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Proposal for development of a guideline in maintaining quality cancer care during and post-covid-19 in an upper middle-income country with universal health coverage

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ABSTRACT

Background: During periods of high community transmission of COVID-19, the public hospitals in Malaysia, an upper middle-income country, have been forced to scale down elective surgeries, prioritize cancer treatments based on treatment benefits, and postpone non-emergency imaging procedures. These inevitably led to disruptions in cancer care delivery within the public health care system. This study aims to explore the facilitators and barriers faced by healthcare providers and cancer survivors in cancer care, and to co-design a guideline to maintain the delivery of cancer care amid the disaster situations.

Method: In-depth interviews (IDIs) will be conducted with Malaysian healthcare providers and cancer survivors and findings will be analysed thematically. The insights will be used in a subsequent phase to co-design a guideline to maintain the delivery of quality cancer care in Malaysia via a three-round modified Delphi survey with a broad range of cancer stakeholders.

Expected results: Findings derived from IDIs and existing literature will be included for rating across three rounds by the expert panel. Feedback provided will be refined until consensus on the best practises for cancer care continuity during crises is achieved.

Conclusion: The output of the present study is not only expected to ensure the continuity of delivery of high-quality cancer care in Malaysia during the ongoing pandemic but also to be adapted during unforeseen crises in the near future.

Policy summary statement: Collaborative work between policy makers, public health physicians, members of the multidisciplinary oncology team as well as cancer survivors is vital in developing an evidenced- based contingency plan for maintaining access to cancer care.

1. Background

The World Health Organization (WHO) had declaredthe coronavirus disease 2019 (COVID-19) outbreak as a pandemic on 11 March 2020 due to its rapid spread worldwide [1]. Since then, official figures show that to date, COVID-19 has killed 4.5 million people globally. In addition to the morbidity and mortality caused directly by COVID-19 itself, the pandemic has also negatively impacted the delivery of care across the cancer control continuum, affecting patients, communities, and health care systems worldwide [2–5].

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As an upper-middle income country, Malaysia has progressed toward achieving universal health coverage through a mixed public-private health care delivery system [6]. While the public health care in Malaysia is mainly funded by general revenues, the private health care is delivered via for-profit medical facilities and is funded by a combination of out-of-pocket payments, private health insurance and employer-sponsored health insurance [7]. Central to this discussion is that highly subsidised cancer care in Malaysia is largely delivered via public tertiary hospitals which also serve as COVID-designated facilities amid the pandemic [8]. In the effort to curb the spread of COVID-19, Malaysia had first implemented a Movement Control Order (MCO) (nationwide lockdown) on 18th March 2020 [9]. The movement restrictions were gradually eased, with reopening of multiple economic sectors. However, it was again tightened following a larger third wave in September 2020. One year on, there are still areas in the nation that are periodically subjected to full or partial lockdowns, depending on the number of COVID-19 cases in the locality.

During this extraordinary time, the oncology communities in the country have faced unprecedented challenges [10–12], whereby adjustments had to be made in the public hospitals to limit face-to-face contact to reduce the risk of viral transmission, and also to cope with the redistribution of healthcare workers to COVID-19 related tasks. In addition, during periods of high community transmission, there were anecdotal reports that elective surgeries were scaled down for oncology patients, and clinic hours were also shortened [13]. Systemic anticancer treatment and radiotherapy administration were prioritized based on the treatment benefits [14], and imaging procedures were also postponed to later dates, leading to disruptions in cancer care delivery..

Recognising the need to redesign healthcare systems that adheres to social distancing measures and protect healthcare workers without compromising on the quality of cancer care delivery, many international recommendations have been developed to guide the management of cancer patients during the pandemic. Nonetheless, they are limited to certain types of cancer, or designed for high income settings [15–18]. We therefore plan to undertake a study to explore the facilitators and barriers in accessing cancer care in tertiary settings during the COVID-19 pandemic, and to co-design a locally appropriate consensus-based guideline in maintaining high-quality cancer care in these settings in Malaysia. The guideline is not only expected to ensure the continuity of delivery of quality cancer care during the ongoing pandemic but also during unforeseen crises in the nation in the future.

