



A narrative on the effects of COVID 19 on palliative care in Harare, Zimbabwe.

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Abstract

Palliative care is a crucial service for people suffering from chronic and terminal illnesses as well as their families. The Covid-19 pandemic overwhelmed health systems the world over and disrupted health care inclusive of palliative care. This qualitative study sought to investigate the effects of Covid-19 on palliative care in Harare, Zimbabwe. A phenomenological design was used and a total of 16 participants were purposively selected from 4 health facilities. The study revealed that the Covid-19 pandemic had disrupted palliative care provision in Zimbabwe. In addition, palliative care facilities were unprepared for the transition that would be needed to provide palliative care virtually in response to Covid-19. The study also revealed that, professionals and home caregivers were overwhelmed and at the same time patients deteriorated in mental and in some cases physical wellbeing. Attempts to implement virtual strategies to continue providing palliative care were evidenced but these were hindered by resource limitations and bureaucracy within healthcare facilities. Attempts to implement virtual strategies to continue providing palliative care were evidenced but these were hindered by resource limitations and bureaucracy within healthcare facilities. The study recommends drafting of virtual palliative care policies and strategies, training of professionals to be competent in these and facilities to safeguard and promote psychological wellbeing of palliative care professionals. The study recommends drafting of virtual palliative care policies and strategies, training of professionals to be competent in these and facilities to safeguard and promote psychological wellbeing of palliative care professionals.

Keywords: Palliative care, COVID-19, psychosocial support, psychological wellbeing,

1. Introduction

Palliative care is defined as the prevention and relief of suffering of adult and paediatric patients and their families facing problems associated with life-threatening illness (WHO, 2002). From the above definition illnesses affect the whole gamut of the family and requires attention that is afforded by the provision of palliative care. The problems arising from illness that may need palliative care include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members (Gwyther & Krakauer, 2011). In 2014, the World Health Assembly Resolution on Palliative Care¹ called for all countries to incorporate palliative care provision into their health care systems, an initiative that was intended to ensure access to palliative care for all patients in need. The above resolution was quickly taken aboard by Zimbabwe as in the same year (2014) the country rolled out the National Palliative Care Policy which reported that there was a huge need for palliative care interventions for people suffering from HIV and AIDS, cancer and other chronic diseases (Tapera & Nyakabau, 2020). At the same conference it was also resolved that it was the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured (World Health Assembly, 2014).

Studies of palliative care programs have shown that palliative care is critical as it can improve patient outcomes, including symptom control and quality of life, and caregiver outcomes, such as reduced stress and dysfunctional grief (Hawley, 2017). Preventing and relieving the suffering of patients dying at home is an essential task for primary care providers (WHO, 2018). However, the advent of COVID 19 has affected the palliative care programs

in many countries and Zimbabwe was not spared. The disease has wreaked havoc on health systems and generated immense losses for families, communities, and economies, in addition to the growing death toll. Less than a decade ago, the Worldwide Palliative Care Alliance and the World Health Organization (WHO) declared palliative care as a human right (Singh, Deodhar & Chaturvedi, 2020). Despite its paramount need, providing high-quality palliative care during this pandemic is challenging (Radbruch, Knaul & de Lima, 2020). Health systems are strained by the ongoing pandemic, providing this essential service has become an unaddressed ethical challenge. Health care services are being confronted by a daily dilemma of who can receive critical care and who cannot as the entire fabric of the family is affected (Singh, Deodhar & Chaturvedi, 2020). What is worse is when a patient receiving palliative care contracts the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), it will result in isolation measures extending to the inevitable (Worldwide Hospice and Palliative Care Alliance, 2015; Singh, et al., 2020; Costantini, Sleeman, Peruselli & Higginson, 2020).

