number of unsafe abortions (Peña-Rosas and Viteri, 2006), which cause approximately 15–30 percent of global maternal deaths (Nour, 2008). Safe and legal abortion services are a meaningful and important part of family planning services.

3.3 What offerings can Canadians make to reduce maternal mortality?
Canada, like other high-income countries, plays a role in creating an environment of global maternal well-being. Canada has a global reputation for being a peaceful and humble nation. Canadian non-government organizations (NGOs) such as CUSO International, Oxfam Canada and the Association for Women in Development have a longstanding track record of working in solidarity with organizations in LMICs that promote peace and social justice.
These partnerships model an example of how Canada can work effectively and collaboratively with other countries. One participant stated, “We should be paying decent prices for coffee, for sugar, for bananas, for pineapples, all these wonderful tropical products that we get, whether it’s furniture […] whatever. So that’s one way we can make a difference to poverty in other countries […] by actually paying for things” (Participant 5).

In terms of clinical determinants of maternal health, Canadian expertise may boost efforts to save lives. Well-trained midwives are the most effective clinical solution to the problem of maternal deaths, and the WHO has declared them integral in society’s fight for health (Canadian Institute for Health Information, 2004). Canada’s midwifery education programs are well recognized and offer a method of choice for many Canadian mothers, indicating their effectiveness. Birth planning, a forte of Canadian midwives, is a potentially effective tool to address many of the unanticipated problems associated with birth. Birth plans dictate where, with whom and how childbirth will take place. They also address the preparation of emergency funds and organize transportation in advance.

The interviews with clinical experts included a theme of providing more skilled birth attendants and training more individuals to become skilled birthing attendants as the best way to reduce maternal mortality, as discussed above. Along with physicians, nurses and other health professionals, Canadian midwifery educators are in a strong position to offer training in communication skills and human rights issues. The training of midwives in some nations is clinically sound, yet in some settings, midwives, like other health professionals, display disrespect for women who are living in poverty or from marginalized groups (Interview Participant 2). The training of birth attendants, therefore, should encompass birthing skill as well as social respect for women of all socio-economic classes.

CanWaCH is Canada’s umbrella association that brings together most Canadian organizations working in global maternal and child health. Working directly with both experts and stakeholders, CanWaCH uses knowledge and data to improve policies and strengthen their impact. Through these partnerships, CanWaCH seeks to unite women and girls internationally with the goal of improved health and prosperity (Bajpai, 2008). For the past decade or so, Canadian Governments of different political parties have made maternal health a flagship program for Canadian international development assistance. The current Canadian liberal government has championed for and is preparing to host, Women Deliver 2019 in Vancouver. This high-profile conference on maternal health will see the attendance of many politicians, including the Prime Minister.

Canadian educators can offer perspectives on working effectively with equity-seeking communities within the context of maternal health training. For instance, the Society of Obstetricians and Gynecologists of Canada (SOGC) created Advances in Labour and Risk Management (ALARM) International, which is a collaborative effort to train physicians, midwives and other maternal healthcare providers in LMICs. Another such example is the program “Save the Mothers,” directed by a Canadian obstetrician that works exclusively in Uganda. In collaboration with a Ugandan university, the program created a Masters in Public Health program focused on safe motherhood (savethemothers.org). “Saving Every Woman, Every Child: Within Arm’s Reach,” a Canadian Government initiative, pledges to spend $2.85bn on maternal, newborn and child health by strengthening healthcare systems, reducing the burden of disease and improving nutritional standards (Independent Expert Review Group, 2013). Organizations such as these highlight the resources Canada can provide and the various types of international collaborations that can make a difference.

International Federation of Gynecology and Obstetrics (FIGO) carried out projects in many countries with the aim of strengthening the local capacity within midwifery and OB/GYN professional bodies. Funded by a Swedish organization and co-led by the SOGC, each project focuses on six attributes: community-level collaboration, organizational and professional collaboration, advocacy, strengthened clinical services, human rights and
institutional strengthening of professional associations. In some countries, the FIGO collaborative successfully stimulated changes in national legislation for safe abortion and women’s right to care.

The unique role of the diaspora. A unique attribute of Canada is its large diasporic population. In each of these efforts, diasporic Canadians may make important contributions because of connections to their homelands and linguistic expertise. These emigrés often have a long-term commitment toward the social, economic and political development of their countries of origin. Some international development agencies have recognized the unique position of diasporic Canadians and have created volunteer programs tailored to their strengths. For example, the Diaspora for Development Initiative encourages diasporic Canadians to give back to their countries of origin and created the initiative CUSO, a volunteer-sending organization.

3.4 What is the potential role of holistic healthcare and traditional medicine in reducing maternal mortality?

“One of the greatest deficits in international health initiatives is the lack of understanding: the way that we engineer what is acceptable in maternal mortality is very much focused on a Western biomedical definition of maternal health care […] A huge problem is just the bad blood between biomedical practitioners and traditional practitioners […] There is so much racism and exclusion in the training of medical professionals” (Interview Participant 1).

Approximately 75–90 percent of the population in different LMICs relies on holistic healthcare and traditional medicine, which include health systems such as Ayurveda, Traditional Chinese Medicine and others, and whose evidence base is growing (Imran et al., 2017). Understanding holistic concepts and their roots is a vital step in successful efforts to reduce maternal mortality. By working together, allopathic and holistic practitioners find optimal ways to improve maternal health. In India, for example, where the world’s highest numbers of women die in the perinatal period, ayurvedic physicians, who serve 76 percent of the population, could assist in improving maternal health and giving emergency obstetric care (Imran et al., 2017).

3.5 Keeping up the momentum for global maternal mortality reduction efforts

In September 2015, the UN General Assembly debated a new set of SDGs that aimed to create global social, environmental and economic well-being for all. Many of the SDGs that apply to maternal well-being, for example, the alleviation of poverty, hunger, gender inequalities and access to education, clean water and sanitation are foundational determinants of maternal health. A health-centered goal is still included in the SDGs, but not specifically maternal health, despite the fact that the MDGs did include maternal health as a partly unrealized goal (Kendall and Langer, 2015).

Within a human rights framework, all mothers deserve the right to health and the highest quality care (Ruano et al., 2014). Mothers have a high chance of achieving healthy pregnancies, deliveries and positive birth outcomes when proper attention is given to address all obstacles. Well-trained, adequately compensated and rewarded midwives, nurses, family physicians and OB/GYNs help to deliver healthy newborns and maintain positive maternal health status (Ackers et al., 2016). Policy in this area ought to support opportunities for the achievement of positive maternal health status and access to the highest quality of care for all women, regardless of income, social status or other factors. Canada can play a positive role by supporting these policies, particularly since the implementation of the country’s first Feminist International Assistance Policy.

Consistent with sound community development principles, Canadian maternal health efforts ought to emerge from solid partnerships with national governments, community-based organizations and other stakeholders. Canada is a learner, as well as a teacher, in these endeavors. A Canadian team comprised of diverse professionals is recommended to
implement this work. Effective teams would include literacy professionals, researchers, midwives, nurses, family physicians, OB/GYNs and community development professionals who specialize in anti-poverty work, mediation, dialogue and education campaigns that emphasize the value of all people regardless of their gender, ethnicity, religion or income. This team would ideally commit to working in one country or region for a 5- to 10-year period. All team members would speak or eventually learn the lingua franca of that region, and ideally, some team members may come from the diaspora of the community. Working with an NGO that focuses on gender equality may facilitate this process. The team would work to train TBAs, midwives and local physicians, encouraging links with the healthcare system and opportunities for continual and regular education with attention to logistics and other issues related to the improvement of maternal health, such as transportation.

Bringing together physicians, midwives, TBAs, village health workers and others in genuine dialogue with the aim of improving maternal health may also prove an effective strategy (Interview Participants 2, 5 and 10). Consulting with practitioners of holistic and/or traditional healthcare would enhance these projects. Canadian practitioners of holistic healthcare may be the most appropriate team members to initiate such conversations. Most global health projects do not include practitioners of holistic and traditional healthcare. However, as mentioned above, including practitioners of holistic and traditional medicine could potentially improve maternal health. Moreover, all team members should seek to demonstrate cultural sensitivity and respectful communication skills (Interview Participant 4).

Figure 1 illustrates the proposed model, which focuses on community health center (CHC) ideals. CHCs integrate primary care, illness prevention, health promotion, community capacity building, food security and more. They exemplify patient/person-centered care and are based on a model that is comprehensive and accessible.

The high-level administrators of CHCs in Canada are usually nurses, health administrators or other non-clinicians. CHCs are interdisciplinary, one stop shops that integrate healthcare providers such as nurse practitioners, nurses, dieticians, counselors, massage therapists and physicians. Social services such as assistance for subsidized housing and income assistance are also provided at many CHCs which is why they excel at meeting the needs of marginalized communities. They are thus implementing health services that are grounded in a community development approach and reflect an understanding of social determinants of health. Committed to health equity and social justice, CHCs strive to be part of larger movements for fairness in society, advocating for public schooling, public services, labor law and more (Canadian Association of Community Health Centers, n.d.).

Most practitioners at CHCs are salaried professionals which distinguish them, at least in Canada, from others, who are paid on models such as fee for services and other payment modes. This payment model allows clinicians to spend longer periods of time with patients who have complex chronic disease, mental health conditions and poverty-related conditions. Because CHCs work “upstream” in health promotion and disease prevention, patients typically avoid accessing expensive emergency room services (Longhurst and Cohen, 2019).

In Canada, CHCs are typically governed by a board of directors that includes members of the community which is being served. All members of the board of governors have opportunities to contribute to policy development and other governance decisions. Community members who serve on CHC boards provide a critical perspective from those who access services. In serving on CHC boards, community members gain valuable professional experience (Law, 2013).