2. Methods

The conceptual framework of this study is guided by the Quality-of-Care Framework by Donabedian [19]. It outlines three areas to improve the quality of care – structure, processes and outcomes. This study will follow a co-design methodology, occurring over two phases. Phase 1 will identify the facilitators and barriers of cancer care during the COVID-19 pandemic whereas Phase 2 will involve the development of a best practices guide for maintaining access to high-quality cancer care in tertiary hospitals located in resource-limited setting.

2.1. Phase 1: Identification of facilitators and barriers of cancer care during COVID-19 pandemic

Stakeholder mapping will be conducted to ascertain the roles of individuals and the level of impact of the change on their organisations (Fig. 1). This will be followed by in-depth interviews (IDIs) with three groups of stakeholders, (a) cancer patients, caregivers, patient support groups (non-governmental organizations), (b) physicians, healthcare professionals, and hospital administrators as well as (c) health-related policymakers until data saturation is achieved.

2.1.1. Setting, recruitment and study participants

Hospital- and community-based recruitment will be conducted. Patients will be recruited from a Ministry of Health hospital (Kuala Lumpur Hospital), a public university hospital (University Malaya Medical Centre), and a private hospital (Subang Jaya Medical Centre). Eligible patients will be identified by the investigator during their routine follow-up in the oncology clinics. Community-based recruitment will be carried out through cancer-related civil societies and social media outreach. A sampling matrix will ensure adequate representation of patients from diverse ethnic and socio-demographic backgrounds, as well as different phases of treatment.

The inclusion criteria for the patients will comprise: (1) currently seeking any form of cancer care, (2) Malaysians above the age of 18, and (3) being able to understand and converse comfortably in Malay language or English. For patients who express interest to participate in the study but are limited by language barriers, their caregivers will be invited to serve as proxies if they are heavily involved in patient care. Patients with carcinoma in situ will be excluded. Local non-governmental organizations, which are involved in the delivery of supportive care to cancer survivors will be invited to participate.

Physicians and hospital administrators, from both public and private institutions (as mentioned above), including those from the National

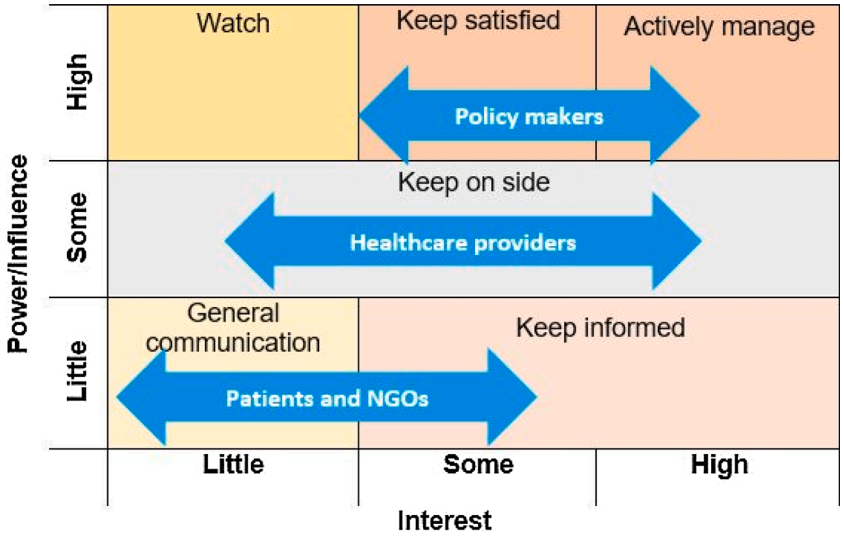

Fig. 1. Stakeholder mapping to ascertain the roles of individuals and the level of impact of the change on their organisations.

Cancer Institute (NCI), the only dedicated cancer institute in the country will be selected based on their roles and experiences in their respective institutions. Health-related policymakers who are directly involved in development and evaluation of cancer control policies will be selected.

Purposive sampling is considered the appropriate method to identify individuals who are well-informed about the challenges in cancer care and can communicate experiences and insights in an articulate, expressive and reflective manner [20]. Those who express interest will be contacted by the researcher via telephone calls. This method is deemed suitable given the movement restrictions during the pandemic.