Limiting the contact of staff and family members who provide palliative care to the person with COVID-19 diminishes care system responses (Chapman, Russell & Philip, 2020). Patients may deteriorate quickly, healthcare resources are under pressure, isolation is required and family visits are restricted (Rosenbaum, 2020). Strict physical distancing regulations to slow disease transmission mean that patients who die from COVID-19 and other ailments will usually be without loved ones by their side, who in turn will be unable to say goodbye or undertake traditional grieving rituals. (Costantini, Sleeman, Peruselli & Higginson, 2020). Traditionally, the presence of families and friends at bedsides are critical supplements to palliative care (Chapman, Russell & Philip, 2020). However, this has been seriously affected by the faceless COVID 19 pandemic.

Families and friends enable palliative care systems through their presence and by speaking for the person when they are not able to, and in community settings may be major contributors to palliative care systems (Chapman, et al., 2020). Limiting the presence of families and friends due to COVID 19 diminishes these possibilities and in turn diminishes the impacts of care (Chapman et al., 2020). This study becomes very critical as it assesses the effects of COVID 19 on palliative care in Harare.

2. Materials and Methods

2.1 Research Approach

The researcher will employ the qualitative research approach. Qualitative research is an approach concerned with developing explanations of social phenomena and with the opinions, experiences and feelings of individuals. This approach has been noted to be a useful tool in providing descriptions of complicated phenomena (Robert, 2013). Qualitative research approach is most appropriate for the current study as the researcher tries to assess the effects of COVID 19 on palliative care.

2.2 Research Design

The study will use the phenomenological research design. Phenomenological research design endeavours to explain how participants experience and give meaning to an event, concept or phenomenon (Gray, 2014). It seeks the opinions and subjective accounts and interpretation of participants (Gray, 2014). The current study will unpack the effects of COVID 19 among the patients and caregivers who are affected by challenges in palliative care provision.

2.3 Population and Sampling

Palliative care professionals, patients receiving palliative care (both in public and private institutions) in Harare, Zimbabwe and their caregivers were the target population from whom a sample was selected. The study made use of purposive sampling to choose participants. Purposive sampling tends to select individuals who share common experiences so that detailed patterns of meaning and relationships can be identified (Gray, 2014). Purposive sampling was used to select health facilities in Harare which offered palliative care from where caregivers and patients would be accessed. 4 facilities (2 hospitals and 2 private clinics) were selected for having been offering palliative care services prior to the COVID-19 pandemic. Within each selected facility, 1 palliative care nurse, 2 patients and 1 caregiver were also purposively selected per facility giving a total sample of 16 participants (4 palliative care professionals, 8 patients and 4 caregivers).

2.4 Research Instruments

The researcher will use in-depth interviews. This instrument gives the researcher the platform to ask open-ended questions about the effects of COVID 19 on palliative care (De Vos, et al 2005). In-depth mode of interviewing is flexible and encourages the research participants to speak at length, introduce, and articulate their own concerns (Boyce & Neale, 2006).

2.5 Data analysis

Thematic approach will be used in this study. According to Bryne, (2001) thematic analysis is a way of seeing, as well as a process of coding qualitative information, and ultimately allows for interpretations to be made. The process will involve reading the interview transcripts and coding the descriptive concepts that emerges from the interviewees.

3. Results

3.1 Challenges in palliative care provision

Palliative care providers at the selected institutions shared that the COVID-19 pandemic had undeniably affected their ability to provide quality palliative care. Some palliative care nurses shared that:

The lockdowns affected our palliative care program because the patients could not meet for their scheduled group meetings which are very important and beneficial to them.

... even individual therapy was stopped because the psychologist who visits once a week was working from home and the clinic was trying to limit traffic into and out of the clinic to avoid spreading COVID-19.

The study revealed that the institutions' palliative care programs were aimed at both the patients themselves and their caregivers and yet relatives could not travel to the facilities. Some respondents shared that:

The relatives of the patients we have are a critical part of the palliative care we offer here. Relatives are sometimes stressors to the patients and family feuds can worsen a patient's psychological health and thereby also affect their physical health. Because of COVID-19 restrictions relatives have been unable to come to the facility for these programs.