Governance of CHCs thus reflects the multiplicity of voices that provide services within the CHC. Diverse governors catalyze decisions that take into account the needs of various stakeholders. This democratic governance structure is one which we believe could be replicated in the kinds of maternal health projects described in this paper.
Legislative changes that support comprehensive reproductive healthcare, such as free and universal access to abortion would markedly reduce maternal mortality rates in countries where abortion is illegal (Independent Expert Review Group, 2013). Again, the nations, within their own context and with the aid of Canada, ought to lead national legislative efforts. With political will and genuine desire to change the underlying social and economic conditions of maternal health, international collaboration can play a positive role in the reduction of maternal deaths.

Study limitations. This study has several limitations, which should be addressed by future research studies. First, the study only focuses upon perspectives of Canadian health experts and policy makers and does not include the opinions of health experts from LMICs themselves. Their opinions would help in understanding how they expect a country, like Canada, to help achieve better maternal health. Second, receiving and connecting opinions from pregnant women and mothers would have created more comprehensive finding. Third, this study could have been improved by focusing upon a few case studies from LMICs, along with investigating the opinions of all the stakeholders involved.

Notes: *Community development professionals, literacy teachers, midwives, nurses, physicians, researchers and possibly others
4. Key points

- Canada is not a driver of global maternal mortality reduction work but has a responsibility to work in partnership with countries or regions in a humble and supportive role.

- Applying a comprehensive and interdisciplinary approach to reducing maternal mortality in the Global South includes adopting a CHC model: a community development approach to address social determinants of health and integrating various systems of evidence-informed healthcare with a commitment to social justice.

- Interdisciplinary teams would include literacy professionals, researchers, midwives, nurses, family physicians, OB/GYNs and community development professionals who specialize in anti-poverty work, mediation/dialogue and education campaigns that emphasize the value of all people regardless of their gender, ethnicity, religion and income.

- Diasporic Canadians are invaluable members of these teams due to their linguistic and cultural knowledge as well as their enthusiasm for working with their countries of origin.

- Establishment of long-term partnerships of 5–10 years between a Canadian team and a region or nation in the Global South that is dedicated to reducing maternal mortality and improving women’s health are valuable.

- Canada’s midwifery education programs are rated as world leaders so connecting midwives from Canada with those of the Global South will facilitate essential transfer of knowledge such as using birth plans and other evidence-based practices. Skilled attendants at the birth place will save women’s lives; in most cases, trained midwives are the most appropriate attendants.

Video link to a primer about this paper by Dr Farah Shroff: https://maa.med.ubc.ca/videos-and-media/

5. Conclusions

Canada, with its new Feminist International Assistance Policy, is an emerging leader in global maternal health, and like other such nations, has an ongoing responsibility to work in partnership with LMICs in a humble, supportive role to reduce maternal deaths. Applying a comprehensive and interdisciplinary approach to maternal mortality reduction in LMICs includes adopting a CHC approach to address social determinants of health and integrate various systems of evidence-informed health care with a commitment to social justice. Interdisciplinary teams show the greatest promise for realizing the goal of better women’s health, especially if they include literacy professionals, researchers, midwives, nurses, family physicians, OB/GYNs and community development professionals who specialize in anti-poverty work, mediation, dialogue and education campaigns that emphasize the value of all people regardless of gender, ethnicity, religion and income. Diasporic Canadians are invaluable members of these teams due to their linguistic and cultural knowledge, as well as their enthusiasm for working with their countries of origin. Long-term partnerships between a region/nation and a Canadian team of 5–10 years dedicated to reducing maternal mortality and improving women’s health are ideal. Canada’s midwifery education programs are world leaders so connecting midwives from Canada with those of the LMIC will facilitate knowledge transfer such as using birth plans and other evidence-based practices.
Having skilled attendants at the place of birth will save women’s lives and, in most cases, trained midwives are the most appropriate attendants.

Canada can play an even larger role in reducing maternal mortality in LMICs by employing advantages of a relatively strong economy, an emphasis on human rights and skilled health professionals.

References


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Equity analysis of health system accessibility from perspective of people with disability

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Abstract

Purpose – Self-evaluated access and accessibility has been found to be associated with healthcare seeking and quality of life. Studies have shown that, however, a vast majority of individuals with disability living in poor countries have limited access to healthcare influenced by several barriers. The purpose of this paper is to compare the perception of general accessibility of health care services and its association with access barriers and other contextual factors between people with physical disabilities and counterparts without disability.

Design/methodology/approach – This study is a cross sectional survey involving 213 individuals with physical disabilities and 213 counterparts without disability sampled using a multi-stage method. Data were collected using a structured questionnaire with sections on socioeconomic and living conditions, education, health, employment and access to health care. Data analysis involved using $\chi^2$ for proportions and $T$-test and multiple regressions (stepwise) method to determine significant factors that influence perception on accessibility.

Findings – The study finds that people with disabilities fared worse in various socioeconomic factors such as education, employment, income and assets possession. People with disabilities also experience more dimensional barriers and reported poor health system accessibility. The difference in accessibility continued after adjusting for other variables, implying that there are more inherent factors that explain the perception of access for people with disabilities.

Practical implications – Governments should ensure equitable access to health care delivery for people with disabilities through equitable health policies and services that are responsive to the needs of people with disabilities and promote the creation of enabling environment to enhance participation in health care delivery.

Originality/value – The authors confirm that the paper has neither been submitted to peer review, nor is in the process of peer reviewing or accepted for publishing in another journal. The author(s) confirms that the research in this work is original, and that all the data given in the paper are real and authentic. If necessary, the paper can be recalled, and errors corrected. The undersigned authors transfer the copyright for this work to the International Journal of Health Governance. The authors are free of any personal or business association that could represent a conflict of interest regarding the paper submitted, and the authors have respected the research ethics principles.

Keywords Primary care, Patient perspectives, Emerging healthcare delivery structures, Quantitative research, Health law or regulation, Public health regulations

Paper type Research paper

Introduction

Equity in healthcare is a desirable state and is considered to be a right of all individuals (Sowney and Barr, 2004) and implies that everyone should have a fair opportunity to access needed healthcare including minority subgroups of a population (Layte and Nolan, 2004; WHO, 2012; Whitehead, 1992). This is particularly important in poor countries where many demand and supply side barriers hamper utilization of needed healthcare (Jacobs et al., 2012). While most people face some problems in accessing health care in resource poor settings, people with disabilities face additional and particular barriers (Eide et al., 2015). Studies have shown that a vast majority of individuals with disability living in low-income
and middle-income countries have limited access to healthcare that is influenced by several factors (Davidsson and Södergård, 2016; Eide et al., 2015; Gudlavalleti, John, Allagh, Sagar, Kamalakannan and Ramachandra, 2014; Moodley and Ross, 2015). The relationship between having a disability and access to healthcare is framed within general context of vulnerability as described by Grabovschi et al. (2013). In their model based on the inverse care law (Hart, 1971), they illustrated a relationship where vulnerability varies inversely with healthcare accessibility and varies directly with health care needs. This illustrates the adverse effect of vulnerability such as disability by negatively influencing accessibility of healthcare and amplifying healthcare need.

Evaluating the experiences of people with disabilities with health systems has been suggested as an indicator of general accessibility and equity in responding to the rights of all users (Maclachlan et al., 2011). Access to healthcare is of major development interest because it is regarded as a vital component of human capital that ensures healthy living and good quality of life (Galama and van Kippersluis, 2013; Sen, 2002). Despite its importance, the concept of equity in access in healthcare has been known to generate confusion and proved difficult to evaluate in healthcare policies. Access to healthcare in general has been regarded as a “nebulous and obscure” concept to researchers and policy makers (Thiede and McIntyre, 2008; Racher and Vollman, 2002). The equity perspective is more obscure and difficult to evaluate because most of the available models were developed for general populations that do not capture peculiar needs and challenges experienced by vulnerable populations (Garcia-Subirats et al., 2014; Unger et al., 2008; Gwatkin et al., 2004). Penchansky and Thomas’ (1981) model of “fit” principle defined access explicitly as the interface between potential users and health care resources, which can be used to optimize equity for vulnerable populations. This is because they particularly emphasized the concept of “fit” between the patient’s needs, including their specific characteristics, and the system’s ability to meet those needs. The researchers optimized those characteristics and needs by disaggregating the broad and ambiguous concept of access into a set of five dimensions (5As) of operational measures (availability, accessibility, affordability, acceptability and accommodation). Availability is defined as the relationship between healthcare need and availability of health services, facilities and human resources. Accessibility captures the relationship between location of supply and location of clients in terms of distance and travel time. Accommodation addressed the state in which supply services are organized and able to meet client-specific needs. Affordability is based on the relationship of prices or fees and the clients’ perception of value and ability to pay for services. Lastly, acceptability is defined as the relationship of clients’ service expectations compared to what is actually delivered. However, the model has been further improved by adding other dimensions in order to maximize community needs (Braveman and Gruskin, 2003). Levesque et al. (2013) suggested that health services researchers and organizers should consider system “approachability” based on the notion that people with healthcare needs have to first identify the existence of needed services determined by factors such as knowledge about health and services, attitudes and beliefs related to health and healthcare seeking. Saurman (2016) proposed similar arguments but using different terminology referred to it as the “awareness” dimension. Based on these developments, the “6As” dimension was used in this study by adding the approachability dimension from the Levesque model on to the Penchasky model. The approachability dimension is deemed to be more comprehensive than awareness. Operationalizing access along these dimensions makes it easier to characterize barriers and help identify domains and axes of differentiation from identification of need, healthcare seeking and utilization of services (Lagu et al., 2014).

