

Patient and Family Engagement Strategies & Contributions in the COVID-19 Pandemic

Summary of the June 22, 2020 World Health Organization Patients for Patient Safety (WHO PFPS) webinar hosted by the Canadian Patient Safety Institute (CPSI) and Patients for Patients Safety Canada (PFPS)

The webinar recording, key resources, and slides are available [here](#).

Objectives:

1. To engage webinar participants in thinking through patient and family engagement strategies that promote safety for patients, families, and healthcare workers during the COVID-19 pandemic;
2. To share innovative responses by the Patients for Patient Safety (PFPS) community to the new threats to safety posed by COVID-19 pandemic; and
3. To spread useful tools and resources through the PSMF community.

Webinar Overview

The webinar offered via Cisco WebEx was attended by 282 participants from 18 countries: Canada, Finland, Ghana, India, Iran, Ireland, Israel, Italy, Macedonia, Nigeria, Pakistan, Saudi Arabia, Switzerland, Turkey, Uganda, The United Kingdom (UK), United States of America (USA), and Yemen. Most of the participants were from Canada. A total of 423 people registered from 26 countries, all of whom received the proceedings from the webinar by email.

Introduction

Helen Haskell, PFPS Champion from the USA and webinar moderator, welcomed the participants and introduced both the webinar and the speakers. In her introduction, she highlighted the objectives of the webinar and framed some of the issues currently faced by the PFPS community and the populations they serve. Helen proceeded to give some housekeeping tips to the participants about using the chat box, which was managed by Marty Hatlie, PFPS Champion from the USA, to ensure the comments and questions for discussions were addressed during the webinar. She notified all participants that the session was being recorded and that all the information would be made available to them via email and shared publicly.

Welcome message from WHO

Neelam Dhingra, the Unit Head of Patient Safety Flagship, welcomed the participants on behalf of WHO and extended appreciation to the PFPS Champions for the work they continue to do in their various countries to advance patient safety. She noted that the WHO is developing a Global Patient Safety Action Plan and would appreciate critical review from the PFPS community and global participants. Neelam also mentioned the upcoming [World Patient Safety Day](#) (WPSD) celebrated annually on September 17. The theme of WPSD 2020 is “Health Worker Safety: A priority for patient safety”. She encouraged participants to join in commemorating this day in their various communities.

Pakistani patient advocacy groups work with government to address the needs of the public

Hussain Jafri, PFPS Champion, Pakistan

Hussain started by sharing the current COVID-19 status in Pakistan. He noted that though Pakistan has a low death rate from COVID-19, the outbreak has increased health inequalities in the most hit areas like Punjab. Thus, community and patient organizations have collaborated with the government to curb these impacts. Some of the strategies include the government easing the national lockdown that was implemented sooner to ease economic pressures. Instead they moved to a smart lockdown approach to only impose lockdown on areas with increasing cases. Another strategy was the Patient Safety Friendly Hospital Initiative (PSFHI) to increase patient safety. The PSFHI has five domains for action: leadership and commitment, clear policies and guidelines, competent and compassionate health professionals, engaging patients and families, and using data to drive improvements. Through the PSFHI, there has been more public and patient involvement in patient safety.

One of the reasons for Pakistan to have done better with COVID19 is because Pakistani patients and community have been very actively collaborating with the government to improve the situation on the ground. Hussain provided examples of how patient advocates and community organizations have come forward to help the government in a variety of ways in Pakistan.

Alzheimer's Pakistan, a patient organization, has established telephone helplines for psychological counselling for care givers of patients with dementia during the pandemic. Patients and community organizations are utilizing social media to create awareness campaigns and offer support to COVID and non-COVID patients. A specific example for non-COVID patients support is the awareness campaign created by a Thalassaemia Federation of Pakistan to increase access to fresh blood for transfusion required by Thalassaemia patients. Further support to people with special needs includes the creation of patient safety networks to support them since they are mostly overlooked. Distribution of food to people experiencing financial hardship, providing free medication to patients with chronic diseases who are unable to pay for their medication, and support from a Coronavirus relief task force which was distributing facemasks to people with dementia and their families.

