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Delivering eye health education to deprived communities in India through a social media-based innovation

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Abstract

In this article, Chandrani Maitra, with her supervisor, Prof. Jennifer Rowley, reports on her PhD research conducted at Manchester Metropolitan University. This research aimed to develop understanding of the benefits of, and the challenges associated with the use of social media to disseminate eye health information in deprived communities in India. Such communities typically have a low level of access to health information, as the result of poor literacy, poverty, lack of women's empowerment, cultural practices, society dynamics, and medical malpractice. This study used an intervention based on the social media platform, WhatsApp, to educate a group of women volunteers so that they were able to contribute to the management of the eye health of their family, friends, and neighbours. Interviews were conducted with deprived community members (DCMs), community healthcare advocates (CHAs) and, healthcare professionals (HCPs). The DCMs reported a number of benefits associated with their participation in the eye health intervention. CHAs and HCPs agreed that an extended roll out of the intervention had potential to deliver benefits, but expressed concerns that some of the ongoing social challenges facing deprived communities might act as barriers to progress. F.J.

KEYWORDS

Asia, south; developing economies; health care; health education; social media

INTRODUCTION AND CONTEXT

This study focusses on the use of the social media platform WhatsApp for education regarding eye health. Eye health is a major global problem, with 285 million people suffering from visual impairment, 90% of whom reside in the developing world. According to the World Health Organisation, 80% of this blindness is preventable. Since India hosts almost a quarter of the global burden of vision impairment, posing a major challenge for India's healthcare agenda (Nair, 2015), this research focusses on an intervention on the use of WhatsApp in a marginalised, deprived and hard to reach semi-urban community in the village of Chowbaga, near the metropolitan city of Kolkata, in West Bengal, India. The policy of the Government of India, in public–private partnership with non-government organisations, is to provide eye care services, including raising awareness through health education, through hospitals and mobile dispensing services. However, for a variety of social, economic and cultural reasons, the deprived community in this study, together with many similar communities living in poverty in rural or city overflow settings, rarely engages with formal healthcare services. Traditional communication channels, such as radio, television and print media have been widely used to educate and empower communities, but have met with limited success (Finkelstein et al., 2012). Social media, however, has the potential for both two-way and multi-way communication between

information providers and recipients, as well as between individual recipients, including members of disadvantaged groups (O-Adewuyi, 2016). For example, Whitehead and Seaton (2016) suggest social media can be exceptionally useful in educating people using their own language. Social media can be used in health education, disease surveillance, tracking and monitoring of disease outbreaks and providing cost-effective and rapid communication (O-Adewuyi, 2016). It can also be used to identify the need for information, to monitor public response to health issues, and to communicate health messages to targeted communities. Furthermore, social media platforms such as WhatsApp that provide audio-visual communication can be of particular benefit to people with relatively low levels of literacy.

There is an established and growing body of research into the use of social media in healthcare settings but most of this is restricted to platforms such as Skype, Twitter and Facebook (e.g., Lim, 2016; Moorhead et al., 2013). This study, instead, focusses on WhatsApp, a social media platform that is widely used in India, and which has audio-visual features that can enhance communication at a number of different levels. In addition, this study is unique in its focus on three groups: women who were members of the deprived community, healthcare professionals and community health advocates. Opinions from members of all three groups, regarding a WhatsApp-based intervention, were solicited. The women were from a community that is often difficult to reach, in terms of both health care and research. The health professionals and community health advocates worked closely with the members of the chosen community. The study reports on the existing barriers to access to eye health information amongst the deprived community, and on the benefits and challenges associated with a change in practice and policy requiring investment in enhanced access to eye health information, via a multimedia platform such as WhatsApp.

LITERATURE REVIEW

There is an increasing interest in the use of social media in disseminating health information. More specifically, the access and appeal of social media in the developing world has increased exponentially with the availability of affordable mobile technology and cheaper data costs (O-Adewuyi, 2016). Social media can be used to educate and empower communities through the transfer of information from the healthcare provider to the target population (Whitehead & Seaton, 2016). Social media is perceived to have a greater potential to influence members of the public and decision makers than traditional media (Côté & Darling, 2018).

Social media has been used by healthcare providers in the context of information dissemination pertaining to public health issues such as viral outbreaks (Househ, 2016; Sesagiri Raamkumar et al., 2020) in health promotion campaigns (Park et al., 2016), and in specific disease contexts such as hypertension (Al Mamun et al., 2015) and dengue (Lwin et al., 2016). However, only three studies have explored the use of social media to support communities in taking care of their eyes. One study evaluated technology utilisation and patient preferences, but only 3% of participants preferred social media for health reminders (Aleo et al., 2014). Two other studies examined social media as an epidemiological surveillance tool for allergic eye diseases; one reported good correlation with clinically confirmed cases (Deiner et al., 2018) and the other with pollen counts (Gesualdo et al., 2015). Only one study has explored the potential of social media as an interventional tool (Sanguansak et al., 2017). In this study, two-way social media messaging was used to deliver reminders and educational information about postop care to cataract patients. Although patients expressed satisfaction with messaging, no difference in medication adherence or clinical outcomes was noted at the end of the study period.