Studies on access to health care for people with disabilities in sub-Saharan African countries are limited and majority of the available studies did not analyze the impact of disability on access to healthcare by controlling for contextual factors (Eide et al., 2015).
Access to health for people with disabilities in Nigeria is largely unexplored despite the fact that people with disabilities encounter a plethora of barriers in accessing social and economic services (Eleweke and Ebenso, 2016). The main challenge is that, generally, disability issue in Nigeria is generally viewed as a charity and welfare instead of rights, which has led to ineffective enforcement of disability discrimination laws and exclusion in government programs and services (Eleweke, 2013; Lang and Upah, 2008). Disability was found to negatively affect individual’s ability to participate in education, work, family life and healthcare seeking in Nigeria (Smith, 2011). In the study, it was found that over 70 percent of people with disabilities encountered difficulties in accessing health services and other services such as counseling, vocational training and economic empowerment services (Smith, 2011). Health and healthcare challenges among people with physical disabilities has been identified as a huge burden considering survivors of various physically disabling medical conditions such as stroke, spinal cord injury, poliomyelitis, accidents and trauma have been shown to continue to battle health challenges and poor health-related quality of life (Ekuchukwu et al., 2017; Gbiri and Akinpelu, 2012; Hamza et al., 2014; Tella et al., 2011). However, majority of these studies were facility-based, which are limited in examining barriers and difficulties in accessing healthcare. Health systems are mandated to address the diverse needs of the population in an equitable and responsive way; however, in sub-Saharan Africa, a gap exists in research on how equitable health systems are in meeting the needs of people with disabilities (Eide et al., 2015). This study is aimed to assess and compare the perception of general accessibility of health care services and its association with access barriers together with other contextual factors.

Methodology
This study is a population-based survey conducted in Jigawa state, Nigeria. The study participant included individuals with physical disabilities and matched counterparts without disability recruited using multi-stage sampling method. Sampling started at the state level where five districts were randomly selected representing nine health districts in the state. Two local government areas were randomly selected out of the three local government areas in each district. Each local government was stratified into enumeration areas (EAs) based on the 2006 National Population Census. A total of 24 EAs were selected based on probability-proportional to size. Approximately 25 eligible households from each of 24 EAs were calculated to identify a representative sample of individuals with disabilities, assuming a disability prevalence of 5 percent, statistical power of 90 percent, a significance level of 95 percent and an estimated design effect of 2.5. At the final sampling stage, approximately 25 households were randomly selected from each EA for a total sample of 600 households. A total of 213 disabled respondents as well as an equal control group of 213 non-disabled matched according to age, gender and location. The eligibility criteria for people with physical disabilities in this study were identified based on having any form of physical visible impairments/abnormalities affecting mobility that lasted at least six months and reporting having “some difficulty” or “a lot of difficulty” or “unable” in any activity including walking, climbing stairs, and or taking care of self based on the (Madans et al., 2011) Washington Group on Disability statistics. Data collection instrument included a structured questionnaire with sections on socioeconomic and living conditions, education, health, employment and access to health care. The perceived health system accessibility and six access dimensions were measured using a five-point Likert scale. The access to healthcare instrument was developed purposely for the study using a method described by Colton and Covert (2007). The instrument was validated using a population-based survey using structural validity, construct validity and known-groups validity tests (Zandam et al., 2017). Each access dimension represents quantitative component of an array of barriers prevalent in the study location identified during instrument development. Indexing with composite means, with a value between 0 and 1 was used to assess the participants’ overall
level of perceptions in each dimension and general accessibility (0 means low resistance and values more than 0 to 1 represents increasing resistance). Data analysis involved comparison analysis using \( \chi^2 \) for proportions and \( T \)-test for means. Multivariate relationships were tested using multiple regressions (forward stepwise) method (derived from the SPSS software version 22) to determine significant association between access dimensions and general perception of accessibility. Variables with 0.05 or less (\( p \leq 0.05 \)) probability were considered significant.

Three sets of regression analyses were made. First, all the variables and a variable, 0 for non-disable and 1 for disabled were put in the regression model and run (using enter). This was to find out whether there was a significant difference between the two groups. Second, the disability variable was eliminated from the data set and the stepwise method used to select the significant variables for each group separately. Third, all variables that were significant in either of the groups were put together in another regression model and run. The overall confidence in the multiple regression data for each of the districts was determined by the adjusted coefficient of determination (adjusted \( R^2 \)). The linear relationship assumption between the IVs and the DV was tested using scatterplots and this assumption was met. Assumption of multicollinearity and residuals independence were tested using VIF and tolerance statistics and Durbin–Watson statistic, respectively.

**Results**

The descriptive analysis brings out significant differences between the disabled and non-disabled in various factors variables but gender and age, which were matched as seen in Table I. However, the age distribution is skewed toward lower age values, i.e. reflecting the demographic profile of most of the population with a large proportion of individuals within 16–29 years of age. People with disabilities have significantly higher proportion of single (39 percent) at the time of the study and more people living in rural areas (73 percent) compared to non-disabled proportions of singles (27 percent). With respect to other factors, result shows that group with disability have significantly higher proportion of those with no formal education (42 percent) and those not literate (42 percent) compared to those without disability. Employment/unemployment proportion among the study participants appears to be large and a significantly higher proportion of people with disabilities (54.5 percent) are not employed compared to those without disabilities (42.0 percent). Socioeconomic status (SES) was measured by analyzing possessions of 26 different assets in the household. The result shows that 49 percent of those with disability belonged to the poorest group compared to 36 percent of those without disability. Per capita expenditure was calculated for each household and was found to be significantly lower among disabled participants than non-disabled. The results show that 28 percent of respondents with disabilities describe themselves as being in good or rather good health compared to 42 percent of non-disabled respondents (\( p < 0.05 \)).

Result from the analysis of access indices calculated for each group and compared. The access indices were calculated as simple weighted average index of the six dimensions and general health system accessibility. A higher score on this scale describes a situation of increased difficulty in accessibility while a lower score typifies less difficulty in each dimension. Result across all dimensions was generally found to be significantly higher among group with disabilities, indicating the experience of higher resistance compared to group without disability (\( p < 0.05 \)). Approachability dimension was found to have one of the least gap between the two groups with disabled group having (0.44) compared to non-disabled (0.26). However, the accommodation dimension was found to have the widest gap and significantly different at 0.68 and 0.24 for disabled and non-disabled, respectively. Other dimensions including affordability, availability, accessibility and acceptability dimensions values were found to be consistently and significantly different as well. Overall the healthcare accessibility index was found to be higher with value of 0.71 among disabled, compared to 0.52 among non-disabled.
Do these differences in the level of the independent variables explain the differences in general accessibility? A regression analysis gives a clue to the reality of the differences. The model parameters can be interpreted as the perceived general healthcare accessibility for a man without disability between ages 16 and 29 years, employed, with the highest level of education, and living in an urban area. The regression results (adding the variable of disability)

<table>
<thead>
<tr>
<th></th>
<th>Disabled n (%)</th>
<th>Non-disabled n (%)</th>
<th>p-value*</th>
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<tr>
<td><strong>Sex n (%)</strong></td>
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<td>Less than 10,000</td>
<td>(67)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 10,000</td>
<td>(33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Usual source of care (%)</strong></td>
<td></td>
<td></td>
<td>0.00*</td>
</tr>
<tr>
<td>Public PHC</td>
<td>34 (16)</td>
<td>51 (24)</td>
<td></td>
</tr>
<tr>
<td>Public hospital</td>
<td>49 (23)</td>
<td>43 (20)</td>
<td></td>
</tr>
<tr>
<td>Private clinic</td>
<td>15 (7)</td>
<td>36 (17)</td>
<td></td>
</tr>
<tr>
<td>OTP</td>
<td>45 (21)</td>
<td>38 (18)</td>
<td></td>
</tr>
<tr>
<td>Traditional/home remedy</td>
<td>70 (33)</td>
<td>45 (21)</td>
<td></td>
</tr>
<tr>
<td><strong>Access indicators (WAI)</strong></td>
<td></td>
<td></td>
<td>0.00*</td>
</tr>
<tr>
<td>Approachability</td>
<td>0.44</td>
<td>0.26</td>
<td></td>
</tr>
<tr>
<td>Availability</td>
<td>0.68</td>
<td>0.44</td>
<td>0.00*</td>
</tr>
<tr>
<td>Accessibility</td>
<td>0.74</td>
<td>0.48</td>
<td>0.00*</td>
</tr>
<tr>
<td>Affordability</td>
<td>0.84</td>
<td>0.71</td>
<td>0.00*</td>
</tr>
<tr>
<td>Acceptability</td>
<td>0.71</td>
<td>0.52</td>
<td>0.01*</td>
</tr>
<tr>
<td>Accommodation</td>
<td>0.44</td>
<td>0.24</td>
<td>0.01*</td>
</tr>
<tr>
<td>Overall accessibility</td>
<td>0.72</td>
<td>0.52</td>
<td>0.00*</td>
</tr>
</tbody>
</table>

Table I. Socioeconomic characteristics of participants

Notes: WAI, weighted average index; NN, Nigerian Naira (local currency). *Significant at $p \leq 0.05$
status) indicate that the impact of having a disability on accessibility is significant (Table II). The influence of the disability factor remains after introducing other independent variables (0.56, 0.41–0.75). To select the variables for the final analysis, a separate stepwise regression for each group was run and variables that were significant in one or both of the groups were then used for the analysis. The final analysis was conducted to examine the differences in the perception of accessibility across disability status and also to compare the significant factors that influence the perception of accessibility for each group. In the regression model, the variables that proved significant at a probability ($p$) value equal to or less than 0.05 were selected. Values that were significant, using the stepwise method, were all put in a single regression model to get a common basis for comparison. The result is shown in Table III.