Palliative care was essentially minimized during COVID (lockdowns) because we could not have relatives coming to see patients because of the risk of spreading COVID and at the same time we could not gather patients for group therapy.

The healthcare providers at the different institutions concurred that COVID-19 restrictions had disrupted the smooth flow of their palliative care programs which had already been struggling due to the difficult economic climate the country is currently experiencing. In some instances, resources previously used for palliative care programs have been diverted towards meeting the demands of the COVID-19 pandemic. One healthcare worker indicated that:

We usually conducted home visits for patients suffering from terminal illnesses who usually alternate between being in the clinic and being discharged and going home. The goal was to provide psychosocial support for them and their caregivers. Due to COVID-19 restrictions, we could no longer travel to their homes and the monies we would have used anyway were used to purchase PPEs for staff attending to the patients admitted to the facility.

Besides the challenges in traveling to and from the facility, the facilities themselves could not risk allowing a high volume of traffic into and out of the facility and this would increase the risk of spreading the virus. The institutions indicated that contact with other people had been a necessity in nearly all their programs and therefore COVID-19 restrictions, particularly social distancing ensured that palliative care became nearly none existent. The risk of COVID-19 especially for people in palliative care whom most of their immune systems were depressed was high. Therefore, physical contact could not be risked in order to continue with palliative care programs. Admitted patients were said to have been lonely only seeing the nurses on duty for extended periods.

The study also revealed that most of the facilities attempted to come up with strategies to continue providing palliative care during the pandemic but the lack of resources was the major limiting factor preventing them from implementing their ideas.

We may have very excellent ideas to help our patients during this time of COVID but those ideas need money and we do not have the money. Even before COVID things were already difficult financially.

Most of the ideas we had to keep in touch with our patients and continue to provide some sort of support were not effective as they required data for internet use which most of our patients cannot afford, some do not even have the gadget to use for online sessions let alone the data.

Other healthcare workers also highlighted that strict protocols that needed to be adhered to were a good thing but also a hindrance when change was required especially where it was required fast.

One cannot just wake up and change the way things are done here. It takes a very long process from putting your ideas to paper until you get approval to implement those ideas.

The palliative care professionals admitted to having experienced elevated levels of stress during the pandemic. The pandemic took a toll on their mental health due to COVID-19 related personal and work factors which in turn affected their work. Some respondents said:

It was very difficult time dealing with the palliative care patients some of whom would die lonely without any relatives with them while at the same time I was also stressed by all the things happening in my personal life. I had close relatives who died from COVID-19 and this took a toll on me and made it difficult for me to work properly and had to take some time off of work.

I almost quit my job. Every day you would hear of people you know dying of COVID-19. I would have rather stayed at home during that time but being healthcare professional, I had to go in to work every day despite my fears.

3.2 Challenges faced by patients in palliative care

The study revealed that the patients who took part in the study felt a loss at being unable to attend palliative care programs. The patients stated that they benefited immensely from the group and individual counselling sessions which they participated in at the different facilities such that being unable to attend them had left them worse off. They shared that the emotional support they received from being with other people suffering from severe and chronic illnesses helped them to cope. One patient said:

I have been feeling really low and much stressed. When you interact with other people in a similar situation to yours, it makes you feel better hearing their experiences. It gives you strength to know you are not alone.

Those people I met at the clinic are now like my family to me. They helped me accept my condition when all I wanted was to die. Hearing that one of them got really sick and died and being unable to go and see them and bury them was painful.

Another patient who lived alone in his home during the lockdowns said,

Knowing that you are dying is a very difficult thing to live with. I longed to see friends and relatives before I got too sick and bed ridden but I could not because of this disease (COVID) and was alone and ended up thinking a lot.