Hussain concluded that despite being a low-resourced country, Pakistan has so far been able to meet the challenge of the COVID-19 pandemic. Reported death rates are low compared to many other countries. One reason for this is that patient and community organisations have joined hands with the government during this crisis. This provides a great example of collaborative action which other countries can learn from.

Tools and strategies for supporting the homebound elderly in Canada

Sharon Nettleton, PFPS Champion, Canada

Sharon started off by talking about a pre-COVID-19 initiative (Scarboro Community Association's Coffee Klatch) that she and two other members started about six years ago in in Calgary, Alberta to help seniors living in their own homes stay connected. The 'Klatch' meets 4-5 times a year and has been a successful way for seniors to stay connected and engaged with each other and the community.

When COVID-19 struck, the Community Association looked to the 'Klatch' as a way of reaching out to seniors and others who might be at risk. Using the community directory, community newsletters, and by making personal phone calls, a group of community volunteers reached out and connected with those who might be most 'at-risk' in the community. Some of these connections were made to assist with very specific needs:

getting groceries, picking up prescriptions, taking people to necessary (albeit limited) appointments, and helping to reinforce the need to isolate, to social distance the importance of hand-washing, masking etc.

More than 50 volunteers stepped into action. Many of them acted as ‘buddies’ by staying connected and in touch with more isolated seniors. For several, who were extremely isolated, and/or frail, with health issues, and did not have family or loved ones in the city or province, a ‘[connection sheet](#)’ was created to help them collect and collate essential information so that they could share it with whomever they deemed necessary (i.e., their children, other family members, family physician, pharmacist, members of their faith community etc.). In the process, it was discovered that many did not have medical directives written up and in their home. This will be something that the ‘Klatch’ takes forward. It is something that all should be aware of and complete so that our medical wishes are understood and followed. Other barriers noted during the early days of COVID-19 related to communication, hearing impairments, and the difficulty in using the telephone - and understanding messages that were being relayed, as a result of problems with hearing aids (changing batteries, getting aids cleaned etc.). For others, being able to rely on and consistently use technology was noted.

Sharon explained that Calgary was moving into the second phase of reopening, and that this initiative continues to reinforce to seniors and all members of the community, the key messages of proper handwashing, social distancing and wearing masks when social distancing is not possible, as well as getting outside to stay mentally and physically healthy. Sharon concluded her presentation by mentioning that a large majority of the COVID-19 deaths in Calgary to date have been seniors living in care facilities. It was noted that the initial spread of infection was found to be through health care workers working in multiple homes/sites. She also raised the need to have opportunities to discuss the spread and impact of COVID-19 in racial groups, where culture and language can be barriers, with different age and socio-economic groups, and where people live in denser communities.

Challenges and solutions in responding to coronavirus in Ghana

Alex Adusei, PFPS Champion, Ghana

Alex started his presentation with an overview of the COVID-19 situation in Ghana, stating that most of the cases are registered in Greater Kumasi and Greater Accra areas which are the hubs of Ghana’s economic activities. He noted that to decrease the spread of the COVID-19 virus, the government has put in place a 3T strategy of Tracing, Testing and Treatment of affected individuals. The government has also mandated wearing facemasks in public and restricted large gatherings of greater than 100 persons. In addition, the government is promoting the production of domestic hand sanitizers per WHO recommendation and PPE. He also mentioned that despite these strategies, stigmatization around COVID-19, the lack of resources, and misinformation continue to increase population vulnerabilities. Additionally, the government interventions do not take into account vulnerable groups who do not have adequate access to water and soap, and cannot afford facemasks. The lockdown itself caused other problems, like increased domestic violence, decreased attention to other diseases like HIV/AIDS, and limited interaction between people due to movement restrictions which led to decrease in food supply, causing malnutrition in marginalized populations.

Some of the strategies his team is implementing include conducting awareness campaigns to vulnerable communities, translating the government health information into local languages for those who do not understand English, disseminating health information related to COVID-19, demonstrating appropriate hand washing, and producing and distributing free hand sanitizers. He concluded by stating that the main objective

of his team's strategies is to save lives of vulnerable populations and promote safety among patients and health care providers during the COVID-19 crisis.