### Table II.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Coefficient</th>
<th>95% CI</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>0.56</td>
<td>0.41–0.75</td>
<td>0.02*</td>
</tr>
<tr>
<td>Sex</td>
<td>0.32</td>
<td>0.22–0.54</td>
<td>0.20*</td>
</tr>
<tr>
<td>Age</td>
<td>0.13</td>
<td>0.33–0.76</td>
<td>0.34</td>
</tr>
<tr>
<td>Employment</td>
<td>0.33</td>
<td>0.32–0.73</td>
<td>0.90</td>
</tr>
<tr>
<td>Marital status</td>
<td>0.15</td>
<td>0.30–0.45</td>
<td>0.00*</td>
</tr>
<tr>
<td>Education</td>
<td>0.12</td>
<td>0.27–0.44</td>
<td>0.01*</td>
</tr>
<tr>
<td>Location</td>
<td>0.48</td>
<td>0.14–0.53</td>
<td>0.00*</td>
</tr>
<tr>
<td>SES</td>
<td>0.51</td>
<td>0.57–0.80</td>
<td>0.35</td>
</tr>
<tr>
<td>Income</td>
<td>0.34</td>
<td>0.30–0.45</td>
<td>0.00*</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>0.32</td>
<td>0.41–0.64</td>
<td>0.00*</td>
</tr>
<tr>
<td>Usual source of care</td>
<td>0.41</td>
<td>0.44–0.72</td>
<td>0.00*</td>
</tr>
<tr>
<td>Approachability</td>
<td>0.11</td>
<td>0.23–0.76</td>
<td>0.02*</td>
</tr>
<tr>
<td>Availability</td>
<td>0.41</td>
<td>0.32–0.73</td>
<td>0.00*</td>
</tr>
<tr>
<td>Accessibility</td>
<td>0.35</td>
<td>0.42–0.64</td>
<td>0.00*</td>
</tr>
<tr>
<td>Affordability</td>
<td>0.39</td>
<td>0.37–0.42</td>
<td>0.02*</td>
</tr>
<tr>
<td>Acceptability</td>
<td>0.26</td>
<td>0.64–0.84</td>
<td>0.00</td>
</tr>
<tr>
<td>Accommodation</td>
<td>0.19</td>
<td>0.57–0.80</td>
<td>0.11</td>
</tr>
</tbody>
</table>

**Note:** *Significant at $p \leq 0.05$

### Table III.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Coefficient</th>
<th>95% CI</th>
<th>$p$-value</th>
<th>Disabled group Coefficient</th>
<th>95% CI</th>
<th>$p$-value</th>
<th>Non-disabled group Coefficient</th>
<th>95% CI</th>
<th>$p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>0.52</td>
<td>0.49–0.73</td>
<td>0.00*</td>
<td>0.30</td>
<td>0.22–0.36</td>
<td>0.00*</td>
<td></td>
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<td></td>
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<tr>
<td>Affordability</td>
<td>0.49</td>
<td>0.40–0.68</td>
<td>0.00*</td>
<td>0.33</td>
<td>0.26–0.37</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>0.35</td>
<td>0.21–0.47</td>
<td>0.04*</td>
<td>0.38</td>
<td>0.30–0.41</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SES</td>
<td>0.31</td>
<td>0.26–0.53</td>
<td>0.01*</td>
<td>0.32</td>
<td>0.25–0.37</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability</td>
<td>0.30</td>
<td>0.24–0.41</td>
<td>0.00*</td>
<td>0.18</td>
<td>0.15–0.23</td>
<td>0.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation</td>
<td>0.28</td>
<td>0.20–0.34</td>
<td>0.00*</td>
<td>0.04</td>
<td>0.26–0.67</td>
<td>0.34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>0.24</td>
<td>0.23–0.54</td>
<td>0.03*</td>
<td>0.27</td>
<td>0.25–0.33</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approachability</td>
<td>0.21</td>
<td>0.17–0.23</td>
<td>0.00*</td>
<td>0.71</td>
<td>0.42–0.86</td>
<td>0.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-reported health</td>
<td>0.20</td>
<td>0.11–0.28</td>
<td>0.04*</td>
<td>0.24</td>
<td>0.16–0.27</td>
<td>0.01*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>0.19</td>
<td>0.12–0.23</td>
<td>0.00*</td>
<td>0.19</td>
<td>0.15–0.23</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usual source of care</td>
<td>0.18</td>
<td>0.09–0.31</td>
<td>0.02*</td>
<td>0.66</td>
<td>0.53–0.97</td>
<td>0.02*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>0.18</td>
<td>0.12–0.28</td>
<td>0.00*</td>
<td>0.59</td>
<td>0.26–0.67</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.16</td>
<td>0.25–0.53</td>
<td>0.09</td>
<td>0.12</td>
<td>0.11–0.15</td>
<td>0.00*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.15</td>
<td>0.11–0.21</td>
<td>0.13</td>
<td>0.21</td>
<td>0.17–0.24</td>
<td>0.04*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>0.11</td>
<td>0.08–0.16</td>
<td>0.78</td>
<td>0.08</td>
<td>0.07–0.13</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptability</td>
<td>0.07</td>
<td>0.20–0.33</td>
<td>0.51</td>
<td>0.11</td>
<td>0.32–0.76</td>
<td>0.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.434</td>
<td></td>
<td></td>
<td></td>
<td>0.459</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note:** *Significant at $p \leq 0.05$
For the single regression model based on common significant variables for both disabled and non-disabled, the variables that make significant impact on perceived accessibility for disabled (in order of importance) are accessibility (0.52, 0.49–0.73), affordability (0.49, 0.40–0.68), location (0.35, 0.21–0.47), SES (0.31, 0.26–0.53), availability (0.30, 0.24–0.41), accommodation (0.28, 0.20–0.34), education (0.24, 0.23–0.54), approachability (0.21, 0.17–0.23), self-reported health (0.20, 0.11–0.28), employment (0.19, 0.12–0.23), usual source of care (0.18, 0.09–0.31), income (0.18, 0.12–0.28). Gender, age, marital status and acceptability were not significant for the disabled group. For non-disabled group the variables in order of importance are different including approachability (0.71, 0.42–0.86), usual source of care (0.66, 0.53–0.97), affordability (0.33, 0.26–0.37), SES (0.32, 0.25–0.37), accessibility (0.30, 0.22–0.36), education (0.27, 0.25–0.33), self-reported health (0.24, 0.16–0.27), age (0.21, 0.17–0.24) employment (0.19, 0.15–0.23) and gender (0.12, 0.11–0.15). Gender, approachability and accommodation were not significant in non-disabled group, whereas age and employment have greater effects on access for non-disabled than disabled, consumption, location, gender, assets and education have greater effects on access perception of disabled than non-disabled. Whereas the adjusted regression square (adjusted $R^2$) for non-disabled is 0.521, it is 0.478 for disabled, implying that there are more inherent factors that explain the perception of access for people with disabilities.

**Discussion**
Achieving equity in access to healthcare is a component of social determinant of health and is considered as a strategy for achieving health equity (WHO, 2008). This study shows inequitable access: people with disabilities experience poor health system accessibility despite their high healthcare need, compared to people without disabilities. This is consistent with the model proposed by Grabovschi et al. (2013), showing that vulnerabilities such as disability vary inversely with accessibility and quality of healthcare.

The contextual link between having a disability and access to healthcare can also be explained using the capability approach, which has been used to deal with different disability-related equity issues by Martha Nussbaum (2006) and Amartya Sen (2009). In fact, Sen’s (2009) capability approach of justice motivates comparative assessments of well-being that may lead to insights on the extent and nature of deprivations and inequities experienced by people with disabilities. This centers on the inability of such metrics to take note of the diversity of human beings in converting primary goods into what people are able to be and do in their lives. Sen’s arguments have particular resonance for people with disabilities who may be born with different capabilities and potential opportunities as everyone else but may face restrictions in realizing them. Such restrictions are due to a number of factors both internal (physical limitations) and external (how society responds to these limitations for example discriminatory practices).

In this study access dimensions and contextual variables, i.e. sociodemographic and economic factors, can explain differences in accessibility. The differences in access dimensions explains access from a broad perspective, not only entry into the health care system but also what occurs as people travel through the system in the process of seeking and utilizing health care. They thus represent barriers to access at various stages involved in an episode of care, often occurring in a cumulative manner, from initiation of the health care seeking process to the actual benefit from available options for care (Levesque et al., 2013). This highlights the importance of procedural justice according to Aday (2004), referred as to the extent to which the structural and process features of health services delivery result in an equitable access of services for individuals and population groups with comparable needs and wants.

This study also provides clues into the various factors influencing perception of health system accessibility between the groups. Together with income, affordability has been a strong determinant of access, implying that wealthy have better perception of accessibility.
This situation has implications for researchers and policy makers to appreciate and highlights the need for innovative health financing policies based on economic principles that will reduce out of pocket and offers financial protection (Banks and Polack, 2014; Zandam and Juni, 2015). This can be achieved in several health system financing options that include a mix services across range of promotion, prevention, treatment and rehabilitation services (Normand and Thomas, 2008; WHO, 2013).

The factors of SES and location have a considerable impact on accessibility in both disabled and non-disabled groups. However, the restrictive factor of geographic accessibility and availability dimensions has a far greater effect on the disabled group than the non-disabled. This is because majority of the participants from the disabled group live in rural districts where services are not always available. Distances to health facilities, transportation difficulty and poor quality of the roads may also negatively influence accessibility. Availability barriers relating to how easy it is to get a consultation, waiting time at facility and general problem with specialized services were also found to be prevalent among people with physical disabilities. These barriers reflects a contextual and structural challenges between supply and demand factors as well organization for services delivery (Ahmad, 2013; Eide et al., 2015; Gudlavalleti, John, Allagh, Sagar, Kamalakannan and Ramachandra, 2014; Gudlavalleti, John, Allagh, Sagar, Kamalakannan, Ramachandra and South India Disability Evidence Study Group, 2014). Decentralization of resources for healthcare and hospitals to rural areas makes healthcare resources easier to access for people with disability who lives in rural areas.