The researchers will first brief potential study participants and address arising questions. Informed consent will be obtained verbally before the IDI, which may be conducted via phone calls or video calls, secured with passcodes. Different sets of topic guides for different groups of individuals containing probes on facilitators and barriers in delivery of cancer care due to the COVID-19 pandemic in any of these areas: diagnosis, treatment, follow-ups, survivorship care, palliative care or end of life care will be used by the interviewers. The topic guides may be modified as the study progresses based on findings from the previous IDIs. All IDIs are expected to last approximately 45 minutes each. At the end of the IDIs, participants will be asked a few sociodemographic questions. Participants who are either patients or caregivers will be given a small honorarium upon completion of the interview.

2.1.2. Sample size

An estimated 20 IDIs will be conducted among cancer patients, caregivers and civil society representatives, upon which theoretical saturation is expected to be achieved. Likewise, up to 20 IDIs will be conducted with physicians, healthcare professionals, and hospital administrators.

2.1.3. Data analysis plan

All IDIs will be audio-recorded and transcribed verbatim. Selected codes that are in the Malay language will be forward translated to English. Thematic analysis using Nvivo - Windows software will be carried out to analyze the transcripts. In the initial stage, data familiarization will be conducted. After data transcription, codes will be extracted from the transcript to identify key themes and sub-themes. Transcripts of each IDIs will be analyzed and compared with the analysis of the previous discussions to help shape subsequent data collection and analysis. Data collection will continue until no new themes emerged from the data (theoretical saturation).

2.2. Phase 2: Development of a best practices guide

Relevant experts from professional societies (surgeons, cancer physicians), healthcare providers, policymakers, cancer patients, and civil society representatives who participated in the Phase 1 study will be invited to participate. In addition, we will also be snowballing to capture other relevant stakeholders with deep understanding of the challenges of accessing or providing cancer care during the pandemic, and are also able to provide recommendations to overcome such challenges. We will also perform a desk review to identify emergency preparedness plans or guidelines for cancer care for consumption during disaster situations in the low- and middle-income countries.

2.2.1. Setting, recruitment and study participants

A three-round Delphi is proposed to seek relevant recommendations (Round 1), explore preliminary consensus (Round 2) and finally assess the shortlisted items to determine the best practices to maintain quality cancer care during and post−COVID-19 crisis based on levels of consensus achieved (Round 3). Each subsequent questionnaire will be developed based on the results of the previous questionnaire.

The process will stop when a consensus is reached on how to maintain quality of care during an outbreak or crisis. The questionnaires will be emailed to professional societies (surgeons, cancer physicians), patient representatives and civil societies. The proposed progressive and iterative steps have been proven to be effective in developing agreed summary outcomes [21]. The Delphi study flow is illustrated in Fig. 2.

2.2.2. Sample size

A panel of 10–18 experts is recommended to ensure sufficient contribution and consensus [22]. To account for 30 % attrition rate, around 35 experts will be identified to participate in this phase.

2.2.3. Data analysis plan

Data from the first round of Delphi will be qualitative and can be analyzed using content analysis techniques. For subsequent rounds, data from the ratings of items can be analyzed using central tendencies (means, medians and mode) and levels of dispersion (standard deviation and interquartile range). This will enable participants to see where their response stands in relation to that of the group. Kendall's W coefficient of concordance will be used to measure the level of agreement within the panels. All quantitative data analysis in Phase 2 will be analyzed using a statistical software, SPSS.

2.3. Ethical review/ considerations

Ethics clearance has been obtained from the Medical Review & Ethics Committee (MREC), Ministry of Health Malaysia (NMRR-20-1348-55017) and all relevant institutional review boards (SJMC 202010.3). Before the IDIs are initiated, potential study participants will be briefed regarding the study and provided with a participant information sheet. All transcripts will be anonymised on production. Data will be stored in accordance with the data management policies of Universiti Malaya.

A subject can voluntarily withdraw his or her consent to participate in the study at any time without penalty. No further interview will be conducted and no additional identifiable private information will be obtained. However, data collected up to the point of withdrawal may be retained and analyzed to explain the study findings.