Another challenge identified amongst the participants was fear of contracting COVID-19. As the virus ravaged the world and news of high levels of deaths reached the patients, they were scared of contracting the virus too on top of what they were already suffering from.

I am sick but getting better. I was so scared that I would get COVID and end up dying of COVID instead.

I know I am sick and I'm probably going to die of this cancer but at least it takes some time to happen. COVID was killing people in such a short space of time. I was really scared of getting it, I do not want to die yet.

However, in contrast, one terminally ill patient shared that they wished they would have gotten COVID-19.

I am tired of being in pain. I actually hoped I would get COVID and die faster. But I guess God has other plans for me.

Challenges faced by caregivers

Worry about how the patients were faring was the major theme coming from the relatives of the patients who participated. They indicated that the palliative care programs made a noticeable difference in the lives of the patients. This was even more apparent when they could not participate in them because of COVID-19 restrictions. Most caregivers expressed concern about how their relatives had deteriorated in mental health during the periods of isolation.

My father was moody and sometimes aggressive during the lockdowns. He would constantly tell us how it was easy for us to just say 'be strong' because we had no idea what he was going through.

Another caregiver who looked after her mother said,

She always came back from the counselling sessions and their activities feeling better and high in spirit. During the lockdown when she was not going for counselling, she was very difficult to deal with. I would sometimes feel helpless but did my best to support her.

The worry and anxiety over the wellbeing of the patients was worse for those caregivers who were separated from their sick relatives. This was the case for patients who were admitted in health facilities during the lockdowns. Most facilities were not accepting visitors and those who were, only admitted one person allowing only the same person to be the regular visitor.

I would have felt much better being able to see my mother knowing she was very sick but I couldn't because the clinic only allowed one person to visit so this was my sister because she is currently unemployed and would be able to go every day. Relying on another person's judgement of how she was faring was painful, you would want to see for yourself.

Financial difficulties were also faced by some of the caregivers which worsened the caregiving situation for them as they were unable to provide sufficiently both the material and mental needs of their wards.

This thing called COVID has made life very difficult for us. I sell stuff at the market and these were closed during the lockdown which meant I could not sell and make money. Life was very difficult because some days I was unable to get us food and yet she needs food to take her medication.

I am a cross border trader and since borders were closed because of COVID, providing for my family was difficult including buying medication for my father.

Some caregivers expressed that they were denied access into the CBD in order to travel to the facility in order to see their relative in palliative care. One respondent shared that,

There was this one time during the very strict lockdowns when no one except essential workers were allowed to travel into town, I tried to go to the clinic to see my mother who was admitted there and the police and the soldiers at the roadblock

refused for me to pass because I did not have a letter which was the requirement at the time. The soldier said if I was not sick myself, I should go home.

I spent a whole month without seeing my sister. It was a painful time. I tried to go but without the letters one could not get into town.

However, despite all the negative experiences revealed by the study, one caregiver said that the lockdowns were a good time for them because they got to spend more time with their sick spouse.

I enjoyed the lockdown because we got to spend time together. My husband has been sick and unable to work for a while which means I am the breadwinner and had to work at my formal job and then hustle selling clothes to make ends meet. So, we never got much time to spend together.

During the lockdown we were not going to work physically which meant we were together more which was good for our relationship.

Strategies to mitigate challenges in palliative care

Besides the challenges encountered by the professional healthcare workers, the home caregivers and the patients themselves, the study sought to explore strategies to mitigate the identified challenges, both those implemented already and potential ones.

In response to some of the challenges encountered, health care workers at some of the facilities had come up with strategies to try and continue with some aspects of their palliative care programs. One such facility had begun having online counselling sessions with their out patients. These were conducted via WhatsApp as this was seen to be the most common and accessible means. One health care worker said;

We ended up having online sessions on a WhatsApp group. It is not the best method but it was better than nothing. Since we could not travel physically to see the patients or have their usual individual and group counselling sessions physically, we had to find a way to at least keep in touch.