Accommodation was found to be a peculiar problem for people with physical disabilities influenced by organization of services that is not considerate of the needs of people with physical disabilities (Abdi et al., 2015). This can be improved by providing a broad range of reasonable accommodation to overcome barriers, including structural modifications to facilities, equipment with universal design features, adjustments to appointment systems, alternative models of service delivery and communication of information in appropriate formats. Approachability differences show that differences exist in the capability to initiate and seek healthcare. This finding is consistent with previous studies showing that people with disabilities have poor knowledge of health care services (Padhyegurjar and Padhyegurjar, 2012), have poor attitudes toward health care (Abdi et al., 2015), and have poor expectations and satisfaction with services (Mulumba et al., 2014). Approachability can be improved by providing health education and information regarding available treatments and services. Outreach activities could contribute to make the services more or less approachable.

Acceptability dimension in terms of patient-provider relationship and quality of services was not significantly associated with accessibility among people with disabilities. However, it was significantly different in comparison with those without disability. People with disabilities generally experience problems with quality of the services and often report communication difficulties and gaps with service providers (Van Rooy et al., 2012). Service providers need to be trained on proper communication with people disabilities as they have been have reported to feel uncomfortable communicating with people with disabilities (Mulumba et al., 2014).

Government should adhere to equitable principles within health care as a commitment to social justice. Theories of social justice concerned with how goods and resources are shared amongst members of society should be debated about which principles of distributional justice should guide access to health care. Norman Daniels (2001), who extended Rawls’ “fair equality of opportunity” argues that the primary function of health care is to maintain normal species functioning, and thus the range of opportunities that are open to individuals requires universal access to appropriate health care, according to need. Ruger (2007) further developed a capability view of health and access to health care and outlined its implications that health policy should aim to support an individual’s capabilities for health functioning by providing the conditions in which individuals can meet their health needs.
Conclusion

People with disabilities were generally found to have a poor access to health care as they experience a number of barriers to needed health care. The result shows that several access dimensions and socioeconomic factors influence overall accessibility between people with disabilities and counterparts without disability. Increasing access to healthcare through equitable health policy and organizational strategies should be a central focus of policy interventions for reducing disparities in access to healthcare among people with disabilities and larger population. The quantitative nature of this study is a limitation, as it cannot capture the complexities and lived experiences of living with a disability especially as it relates processes of healthcare seeking. The study also did not address some important issues related to disability such as differences with regard to nature of disability, its origin, duration and how these may relate with the study. This study also used self-reported measures, which, in itself, has potential limitations, as there was no independent confirmations of what the participants were reporting.

References


Further reading


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Health delivery system for older adults in academic campus in India

Tulika Bhattacharyya, Chandrima Chatterjee and Suhita Chopra Chatterjee
IIT Kharagpur, Kharagpur, India

Abstract

Purpose – Residential academic campuses generally support a skewed population profile that favours a younger population, mainly the student community, and thereby marginalize the needs of the older people staying within the campus. Health delivery systems are often not in accordance with the needs of staff members co-habiting with their aged parents and relatives as well as older staff members themselves. This poses a serious problem, especially in India, where filial piety is a norm and many employees cohabit with their parents. Moreover, the Government of India has reformulated its retirement policy under which the age for superannuation of teaching staff has been enhanced. This in turn, has raised the older-younger ratio in campuses in recent years. The paper aims to discuss these issues.

Design/methodology/approach – To address these issues, a household survey was carried out on older people staying in a residential academic campus of India followed by a focus group discussion with family caregivers of the older people.

Findings – It was found that older people were a marginalized group in campus, as health delivery system and allied facilities were not consistent with their needs. As a result, they and their family caregivers faced various challenges.

Originality/value – This is the first study exploring the possibility of academic campuses in India to emerge as alternate sites for supporting older care.

Keywords Public health, Health policy, Patient perspectives, Qualitative research, Public health regulations, Population health, Rural health, Health service quality assurance, Anthropology or sociology, Health care commissioning

Paper type Research paper

Background

Recent demographic changes have led to serious transformations in health care needs of the community. Globally, 9.2 percent of the population was aged in 1990, whereas by 2050 the population of the aged is expected to be 21 percent. Presently, developing countries have two-thirds of the world’s older population, which is expected to escalate to eight to tenth by 2050. In absolute terms, the global aged populace is expected to be 2bn in 2050 (United Nations, Department of Economic and Social Affairs, Population Division, 2019). In this era of rapid upsurge in older population, developing adequate care structures for the older people is a major challenge. Hospitals and homes alone would be unable to bear the burden of their care. Therefore, it is becoming important to develop adequate alternative structures for their care in the new and emerging settings, including those which are not conventionally structured for their care, e.g. residential academic campuses.

Residential academic campuses may be thought of as “Growth Centers” as well as centers of social integration apart from merely being the focus of academic activities. They are often located in remote areas to provide a fillip to development of the adjoining regions. Segregated from the main community, they may be considered as a small replica of a “community” where diverse groups of people of differing age, religion, caste, language and culture stay together. According to a campus design report of the University of Pennsylvania (2002), the purpose of a campus is to bring together diverse people and their ideas in an environment that creates potential for intellectual and social exchange.
Campuses promote a sense of community derived from actively shared space and provide for the enriching experiences of both planned and chance encounter of the residents and visitors. In residential academic campuses, people of varying age groups stay together on a long-term basis and have different and varied health needs. Older care is therefore a growing concern in the campus.

Most studies that deals with campus design have emphasized on its development from architectural and/or educational (Delgado, 2018; Alptekin, 2014; Heijer et al., 2012; Rubiralta and Delgado, 2010; Heijer, 2008) or religious/spiritual point of view (Mayhew et al., 2014; Bowman and Smedley, 2013; Patel and Meyer, 2009) or from the perspective of structuring high-end services for enhancing students’ experience and international collaborations (Bocanegra-Valle, 2018; Seeber, 2017; Coulson et al., 2014) without giving due consideration to demographic features and community health issues. Yet, some studies are worth mentioning for their potential to suggest integrative community-academic-health center relationships, like those by Seifer (1998) and Kok et al. (2015), which emphasize on supportive leadership at all levels, adequate human and financial resources, faculty commitment, effective institutional factors and long-term relationship with the community. Seifer (1998) further proposed that there needs to be enhanced collaboration of the campus health delivery system and existing academic departments like the school of health professions – especially nursing and medical schools. The Dependent Care Taskforce report by Syracuse University (2012) suggests that flexibility at the work place is at the core of older care as it can facilitate family members to take older members for a physician’s appointment, drop them off at an adult day care center or wait at home until an aid arrives. It also recommends that a successful campus design is required to identify the need for older care services, and there needs to be collaboration between older care service providers and existing departments. A similar study conducted earlier by Massachusetts Institute of Technology (hereafter MIT) in 2001 found that older care is a growing concern in the campus, as one-fourth of the faculty and staff members expect to have older care responsibility in the near future, whereas one in seven reported that they are currently engaged in older care. The report suggested that MIT needs to provide more comprehensive resources for older care.

Aging is profoundly shaped by local environments, access to economic and health resources and available family members, social relations and support systems (Anjos et al., 2014; Pimenta et al., 2009; Yeung and Fung, 2007; DuPertuis et al., 2001). The next section deals with ageing and older care in India.

**Aging and family caregiving in India**

The population of older people in India is projected to increase from 8 percent in 2015 to 19 percent in 2050 and is expected to be 35 percent by the end of this century (United Nations Population Fund, 2017). A series of studies point out that in India, older population are generally prone to cardiovascular illnesses, stroke, circulatory diseases, cancer, arthritis, hypertension, osteoporosis, high blood pressure, kidney problems, vision problems, diabetes, chronic bronchitis, rheumatism, digestive disorders, genito-urinary disorders, hearing impairment, anemia, skin disorders and dementia (Srinivas and Manjubhashini, 2014; Brijnath, 2011, 2014; Jha et al., 2006; Kant et al., 2004; Kumari, 2001). Older people generally suffer from chronic diseases that require long-term care. They also suffer from multiple morbidities, which increase their need for care. As life span lengthens, the intensity and duration of care that many people require as a result of debilitating chronic illness and frailty also increases. In other words, care of the older people never exclusively affects their experiences and lives alone but also that of their caregivers. In the Indian context, most of the caregiving is provided by family members. Older individuals tend to depend on filial piety and intergenerational support during their old age (Gupta and Pillai, 2002, 2012).
Families meet the care needs of their older kin through co-residence. Most common type of living arrangement emerges to be older people living with their married sons and their families (Devi Prasad and Indira Rani, 2007; Ugargol et al., 2016). Patrilocality prevailing in the Indian context ensures that the wives undertake the responsibility of respectfully caring for their husband’s co-residing older parents (Brijnath, 2014; Lamb, 2000). Family caregiving of older kin is considered to invite good karmas and blessings for the younger family members.

Gupta (2009) found that various factors influence caregivers’ experiences such as attitude of other family members, family structure and location. He also found that the greater the number of caregiving tasks performed by the family caregiver, the greater is the perceived burden. Family caregiving experiences have been found to be varied, both positive and negative (Gupta et al., 2012). They also found that relationship quality and support staffs were negatively related to family caregiver’s burden, whereas role overload and role conflict were positively related. This study also reported that female caregiver’s quality of relationship with older care recipients was poorer than that of males. Gupta et al. (2009) claimed that in households where family caregivers strongly adhered to Indian social norms of filial piety, women experienced a substantial increase in perceived caregiver burden and role overload. Caregiving was also found to be gendered: women undertook the responsibilities of caring at home like cooking, feeding, cleaning and bathing, whereas men undertook care responsibilities outside the home (Bhattacharyya et al., 2017; Buch, 2015; Lamb, 2000). Brinda et al. found that the cost and burden of family caregiving was high in rural Indian communities. Their work also revealed that the average time spent on family caregiving was 38.6 h/week and the estimated annual cost of family caregiving (using “proxy good” method) was $119,210; prevalence of depression among family caregivers was 10.6 percent in rural India; and higher the age of the family caregiver, the greater was their burden.