3. Discussion

Provision of high-quality cancer care in tertiary settings requires good coordination between a multidisciplinary team of oncologists, surgeons, pathologists, hematologists, physicians, radiologists, nurses, rehabilitation experts, and palliative care specialists, among others. Furthermore, it must not be forgotten that supportive cancer care is also provided outside the hospital settings, requiring healthcare professionals from tertiary settings to collaborate with external stakeholders from both the health and non-health sectors including civil organizations for provision of palliative care, psychosocial support and financial support.

While a global pandemic has altered many aspects of care, collective efforts are necessary to maintain cancer therapies for patients, whether they are surgical, radiation- or drug-based [23]. Delayed cancer diagnosis, deferral of elective cancer surgery and radiotherapy as well as reduction in the use of systemic therapies due to reprioritisation of health systems can aggravate cancer health outcomes [24]. These effects can be particularly damaging in the low- and middle-income countries where cancer patients tend to present to tertiary facilities with more advanced stages of cancer [25]. While there is a paucity of data, several countries have reported increases in the proportion of newly diagnosed breast and lung cancer patients presenting at more advanced cancer stages in the pandemic [26,27].

Measures mitigating the spread of COVID-19 pandemic have always centred around the importance of physical distancing, hand hygiene and personal protective equipment. While much of the healthcare resources are diverted to the management of COVID-19 patients, efforts to maintain timely and high-quality care to patients with chronic diseases such as cancer should also be prioritised. The WHO has reported that the

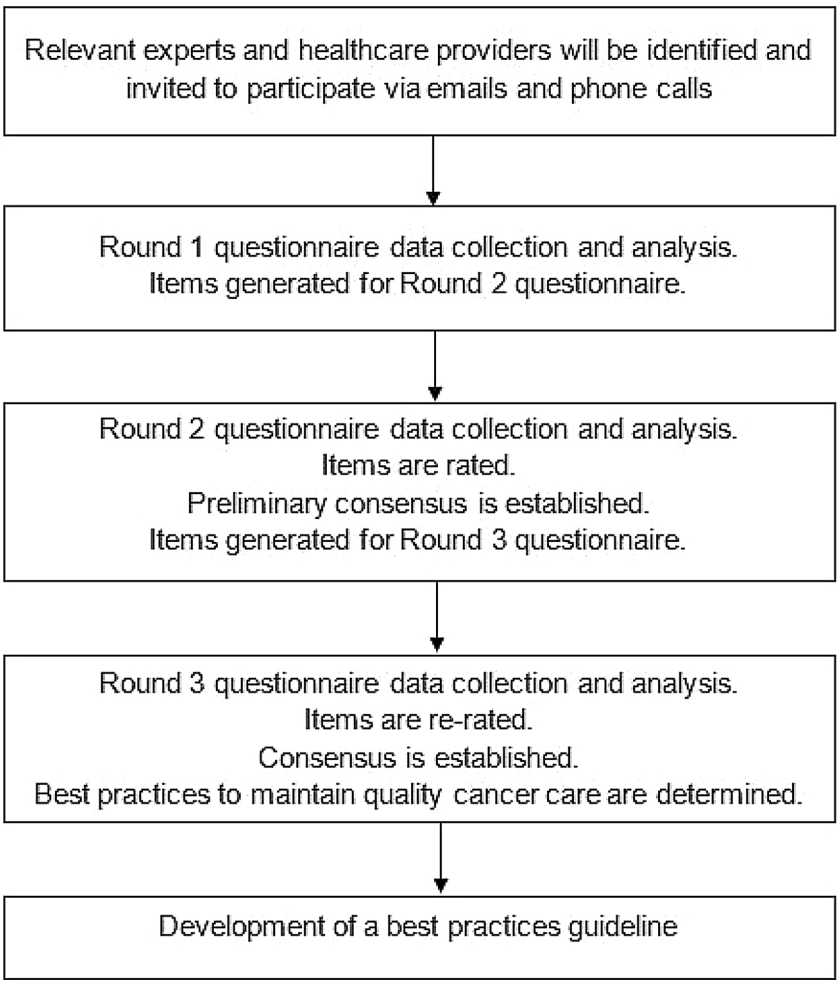

Fig. 2. Design of modified Delphi using a series of three questionnaires.

crude fatality rate for patients living with cancer infected with COVID-19 was 7.6 % as compared to those without comorbidities (1.4 %) [28]. As such, a more specific guideline tailored for continuity of care (from cancer diagnosis, active treatment, palliative care to survivorship) without jeopardizing patient safety is necessary.