RESEARCH METHODS

This study aimed to critically examine the complex phenomenon of health communication and attitudinal change associated with a WhatsApp-based intervention designed to educate women in a deprived community in India with respect to how they could improve the eye health of their family and other members of their community. The study used a qualitative methodology using a single, embedded case study research design (Yin, 2017) that supported a deep understanding and a rich description of the research context. The local women participants (30) were invited to attend five educational sessions organised by a tertiary eye healthcare provider (Susrut Eye Hospital), and facilitated by two local neoliterate women health advocates. The process was coordinated and supervised by the researcher who was embedded in all stages of the intervention and project. Subsequent to their participation in this eye health educational intervention, the women were invited to participate in a focus group interview where they were encouraged to talk about the barriers to information access that they faced, and, what, after their involvement in the intervention, they perceived to be the benefits of WhatsApp-based eye health communication.

Interviews were also conducted with community health advocates (10) and healthcare professionals (10) in order to gather insights on their views on the value and feasibility of WhatsApp as a tool in the promotion of eye health. They were asked for their insights regarding structural benefits, cultural benefits and ongoing challenges. Thematic analyses of data were undertaken to generate a thick rich description

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of the issues surrounding eye care communication prior to, and post, adoption of a WhatsApp-based health communication channel.

FINDINGS AND DISCUSSION

All stakeholder groups agreed that there were a number of barriers to effective access to eye health information for the deprived community.

Healthcare providers (HCP) acknowledged that access to eye care information for deprived communities was limited. Barriers that they identified included: the lack of an effective information dissemination strategy on eye care, together with the population characteristics of the deprived community, such as extreme poverty, illiteracy, lack of awareness, lack of empowerment, pre-existing sociocultural prejudices and taboos and mistrust towards healthcare providers. Community health advocates (CHA) agreed that population characteristics contributed to an eye health information gap, but also suggested that the government and healthcare providers could do more to engage with the deprived community. In addition, CHA's reported on a number of other socio-economic factors that contributed to health information deficits amongst the deprived community: frequent mobility, unplanned settlements, medical malpractice, corrupt pharmaceutical practices, misinformation spread by individuals and organisations with vested interests, political leverage and deprived community members' apathy. Deprived community members overwhelmingly agreed that they had very limited access to accessible, easy to understand, accurate and relevant eye health information.

Subsequent to the social media-based intervention, HCPs and CHAs agreed that social media-based information dissemination strategies could be beneficial in addressing the eye health information gap, and acknowledged the specific benefits of the use of WhatsApp. As compared with other communication channels, the benefits of WhatsApp were seen to be as follows: audio-visual capabilities (video and images); private and convenient accessibility, anytime, anywhere; minimal cost implications; and, two-way communication capabilities, to establish direct links between healthcare providers and end users. On the other hand, concerns were raised as to the credibility, authenticity and trustworthiness of the information, data privacy and security, and finally, but importantly, the financial implications. Stakeholders suggested that WhatsApp could be used to disseminate information on preventative eye care, routine eye care, posthumous eye donation and locally available affordable eye care services.

From the deprived community's perspective, all participants reported benefits from the WhatsApp facilitated educational sessions that had made them significantly more aware of the hazards of poor eye health, preventative measures for good eye care, local availability of good quality affordable

eye care and the importance of posthumous eye donation. The two-way capability of WhatsApp was highlighted as creating a link between healthcare providers and the community; this helped to dispel the prevailing culture of mistrust and misinformation. Audio-visual capabilities were greatly appreciated, as was the pedagogic style of narrative storytelling; the interface was considered easy to use and engaging. After the experience, community members felt that WhatsApp use had boosted their confidence in the use of this technology to access information on a wide range of issues and to share their experience. In addition, participants reported a change in their social status, in that they were now considered as "experts" by their families and the wider community.

IMPLICATIONS FOR PRACTICE AND CONCLUSION

This study offers a range on insights into the perspectives of three key stakeholder groups regarding the use of social media, specifically WhatsApp, to enhance understanding of members of deprived communities of the management of their eye health. This study has demonstrated that access to such technologies can not only educate, but can also empower. On the other hand, for such an intervention to make a significant impact on attitudes and behaviours in eye care and other aspects of digital health information, more interventions of this type need to be conducted both in eye health and other health issues that impact significantly on deprived and underprivileged communities. As demonstrated in this article, the consequences of the implementation of a programme of such interventions could have a significant impact not only on the health of disadvantaged groups and communities, but also on their empowerment, education and confidence in healthcare providers.

Going forwards, whilst this study has surfaced new insights and understandings, there is a need for further research, into both eye care and other fields to inform and evaluate the development of social media-based health resources that are accessible to deprived communities in India and elsewhere. Such research is an important precursor to regional and national policy development regarding the use of social media in health care. Future research should seek to the following:

1. Gather insights into the attitudes towards the use of social media-based eye health interventions from men, and other family members, such as grandparents
2. Conduct further research into the relative merits of the efficiency, acceptability and reach of the various social media platforms
3. Explore the value of WhatsApp as an information-gathering tool, in order to inform healthcare providers about the specific healthcare needs of the society.

One of the main challenges is the need for policy development that bridges the wide gulf between those that are responsible for developing health policy and deprived communities. In short, much more research is necessary to convince policy makers that any investment in WhatsApp-based health information provision will deliver significant and widespread benefits.

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