Aging and family caregiving in residential academic campuses in India

There are no known policies as well as studies on Indian academic campuses from the perspective of older care. The need for restructuring Indian residential campuses as suitable places for older people is increasingly felt because the Government of India has recently raised the age of superannuation of teaching staff from 65 years to 70 years in premier academic campuses/research institutes, which is expected to increase the older-younger ratio in these campuses. Accordingly, residential academic institutions are likely to house larger populations of older people. However, it is unclear whether they can meet their rising health care needs with existing resources.

In the absence of a formal social support program for older people at academic campuses in India, family members play a major role in providing older care. Family caregiving entails substantial physical, emotional, material and social resources. It is thus critical to understand the diverse experiences, meanings and consequences of caregiving for family members of older people in campuses.

The study has two objectives: the study assesses the health status of the older people in terms of their morbidity patterns, functional status including the type of caregiver’s support and treatment choices and the study also attempts to understand perceptions of health services available for older people in the campus.

Methods

Information was obtained about older people who were more than 60 years of age and have been residing in the campus for at least the last five years. The older people in campus consisted of older teaching staff and older family members of both teaching and administrative staff. Data were gathered through face-to-face household survey followed by
focus group discussion (hereafter FGD). The household survey was conducted between November 2014 and May 2015 to address the following research questions:

RQ1. What are the disease profiles of the older people?

RQ2. Whether older people required assistance in maintaining their functional status?

RQ3. Who were the caregivers assisting the functionally dependent older people?

RQ4. What is the opinion of the respondents about the campus health delivery system for the older people?

The researcher approached 660 households, of which 177 had at least one older person. The data were gathered from 184 older people who resided in those households, of which 52 (28.26 percent) were older teaching staff member themselves. Household survey consisted of a questionnaire. The respondent consisted of either the older member himself/herself or their family members, above eighteen years of age – whoever was present at the time of the survey. As recommended by Zuvekas (2014), the researcher requested that the most-knowledgeable person in the household about health and health care of the older person to respond. In order to overcome the obvious limitations which occur in using household survey, like issues with proxy response, item non-response and mis/under-reporting of support/facilities (see Meyer et al., 2009, 2015), FGD was followed. It was carried out in February–March 2016 with a few purposively selected family caregivers identified from the household survey. It involved the interaction among the researcher and small group (five to seven members in each group) of family caregivers of older people, as well as between the family caregivers with the objective to gather information about the family caregiver’s perspective about older care in campus. The researcher used probing for soliciting required information (see Bryman, 2016; Morgan, 1998). FGDs provided an opportunity to build up on each other’s comments, which generated ideas and breadth of discussion about the campus health system. It also helped the researchers to tap information about knowledge, perspectives and attitudes of family caregivers as well as different forms of anecdotes and arguments they use in day-to-day communications. This revealed information which generally remains less easily accessible through direct questions, as in one-to-one interview (see Carter and Henderson, 2005; Kitzinger, 1995). Thus, FGD was apt for understanding the health delivery system for the older people in campus. It also helped in understanding family members’ concerns (see Tausch and Menold, 2016). FGDs were conducted in three small groups, and this has been confirmed by prior studies (Guest et al., 2017) as an optimum number for deducing majority (80–90 percent) of the themes.

All FGDs were audio-recorded and saved in a password-protected personal mobile phone of the researcher, in order to ensure the confidentiality of the participants. As a precaution against accidental loss or corruption, the electronic data were also backed up in a password-protected personal laptop of the researcher. All paper copies of research data – such as signed consent forms by the participants and field notes of the researcher – were stored in a locked cabinet.

All transcriptions were done by the researcher, thereby eliminating any risk associated with the breach of confidentiality/biasness due to the presence of a translator. While transcribing the interviews, specific details about the participant which could make them identifiable were altered, without altering the meaning of the participant’s responses (Bryman, 2016). All participant information and identifiers were removed before data storage. Only anonymized soft data were prepared for data storage and used throughout the study. The anonymized electronic data were transcribed, translated into English and backed up by the researcher. Therefore, all forms of electronic data were stored in password-encoded device, in order to ensure the confidentiality of the participants. Thematic Analysis technique (see Braun and Clark, 2006) was used to interpret the FGDs.
NVivo software was used to manage and analyze the data. This technique was used in order to interpret themes emerging from the data. At first, the researchers familiarized themselves with the FGDs through “data immersion” (Clarke and Braun, 2013), for which the data were reviewed again and again, and therefore, an iterative approach was taken in order to avoid de-contextualization of data as mentioned by Joffe and Yardley (2004) and Vaismoradi et al. (2013).

Locale of the study
The study was conducted in a public residential academic campus of India. The campus is located in a district headquarter, and the nearest metro city is approximately 130 km away. It has an area of more than 2,000 acres, making it one of the largest residential campuses of India. The campus surroundings constitute basically a rural hinterland. Hence, the domestic and informal paid caregivers coming from the surrounding areas of the campus are mostly unskilled in nature. Inside the campus, several academic departments exist that have a potential of providing various inputs to health delivery system. About 22,000 inhabitants reside in the campus, including the dependents of the employees. The primary source of health care is a hospital, situated within the campus that provides basic health services, including emergency services round the clock. It provides equal access and services across class and caste. Due to a recent initiative of the Institute, a fleet of visiting specialist physicians are available on select days, but the giant share of specialized medical services is utilized by the younger population, especially the student community. Free consultations and medicines, inpatient and outpatient services and basic diagnostic services are provided to all campus residents and dependents of employees. However, specialized diagnostic services have to be obtained from either the district headquarters or the cities; the latter is preferred to the district services, which are believed to be of inferior quality. During emergencies, the campus hospital refers critically ill patients to higher referral centers with whom a partnership has been worked out.

Findings
Overall, 14.67 percent (27) older people were found to be financially dependent on younger family members. Very few older people (both older staff and dependents) (0.04 percent) were covered by some kind of private health insurance. Among the rest, 0.05 percent (11) older people were not covered by any health insurance and 23 percent (43) were not aware about the health insurance system. The rest (77 percent) skipped the question on health insurance.

Morbidity patterns, caregivers support sought for maintaining functional status and treatment choice
The Government of India listed the following top ten causes of mortality among older people in the year 2010: cardiovascular disease (24.9 percent), respiratory diseases (11.6 percent), diarrhoeal diseases (5.9 percent), fever of unknown origin (4.1 percent), malignant and other neoplasms (3.8 percent), unintentional injuries other than motor vehicle accidents (3.6 percent), respiratory infections (2.9 percent), diabetes (2.7 percent), digestive disease (2.4 percent), ill-defined/abnormal laboratory findings (29 percent) and all other remaining causes (9.1 percent). About 64 per thousand older persons in rural India and 55 per thousand in urban areas suffer from one or more disabilities (Jeyalakshmi et al., 2011). The findings of the present study also indicate a similar pattern of morbidity among the older campus residents. Table I details the disease profile of the older adults staying inside the campus, including older staff members. The most prevalent disease among older people staying inside the campus was hypertension (59 percent) followed by visual and hearing impairment (54 percent) and diabetes (47 percent). Other significant chronic diseases from
which older people were suffering were arthritis (32 percent), gastro-intestinal disease (18 percent) cardiovascular disease (0.09 percent) and lung diseases (0.06 percent). A few older people also suffered from cancer.

Almost all older people staying inside the campus required some kind of assistance in their daily activities. The assistance was generally provided by informal caregivers or family members. In every household, a large share of assistance was provided by family members. Table II shows that the contribution of informal caregivers (unskilled paid care providers and nurses) in providing assistance to older care was poor. In 117 households, housework-related assistance was provided to older people by family members themselves. For other activities also, contribution of family members was higher.
compared to other informal caregivers. Overall, very few older people were independent and did not require assistance with activities of daily living.

Respondents were also asked about their treatment choices. Almost 98 percent (173) older people sought allopathic treatment, while 7.3 percent (13) relied on complementary and alternative methods of treatment such as Homeopathy, Yoga or Ayurveda along with allopathic treatment.

Problems with campus health services

Respondents were also asked about the kind of problem faced by them in accessing campus health facilities. Unavailability of physicians was found to be the biggest problem followed by absence of home visits, lack of specialist treatment and poor quality of medicine. In total, 58 households found that physicians were not available and 56 households complained about the absence of home visits. Specialist treatment inside the campus also was not satisfactory, as opined by a large number of respondents (55). A few (four) households complained of lack of alternative treatment. Table III highlights the responses regarding health services in the campus.

Table III shows that there exists a huge discontent with the campus health care delivery system. A similar response was evident from the focus group discussion held after the household survey. A considerable number of respondents were called for discussion, using purposive sampling, but eventually few employees’ family caregivers turned up. However, some interesting points emerged from the discussion as mentioned below:

- One of the factors that affect the health of older people is the distributional pattern of residential accommodation inside the campus. It may be mentioned that residential allocation is based on income and designation and not on need. Therefore, lower income employees who support older family members face a severe space crunch. An interesting case was presented by one of the respondents residing in a single-room apartment provided by the institution. The family of four with two grown-up school-going children had to make a make-shift shelter on the ground floor to accommodate his 90-year-old mother who was bed-ridden.

- Most of the participants identified absence of trained paid caregivers as a major problem in care of the older people. In the absence of such support, family members took upon themselves the task of caregiving, which in turn resulted in considerable stress and burden.