Collaboration between healthcare professionals and multisectoral stakeholders is essential to develop a feasible guideline that can be easily adapted in times of crises. The qualitative phase of this study explores the facilitators and barriers to cancer care faced by both the healthcare providers as well as cancer patients in tertiary hospitals during the COVID-19 pandemic. In Malaysia, major public hospitals with oncology departments are clustered based on regions, with a majority clustered in Klang Valley, an urban conglomerate. A critical understanding of challenges in the field is beneficial towards the development of an evidence-based best practices approach to ensure the continuity of cancer care during the COVID-19 pandemic.

Co-design with stakeholders is crucial to produce a plan that is practical and sustainable, especially in domains characterized by complexity and uncertainty [29]. It is important in framing a plan that can be adopted into the current health system with minimal implementation issues. Specifically, through the co-design method, our work provides a platform to incorporate the experiences and perspectives of cancer patients during the design of the guideline. This ensures that the end product is practical and responsive to the patients' needs.

The Delphi technique employed in Phase 2 of this study is relevant to seek information, correlate informed judgements and educate the respondent groups on the diverse and interrelated aspects of the topic [30]. It involves iterative processes of reflection to tailor a workable set of solutions that has contextual fit and responsive to the participants' needs [31].

3.1. *Study limitations*

This study uses purposive sampling that will include urban hospitals with oncology services, including a private hospital in Klang Valley, which may not be entirely representative of the tertiary care settings throughout Malaysia. Nonetheless, as some of the selected study sites are major referral cancer centres in the nation, inclusion of patients and healthcare professionals from these centres may still be able to capture the experiences of cancer patients living in rural settings.

While the study has the advantage of reporting in-depth experiences of the challenges in cancer care delivery at tertiary settings faced by both healthcare providers and patients during the COVID-19 pandemic, it is worthwhile noting that challenges in delivery of oncology care at the district or peripheral hospitals may be different, warranting a separate evaluation and adaptation of the developed cancer care delivery guideline.

4. Conclusion

This is the first time that a pandemic of a mega scale has affected the healthcare systems worldwide. While the focus is still on the management of patients with COVID-19, the needs of other patients living with chronic diseases such as cancer must also be responded to. Developing a contingency plan for maintaining access to cancer care is a collaborative work between policy makers, public health physicians, clinicians as well

as other members of the multidisciplinary oncology team. The output of the present study is not only expected to ensure the continuity of delivery of high-quality cancer care in Malaysia during the ongoing pandemic but also to be adapted during unforeseen crises in the near future.

Authors' contributions

Conceptualization: Nirmala Bhoo-Pathy, Soo-Peng Teoh.

Methodology: Nirmala Bhoo-Pathy, Soo-Peng Teoh, Feisul Idzwan Mustapha, Nik Daliana Nik Farid

Writing – original draft: Nirmala Bhoo-Pathy, Soo-Peng Teoh.

Writing – review & editing: Nirmala Bhoo-Pathy, Soo-Peng Teoh, Feisul Idzwan Mustapha, Ros Suzanna Bustamam, Nik Daliana Nik Farid, Cheng-Har Yip, Marniza Saad, Saunthari Somasundaram, Puteri Norliza Megat Ramli.

Final approval: Nirmala Bhoo-Pathy, Soo-Peng Teoh, Feisul Idzwan Mustapha, Ros Suzanna Bustamam, Nik Daliana Nik Farid, Cheng-Har Yip, Marniza Saad, Saunthari Somasundaram, Puteri Norliza Megat Ramli.

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Declaration of Competing Interest

All authors declare that there is no potential conflict of interest.

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