Another health care worker said,

We ended up making calls to our patients in order to check in on them and see how they were faring.

At other facilities in Harare, health care workers stated that they had not yet done anything to facilitate continuation of palliative care programs in the COVID-19 environment. However, upon inquiry they presented some ideas on what could be done to mitigate the negative impact of the pandemic on patients receiving palliative care.

Our idea was to provide online counselling via Zoom or other similar apps because at least these have a visual aspect which is very important during counselling. With WhatsApp you can only read messages and are prone to misinterpreting what a client means as it is not accompanied by facial expressions, gestures etc.

4. Discussion

Palliative healthcare professionals who participated in the current study indicated that the COVID-19 pandemic has disrupted provision of palliative care services. They cited that COVID-19 regulations particularly physical

distancing made it impossible to continue with their programs as most of them entailed physical contact. These findings concurred with a study by Cairns and Coghlan (2021), who stated that Australian palliative care clinicians are facing significant challenges to the delivery, availability and quality of palliative care for existing and new palliative care patients including those who might die from COVID-19.

The professionals who participated in the study indicated that patients were afraid to travel to the facilities during the pandemic even when it was deemed necessary for fear of contracting the virus. This concurred with findings by WHO Europe (2020) which stated that during the COVID-19 crisis, the hospital observed a reduction of about 50% in inpatient visits for palliative care.

The respondents also highlighted that home caregivers could not travel to the facilities for the different palliative care programs of which they were an important part of. Chapman, Russell and Philip, (2020) concur citing that traditionally, the presence of families and friends at bedsides are critical supplements to palliative care. This means their absence in the palliative care process becomes a significant challenge and deducts from the quality of care.

The study also revealed that resources for the provision of palliative care were already strained prior to the pandemic, due to the difficult economic climate in the country. Therefore, when the pandemic hit, there were no extra resources to be used meaning considerable resources previously allocated for palliative care programs were diverted towards meeting the demands of the pandemic. This diversion of funds towards addressing COVID-19 needs concurs with the situation in Spain where efforts to prevent infection within the hospital and to ensure adequate supplies of personal protective equipment may relegate palliative care to a second instance (WHO Europe, 2020).

Healthcare professionals who participated in the study admitted to having been overwhelmed themselves by deaths of patients they had been working with compounded by personal COVID-19 related challenges like close relations contracting COVID-19. They themselves were also afraid of contracting COVID-19. This concurs with findings which reveal that palliative care professionals are more susceptible to experience anxiety, stress and burnout because of the nature of the services they deliver (WHO Europe, 2021). Also, a similar study revealed that fear of acquiring COVID-19 infection is the main worry that most nursing fraternity who are in direct contact with patients are facing (Pai, Nayak & Sangeetha, 2020).

The study revealed that patients were afraid of contracting COVID-19 given their conditions which meant they had depressed immune systems especially considering that pre-existing conditions were a factor which increases chances of dying from COVID-19. This is in line with WHO Europe (2020) who cited that some patients postponed appointments for palliative care activities given the risk of potential infection.

The study further revealed that patients longed for contact with other people especially fellow patients at their facilities stating that it helped them cope better. The patients shared that they experienced several negative emotions at a time when they were without their usual psychosocial support system comprising of fellow patients and health professionals. This loneliness and longing for companionship were even more pronounced

in patients who lived alone and had very little contact with other people. Marie Curie (2017) support this finding as they emphasize that it helps patients to talk to family and friends or to someone who also has a terminal illness or the same condition as you and is going through a similar experience about how they are coping.

However, in contrast, some terminally ill patients shared that they were in so much pain they wished they would have gotten COVID-19 and died. This was indicative of a dire need for pain management and psychosocial support (significant parts of palliative care) in order to cope with the condition, they were in. Pain management is one of the most important concerns of palliative care (National Hospice and Palliative Care Organization, 2020; Daneker, 2006; Perron & Schonwetter, 2001).