<table>
<thead>
<tr>
<th>Type of problems</th>
<th>No. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unavailability of physicians</td>
<td>58</td>
</tr>
<tr>
<td>Unavailability of home visits</td>
<td>56</td>
</tr>
<tr>
<td>Referral during emergency (getting bed/ICU, etc.)</td>
<td>23</td>
</tr>
<tr>
<td>Difficulty in transport (going to the physician/arranging ambulance etc.)</td>
<td>14</td>
</tr>
<tr>
<td>Lack of integrated treatment (e.g. visiting multiple clinics for one patient)</td>
<td>7</td>
</tr>
<tr>
<td>Exorbitant cost</td>
<td>13</td>
</tr>
<tr>
<td>Poor quality of medicines</td>
<td>49</td>
</tr>
<tr>
<td>Lack of specialist treatment</td>
<td>55</td>
</tr>
<tr>
<td>Unavailability of skilled paid caregivers</td>
<td>6</td>
</tr>
<tr>
<td>Accompanying patients to higher referral centers</td>
<td>20</td>
</tr>
<tr>
<td>Unfriendly behavior</td>
<td>4</td>
</tr>
<tr>
<td>Lack of alternative treatment methods (e.g. ayurveda and homeopathy)</td>
<td>4</td>
</tr>
</tbody>
</table>

Table III: Reported problems related to campus health care services

Notes: n = 177. These data do not reflect on Physician’s capacity/hospital services in real terms but from the perspective of older care
Considerable dissatisfaction was expressed regarding the patient discharge policy of the campus hospital. It emerged that not all cadres of employees received transportation services back to home at the time of discharge, which especially affected older members.

Older family members of the employees who were recipients of their own government pensions and therefore were not financially dependent on the employees were not eligible for campus hospital services even during health emergencies. This created considerable stress, especially in the absence of good health facilities in the hinterland.

Almost all respondents complained of lack of home visits and unavailability of transportation during emergencies.

However, a major strength of campus health structure was community participation among lower-cadre employees, who supported each other during emergencies.

Health mobilization groups within the campus: alternative responses to health care

Among the wellness mobilization networks, a Yoga group, set up by a few staff members, is worth mentioning. An affinity group of non-teaching staff, apparently dissatisfied with the campus health system in particular and the biomedical approach to health in general, was found to have set up an alternative structure for preventive health. Many of the participants consisted of retired employees who lived near the campus and used the existing campus facilities – health center, shopping, recreational and other facilities.

Another community network is operated by a group of low-cadre employees on the principle of micro-finance. It started with small membership strength in the year of 2004–2005. By 2015, the number of members, initially eight, had increased to 27, among whom three were females. The founder member informed that the group was guided by spiritual inclinations to serve society. A minimum subscription fee of Rs. 500 per month was collected from each member by the first week of each month. The total fund collected in this way was kept in a bank savings account. After a period of 12 months, the principal loan amount was paid back with two percent interest added to it. This often coincided with the festive season, thus serving a social purpose as well. The available fund was used to meet emergency needs primarily related to taking sick people to higher referral centers. Maximum limit of a loan was capped at Rs. 15,000 for each episode. However, if any member wished to overdraw, a guarantor was needed. This organization not only provided loans to members but also extended physical help whenever needed, such as donating blood, accompanying sick members to referral centers in the cities and meeting the travel and food expenses of the escort. The group also extended their help to non-member campus residents, if needed.

Discussion

Large numbers of older people were found to reside in the campus, which is in sharp contrast to the popular notion that campuses only house younger population, which is similar to the findings of Bhattacharyya et al. (2019). Most of the older people in campus were financially independent but did not have private health insurance. The morbidity profile shown in Table I indicates the urgent need for introducing geriatric services in the campus hospital. Poor functional status of the older people as shown in Table II and unavailability of trained caregivers highlight an unmet need for older care. It shows the necessity for developing an overall structure for supporting older care in the campus. In the absence of such structures, the family caregivers play major caregiving roles and...
therefore their voices need to be heard. In spite of the large number of older population with physical/functional limitations the campus facilities were not found to be designed to meet the needs of the older people and their family caregivers.

Although the in-campus hospital provides basic care, the findings reflect multiple problems in accessing older care services as shown in Table III, especially related to challenges in transportation and lack of home care, within the small boundary of the campus. Prior studies in India have also shown transportation (Bhattacharyya and Chatterjee, 2019; Bhattacharyya, 2018a, b) and lack of home care (Bhattacharyya et al., 2017; Bhattacharyya and Chatterjee, 2019; Bhattacharyya, 2019) as major challenges for older care in rural India. This suggests the need for quality improvements of the health delivery system for the older people. Findings also indicate the need for special older care clinics to avoid long queues resulting from client-mix of young and old patients. Referrals to city hospitals were found to be difficult to manage as the family caregivers of older people had professional commitments for which they were bound to the campus. This implies the need for improving the existing services to make them congenial for older people.

Some older people, observed during the household survey/reported during FGD, were too fragile to be taken for outdoor consultations in the campus hospital. It was equally challenging to take them to higher referral centers even when ambulatory services were provided by the campus facility. The need for home services within the small radius of the campus may appear to be confounding, but is essential to meet the special needs of the frail older people.

Studies indicate that the unavailability of informal caregivers adds to the burden of caregiving, especially for women (see Gupta et al., 2012; Gupta, 2009). The present study found that families were the principal caregivers in the absence of paid caregivers in the campus, resulting in great stress and caregiving burden. This was primarily on account of a lack of trained people from the rural hinterland and much needs to be done to improve the human resources for the campus health facility, including skills training for palliative care. Challenges of older caregiving in campus also got escalated due to lack of long-term care provisions and respite care.

Conspicuous by its absence is the provision of alternative therapeutics, which have a proven role in chronic diseases of the older people (cf. Kumari, 2001). It may be mentioned that the Government of India has taken several measures to promote the use of complementary and alternative medicines such as Ayurveda, Yoga, Homeopathy, Unani and others, but the campus under study does not have such facilities. However, the number of respondents indicating this as a problem is very low.

In the future, academic campuses may consider focusing on developing academia-health linkages to provide relevant inputs for older care. Overall the academic campus, being a replica of the larger community, needs to gear up for developing end-of-life care structure for older people from public health perspective (see Sengupta and Chatterjee, 2013).

A major strength of the campus health system is the presence of community leadership, though on a small scale. Both of the groups found in this study serve as a strong instance of community mobilization and participation, mutual help and brotherhood. However, a lack of human and financial resources, inadequate managerial and technical skills and poor organizational logistics impede their functioning on a larger basis. These need greater institutional support and involvement of the students, faculties and administrative staff.

**Conclusion**
In the light of existing morbidity patterns, the study shows the need for restructuring the health delivery system of the campus to cater to the needs of the older people and their
family members residing within the campus. Campus health systems need to focus on improving staffing pattern, training of paid and family caregivers, devising separate physician schedules for older consultation and introducing home care and integrative treatment to meet the special needs of the older campus residents. The study also indicates the need to consider the plight of family members and devise programs for their support. Mere focus on medically oriented health services do not suffice for the older people, and there exists need for evolving wellness programmes for them.

Overall, the study indicates the need for restructuring the academic campus, to meet the needs of the older people and their family caregivers. These findings have implications for those involved in campus designs and services.

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Abstract

Purpose – The purpose of this paper is to provide a broad overview of the articles published in the current issue.

Design/methodology/approach – The review editor reads all articles accepted for the current issue of IJHG, identifying common themes and selecting other relevant articles to explore these themes more fully.

Findings – The findings of this review indicate that the most effective way to care for the sick or disabled is with community involvement.

Practical implications – The practical implications are that the review helps readers to gain a better understanding of the journal content and how for each issue, common themes can be developed and discussed.

Originality/value – No other Emerald Journal has a review section of this type so it is a unique selling point for IJHG.

Keywords – User involvement, Culture, Clinical governance, Patient perspectives, Teamwork, Health service quality assurance, Primary care, Maternal child health

Paper type – General review

There is an old African proverb that states “It takes a village to raise a child” (Seymour, 2013). This negates the modern western model espoused by Bowlby (Bretherton, 1992) of the mother as primary caregiver and attachment figure for the human infant. Indeed, examination of non-western models of childcare and of other forms of caring demonstrates the importance of community involvement (AIFS, 2014).

This review highjacks the traditional proverb and reimagines it to explore the importance of community engagement in healthcare. The review examines seven articles with varied perspectives from an exploration of Arabic language YouTube videos providing advice on cancer care through a survey-based study that attempts to qualify how religious belief may affect empathy and action in volunteering with the sick or disabled. All of the articles included in this Special Issue have a common focus on community and collectively provide a lesson for healthcare in both the developing and the developed world that community plays an important role in ensuring essential, effective and equitable healthcare for all.

Community in the internet age

The first article reviewed conceptualised community somewhat differently than the way it is normally discussed in terms of healthcare. In traditional communities people ask advice of friends, relatives and neighbours. In seeking advice on cancer care, a worried individual might ask other people who have come through cancer treatment about what treatments worked for them, what the side effects of medication or radiography were, or if they had tried any alternative or complementary therapies. Today the internet offers new ways of becoming part of a community and this is particularly true in terms of health-related topics. Ask your browser a question about health and you will soon find yourself connected to people willing to provide advice. Health forums can be opportunities to experience continuity of advice and support as McCarthy et al. (2017) found in their study examining the use of Facebook forums as a focus for maternity care advice and support. However, members of the general public may find it difficult to discriminate between legitimate guidance based on current best evidence and untested theories derived from popular opinion. In McCarthy et al’s study, Facebook forums were moderated by professional midwives who ensured the validity of...
advice shared between “Facemums” as the women participating in the Facebook group were known. This level of governance was absent in the majority of YouTube videos analysed by Kharbat and Abu Daabes (2019) who selected YouTube as their medium because it is the second most visited social media site worldwide. They reviewed 150 videos in the Arabic language on the subject of cancer care. While 30 of these were later discarded due to lack of relevance, of the remaining 120 videos, 73 per cent failed to mention risk factors or current recommendations concerning cancer treatment. The most visited videos were those uploaded by non-professionals and from analysing the questions and comments, the authors stated that it was clear that most viewers did not have the knowledge to differentiate between valid information and potentially dangerous misinformation. They concluded that closer governance of health related YouTube videos is needed.