Impact of COVID-19 on diverse population groups in South London

Josephine Ocloo, PFPS Champion, England

Josephine began her presentation by acknowledging the racial diversity of the population in her community in the United Kingdom and challenging the types of models used around patient and family engagement in healthcare. She mentioned that Global Health Research as a discipline had challenged the use of traditional neo-colonial models of research in low- and middle-income countries and that these debates were relevant in the context of Western countries where Black, Asian and Minority Ethnic (BAME) communities were often being excluded from involvement in research. This was particularly pertinent in the context of the COVID-19 pandemic.

She pointed out that there are disproportionate disparities in health inequalities and mortality rates among disabled people, BAME people, those of lower income and those living with poor health or deprived neighborhoods in the UK. These disparities have increased with COVID-19. For example, Black people are at greater risk of dying from COVID-19 than their white counterparts.

Also, the risk for Asian people of dying from COVID-19 in some hospitals had increased and diabetes was a significant contributing factor. She also mentioned that populations in deprived communities have significantly higher COVID-related deaths. She re-iterated that current models of engagement need to involve people who are most affected by the pandemic and health inequalities in research to get effective results. Also, that equal partnerships models be used to involve diverse groups in research and healthcare practice. She noted that such models will give voice to BAME and other disadvantaged groups and therefore, impact patient safety positively.

In order to give groups who are often excluded in research a voice on the impact of the pandemic, she organized a Zoom event with colleagues at King's College, Applied Research Collaboration, South London. She noted the event sold out within 48 hours despite the short notice. Participants voiced several concerns such as pregnant BAME women facing racial discrimination, digital exclusion which prevented disadvantaged people from accessing care and benefits, BAME groups distrust in the health system and of being fearful of visiting the outpatient or hospital appointments, people with disability fearing unfair treatment and not being listened to in hospitals. She stated that this Zoom event gave voice to people who are most affected by engaging them effectively. Josephine concluded by mentioning several actions that can be taken to reduce the health disparities faced by disadvantaged people. Some of them include, ensuring that equity, diversity and inclusion are central to patient engagement in safety and quality improvement, the WHO taking strong leadership in in this area, ensuring diversity of leadership in engagement projects, and democratizing research spaces to ensure that groups most affected by COVID-19 are involved as participants and researchers.

Reflection from WHO

Neelam Dhingra thanked all the participants and panelists after the presentations. She stated that WHO believes that patients are true partners in patient safety. She mentioned the Patients for Patient Safety

Canada (PFPS) patient engagement model as one to emulate. She also emphasized that safety for health care workers is critical for patient safety.

Question and answer/ discussion session

The questions or comments after the presentations and provided during registration focused around:

- 1) **Telehealth.** The speakers highlighted the current use of digital services for primary healthcare in the context of COVID-19 in their various settings. They emphasized the need to advocate for individuals who are unable to communicate and disabled people with barriers to using digital services. There was also a concern about individuals who would not be able to receive health services because they do not have access to digital services. The speakers concluded that research is needed to understand this area better.
- 2) **Visitation.** Concerning family presence in hospitals, in Ghana for example, families use a hotline set by the government to communicate with their loved ones. In Pakistan, families use social media and telephone services to reach their loved ones in hospitals.
- 3) **Equity.** Participants asked how diverse populations were engaged in the community zone event. Josephine mentioned that having an action-focused process that highlighted who benefits from the process was a driver to increasing engagement. She mentioned that the action of submitting participants' responses to Parliament was made clear in the invitation to participate. Also, she added that using her teams contacts and networks to build up a database of people from a range of diverse groups facilitated reaching out to diverse groups. Finally, she stressed the importance of having chairs and leaders in the engagement project or organization who reflect the diversity of the people you want to reach. Hussain also added that social media has been impactful in reaching diverse communities in Pakistan.

Closing remarks

Helen Haskell thanked the participants again for attending and for staying past the scheduled time. She also informed them that the recorded webinar and all shared resources would be disseminated to all and publicly. She also encouraged participants to follow-up with presenters with any other questions or concerns that they may have via email at patients@cpsi-icsp.ca.