Anxiety over the welfare of the patients was common amongst all the respondents. Most caregivers expressed concern about how their relatives had deteriorated in mental health during the periods of isolation. The worry and anxiety over the wellbeing of the patients appeared worse for those caregivers whose relatives were admitted in health facilities and therefore could not see them. Anxiety amongst relatives who were apart from their sick relatives was also evidenced in a study in Australia where a relative said they learned some workers had tested positive at the residency where their mother is and it made them have a remote glimpse about the things one reads of relatives not being able to say good bye." (Cairns & Coghlan, 2021, p3)

Financial difficulties were also faced by some of the caregivers which worsened the caregiving situation for them as they were unable to provide sufficiently for the needs of their wards. Pai, Nayak and Sangeetha (2020) support this finding stating that a pandemic disease often increases the intensity of suffering by causing anxiety, financial concerns and social variability.

However, in contrast, some caregivers and patients were able to see a positive result amongst all the negatives brought by the pandemic. Being at home meant that they were able to spend more time with their sick relative. Several articles cite improved interpersonal relationships due to quality time spent with family as one significant positive effect of the COVID-19 induced lockdowns (Evans, Mikocka-Walus, Klas, Olive, Sciberras, Karantzas, & Westrupp, 2020; Hudson, 2020; Kamdi, & Deogade, 2020).

Despite the numerous challenges encountered, health care workers at some of the facilities had come up with strategies to try and continue with some aspects of their palliative care programs. One such facility had begun having online counselling sessions with their out patients. These were conducted via WhatsApp as this was seen to be the most common and accessible means. At some of the facilities they had resorted to calling their patients in order to follow up on them. According to WHO Europe (2020) a similar strategy was also utilized in Spain where they stated that instead of in-person visits, weekly phone calls and remote follow up were prioritized. Blinderman, Adelman, Kumaraiah, Pan, Palathra, Kaley, Trongone and Spillane (2021) state that palliative care outpatient teams in hospitals in New York resorted to virtual outpatient management early on in the crisis, transitioning to virtual visits for existing patients.

At one facility in Harare, health care workers stated that they had not yet done anything to facilitate continuation of palliative care programs online in the COVID-19 environment citing lack of funds and 'red tape' as the major

limiting factors preventing them from implementing their ideas. Similar findings were revealed where lack of funds and bureaucracy hindered the transition to online teaching and learning in the educational sector (Nature, 2020; Dhawan, 2020).

5. Conclusions

The study concluded that palliative care facilities in Harare, the palliative care professionals working in them, patients in palliative care and their caregivers were negatively affected by the COVID-19 pandemic. Palliative care facilities in Harare were unprepared to adapt to non-contact methods of providing palliative care thereby affecting quality and quantity of palliative care on offer. The pandemic atmosphere of high death rates and fear of contracting the virus had a negative impact on the professionals and negatively impacted execution of their duties. Patients in palliative care experienced deterioration in mental health due to the lack of access to palliative care services. Relatives of patients receiving palliative care experienced elevated levels of anxiety over the wellbeing of their relatives whom they either could not see or saw and witnessed deterioration in physical and mental wellbeing during the pandemic. The facilities had begun transitioning to virtual means of providing palliative care services despite challenges like bureaucracy and resource limitations.

6. Recommendations

The study recommends that;

- Palliative care facilities develop policies and standard operating procedures to guide staff in the provision of palliative care by virtual means. This will ensure well planned, ethical and consistent palliative care provision.
- Virtual and complementary strategies in palliative care provision be developed and standardized.
- Capacity building of staff in the new strategies be conducted to ensure competent delivery of palliative care services during the pandemic and similar scenarios.
- The Government provide funds for palliative care responses in government hospitals making such a crucial service available and more affordable to the greater public.
- Psychosocial support be provided for palliative care professionals to promote their mental wellbeing and facilitate efficient execution of their duties.

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