Conceptualising the wellness journey: first nations communities in Australia and Canada

Aboriginal and Torres Strait Islanders represent a more traditional picture of “community”. First Nation Australians typically have very strong notions of community and attachment to their communities of origin (AIFS, 2014). They also experience reduced life expectancy and higher rates of chronic health problems, compared to non-indigenous Australians (Rendalls et al., 2019). Paradies (2016) suggests that much of this disparity, in Australia as in other post-colonial societies, can be attributed to historical trauma and racism. The tacit acknowledgement of these factors has led to increased effort on the part of the Australian Government to increase community involvement in planning and participation in healthcare in indigenous communities. Government accreditation standards now require community engagement in decision-making around population health targets. A similar requirement to involve communities has existed in Canada for a number of years. As this requirement for community involvement has been maintained throughout the changing political scene in Canada and is now a well-accepted construct of healthcare planning and provision, some lessons have been learned that may also be applicable to other communities such as the Australian Aboriginal and Torres island communities. These relate to how to effectively engage with communities and why this is important in healthcare planning and provision (Berland, 2019). Clarity of purpose is essential together with good leadership and willingness to try different forms of engagement to meet a community’s requirements. Berland (2019) suggests that recognition should be given for effort and not simply for outcomes when changes are being made within communities.

Rendalls et al. (2019), however, point out the importance of differentiating between the community as a whole and consumers of healthcare who represent a subset of the wider community. The National Health and medical Research Council of Australia has developed clear guidelines for community engagement. The central concepts underpinning this guidance are Building Relationships and Conceptualisation. The first of these is self-explanatory. If health professionals, including health researchers and care planners, do not build relationships with the populations they serve then they are unlikely to develop a clear understanding of a community’s true needs. The second concept, conceptualisation, relates to how people within a community visualise their “wellness journey”. If what health providers offer is not congruent with what a community sees as its primary needs, communication and resolution will be complex and unproductive. Health services for indigenous populations must form a partnership based on respect and ethnographic knowledge in order to establish a service providing effective and culturally appropriate care.

The plight of elders trapped on college campuses designed for the young
Another article highlighting the need for culturally appropriate care is by Bhattacharyya et al. (2019) who explain that traditional family structures and customs mean that many
elderly people end up living with younger family members on academic campuses designed for the young. Not only do the campus health services focus on health needs of young people, the very design of campus life can be isolating for older residents. Many older family members are ineligible to use campus medical services even in emergency situations and as many academic campuses have been constructed in rural areas, it is difficult for older people to get to health services designed to meet their needs. While these problems may be exacerbated by campus life, they are by no means restricted to the campus environment. Bhan et al. (2017) report that the ageing population is an increasing problem in a country lacking the health infrastructure to support their needs, particularly in rural areas. One issue raised by Bhan et al. (2017) and Bhattacharyya et al. (2019) is that the burden of care for elderly people falls on family members, particularly female relatives. Often this will be a daughter-in-law as traditionally elderly parents choose to live with a son and his family (Bhattacharyya et al., 2019). The changing structure of family life in India as elsewhere means more women are employed outside the home, often leaving elderly people feeling lonely or isolated. Greater community engagement for the elderly was one proposed solution (Bhattacharyya et al., 2019; Bhan et al., 2017), with Bhattacharyya et al. (2019) reporting on elderly self-help initiatives including a yoga club, a micro-finance initiative and a hospital transport service. However, in order to prosper, such self-help programmes require support from the wider community and national government. Elderly people in India have traditionally been honoured for their life-experience and wisdom. Structuring India’s healthcare to meet the chronic health needs of an ageing population would help elderly people to feel that they are still valued by society while supporting them to take on more active roles in meeting their own individual and collective requirements for health and social inclusion.

**Meeting the healthcare needs of disabled people in rural Nigeria**

Elderly people are not the only members of a community who can have trouble accessing care. Zandam and Juni (2019) report on the problems of disabled people in rural Nigeria as they attempt to access appropriate acute and ongoing healthcare. The authors explain that a major issue is that the disabled lack basic rights afforded to other citizens. Caring for the disabled is considered the remit of charitable institutions and therefore public health services do not have a responsibility to ensure access and equity.

However, evaluating the experiences of people with disabilities, in terms of accessing healthcare serves as a good indicator of how well the service functions for the larger population. In other words, if the service works well for those who are most at a disadvantage in terms of their ability to access care, it works well for the larger population. Such an assessment also serves as a reminder that health is a vital component of human capital, enabling everyone to live a healthy and productive life, contributing to their communities to the best of their ability.

Zandam and Juni’s (2019) research method was a population-based survey in the Jigawa state of Nigeria. A total of 426 participants were evenly divided between disabled people and matched non-disabled counterparts.

The study examined the “fit” between population requirements and current health service provisions using a model first developed by Penchansky and Thomas (1981) and subsequently adapted by other health researchers. The version used in this study employed six dimensions: availability, accessibility, affordability, acceptability, accommodation and approachability. The “6 As” approach was used to identify barriers to expressed needs.

Disabled participants had experienced impaired mobility for at least six months or had difficulty with a range of activities including walking, stair-climbing or self-care. The access to healthcare study instrument was developed as a structured questionnaire that included demographic details and questions relating to the six dimensions of healthcare access.
Results showed that the disabled population was younger, more likely to live in rural areas and to be single. They also had lower levels of education, literacy and employment. A total of 49 per cent of the disabled belonged to the poorest economic group and only 28 per cent considered themselves to be in good health, compared to 42 per cent of non-disabled residents. The results were evaluated using a health accessibility index with the higher scores representing the most difficulty in accessing healthcare.

The areas having the most impact on disabled people’s ability to access healthcare were (in order of importance) accessibility, affordability and location.

Findings demonstrated that disabled people experience high levels of healthcare need but also high levels of difficulty in meeting those needs. Some difficulties are related to the disability itself, but others are due to the perceptions of other people within their communities.

The authors propose changes to the health service, including financing, decentralisation of services, disability-friendly accommodation and better communication on the part of healthcare workers to make healthcare more accessible and equitable for disabled people.

**Does religious belief increase empathy towards the ill or disabled?**

Zandam and Juni (2019) point out that in Nigeria, it is considered the role of charities, many of these run by religious organisations, to care for the disabled. While this is slowly changing to a more community-based approach, a team of researchers in Indonesia asked some interesting questions about whether religion makes people more likely to express empathy in terms of caring for the ill or disabled members of a community. Pratano et al. (2019) became interested in the links between healthcare provision and faith groups, particularly in the charitable sector. In order to explore just how religiosity and empathy interact the researchers developed an online survey tool to test four hypotheses relating to these concepts. A total of 610 respondents between the ages of 18 and 20 completed the survey. Findings seem to suggest that people identifying themselves as religious have less empathy but at the same time, more engagement with the health services in terms of volunteer activities. This lack of empathy may be due to stigma about illnesses associated with activities or lifestyles that conflict with the precepts of a certain faith, for instance sexually transmitted disease. At the same time, there may be expectations for young people who identify as part of a faith community to express altruistic behaviour through activities such as volunteering in healthcare settings. Similar findings were reported by Watson et al. (1985) who separated the concept of religiosity into “intrinsic” and “extrinsic”. Extrinsic religiosity was essentially self-serving and used religious adherence to create social acceptance or gain status or other individual goals. Intrinsic religiosity by contrast did lead to greater empathy and compassion as it was associated with deeply held beliefs.

Pratano et al. (2019) conceptualised their study by starting with an interesting question and developing four hypotheses from this. They collected data using a research tool designed to be attractive to their target age group and they explained their analysis in detail. However, nuances are not revealed by statistics, thus it would be interesting to do a follow-up study using a more in-depth qualitative methodology to examine how religion affects young people’s attitudes and activities relating to illness and care provision.

**Can community engagement occur at a distance?**

In the final article reviewed, Shroff et al. (2019) ask whether partnerships between lower and middle income countries (LMICs) and countries in the Organisation for Economic Co-operation and Development (OECD) can improve maternal health outcomes, particularly in terms of a reduction in maternal mortality rates.

LMICs continue to have difficulty in reducing their maternal mortality rates despite efforts of the UN through implementation of the MDG programme. Shroff et al. (2019) suggest that experts in OECD nations can offer help. Data collected through qualitative interviews with ten
global maternal health experts provided evidence that maternal health can be improved through better collaboration between interdisciplinary teams consisting of health professionals together with literacy teachers, agriculturalists and community development workers.

Using a community health model, the biggest improvements to maternal health are achieved through higher female literacy, gender justice, freedom from violence and food and water security as well as healthcare accessibility. Campbell, Calvert, Testa et al. warn that all too often improving maternity care focuses on emergency responses. These researchers suggest that evaluation of routine care is just as necessary to evaluate providers’ skills, prevent over-intervention.

Shroff’s recommendations include:

- Establishment of long-term partnerships of 5–10 years between Canadian members and a region or nation in the Global South to improve women’s health and reduce maternal mortality.
- Using Canadian midwifery graduates to transfer evidence-based knowledge.
- Provision of trained (midwives) attendants at all births.

Maternity care is an excellent area in which to test such a partnership as health in pregnancy is the foundation for maternal and child health with implications throughout the life span (Steegers, 2015). In addition, there are some existing forums for communication and collaboration between maternity care providers such as midwives and obstetricians from MLIC and HIC.

Conclusion
Raising children and raising awareness of the benefits of collaborative healthcare requires a change of attitude to a less individualistic, more holistic and community-based model. We can help each other to birth well, to live well and to die well. Today many traditional communities have become, or are becoming, lost. It is important to save old ways of being in communion with one another while we look for ways forge bonds for the future.

References


Further reading

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