



Overview of the Patient Autonomy Challenging the Healthcare Providers during Pandemic Management; a Study Evoked During Covid-19 Pandemic

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Abstract

During pandemics many exceptional regulations are planned to facilitate risk management and ensure safety of the whole community. These exceptional practices during the pandemic situation may evoke some issues with ethical debate. There would be some limitations to patient's rights and confidentiality during pandemics. There are many issues in which the healthcare provider should balance between ethical practice and the safety of the whole community. The aim of this research is to highlight and discuss the ethical concerns that may be faced during pandemic management in a trial to find out the most appropriate practice in such times. In order to answer these dilemmas, literatures were reviewed and discussed against the ethical codes. It is concluded that during pandemic there are specific situational regulations and guidelines to be followed in order to combat against the rapid infection dissemination while maintaining professionalism and satisfaction to both public as well to healthcare-providers. In conclusion, this study believes that there must be a mutual understanding between these two parties that could be mediated by legislative body or authorities to obtain the most effectiveness of the healthcare system for combating pandemic.

Keywords: Ethical issues; Covid-19; Pandemic; Healthcare

Introduction

A pandemic disease is that highly infectious disease spreading from one person to another at a steady rate in a population worldwide [1]. In the year 2020, the world has met with another outbreak that happens to be devastating which is known to be SARS-CoV-2 or better known as COVID-19 affecting as much as 100 countries [2]. with death rates many as 154, 311 as of 18th April 2020 and when in comparison to past pandemics as H1N1 and the Spanish Flu which has the death rate of 3,645 and 39 million respectively, the COVID-19 has the same lethality [3,4]. By the end of March 2020, Europe has accounted for 56.4% of the total of the global cases which exponentially increased by 319

times and at the same time, the American and African region have 2,000 times increase in confirmed cases as well [5]. In Malaysia, it started off as a small wave with 22 confirmed cases [6]. However, the country was sent into a shocking second wave when 790 cases were diagnosed in the span of less than three weeks and this has made the government to implement what is known as Movement Control Order (MCO) as a means to curb down the number of cases [7]. In the said order, the public was strictly not allowed to travel interstate and only the head of family is allowed to leave the house for grocery shopping within 10-KM radius hence a question raised here, has this order gone against the basic human rights in freedom of movement? How does The Siracusa Principle help in maintaining humans' rights? In other spectrum,

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General practitioners and nurses was advised to assess possibly infected patients when they arrive at triage counters following Ministry of Health's risk assessment guidelines [8]. With a known infectivity rate and mortality rate, must a physician or GP put themselves on the line treating this patient? What is the limitation for a physician to risk their lives during a pandemic? When a patient is confirmed to be diagnosed with COVID-19, what is the next step for the physician? If cases of COVID-19 were found through Contact tracing, is the patient's autonomy as well their confidentiality and privacy to be upheld? The physicians of the detected cases must have breached this rule [9]. In pandemic, a scenario where there is scarce of resource allocated could happen and at that time, is it justifiable to serve doctors preferential treatment during this time when an equal distribution should be practised [10]. This paper will discuss an overview of the ethical challenges of patient rights and autonomy that may face the medical practitioners during pandemic fighting. The issues that will be touched upon will include issues related to patient consent to examination and treatment against mandatory testing and treatment, consent for research, issues related to patient rights during quarantine.

Search Strategy

This a qualitative review study. The research engines utilized to collect data for this study included Google scholar, Biomed central, Research gate and PubMed. The collection of data targeted research papers published in scientific journals and WHO generalizations during and after pandemics and including experiences involving ethical or legal practices during pandemics. Terms used as keywords included "ethical debate during pandemic", "medical ethics of pandemic", "legal regulations during pandemics", "patient autonomy and privacy during pandemic", contact tracing and patient privacy". Then the references were summarized in evidence table to extract the practice and point of view in each research then the researches related to each of the discussed issues were reviewed to extract its point of view and supporting evidence and lastly the authors presented the different points of view and criticize each to reach a conclusion regarding each of the studied issue.

Consent for examination and/or treatment

Autonomy is the patient's rights to think, decide and act on their own capability or assisted by the physician, where the decision should be taken voluntarily by the patient [11]. Autonomy usually convey as an individual's rights to give consent regarding their own healthcare. This is being enhanced more importantly in almost all the countries since long time ago [12]. Informed consent is a legal procedure whereby healthcare providers inform the patients about the risk, benefits and any other alternatives before performing any medical interventions [13]. Furthermore,

physicians should be responsible in explaining and guiding the patient whenever they performing any medical interventions. Failure to do this can lead to unnecessary trouble to the patients as well as the health professionals [14]. Obtaining an informed consent aids in patient's autonomy and secure them from getting cheated or forced to make decision and support them to make decision wisely [15]. ACOG Committee has proclaimed that informed consent is the foremost concept of respect for patients which is associated with patient's autonomy [16]. Legally valid informed consent should include 4 components. First, consent should be given voluntarily by a patient. Second, patient should have the mental capacity to think. Third, disclosure of information to the patient regarding own medical conditions and further progressions. Lastly, the ability of the patient to understand the information given by the healthcare providers [17]. According to medical ethics, health care providers have no rights to treat or even touch the patient, it is considered as immoral, against the law and can be punishable, without the patient's consent unless it is emergency situation [18]. During medical disasters like pandemic, do we still need to get consent to examine patients or suspect cases to safe the community from spreading infection? In cases of any disease outbreaks such as SARS, H1N1, Ebola virus disease, Influenza and lately COVID-19, is it still ethically or legally important to take consent during pandemic? In fact there is a debate that challenges to the healthcare workers in times of pandemic. Several studies confirm that informed consent still considered as important to obtain, while some of the authors mentioned that it can be legally waived. During a pandemic, the concept of autonomy should be evaluated according to the current emergency situation. In such cases, the importance of patient's autonomy becomes secondary when compared to the patient's life [19]. Issues that challenge the health care providers are patient's informed consent, refusal of treatment and discharge from the emergency department [20]. In such situations, even though a patient has the right to refuse medical interventions, it may be in dispute with a physician's duty to fight against disease during a pandemic. Physicians should try to explain to patients regarding the disease complications and convince them to receive treatment in order to reduce the consequences to the patient and others [21]. According to WHO, it is compulsory for health care workers to take informed consent from patients before carrying out any medical interventions. Despite that, physicians have the right to overrule a patient's autonomy to refuse treatment during an emergency situation like a pandemic [22].

Mandatory examination and/or treatment

The role of informed consent can be limited in emergency situations where consent seems to be impossible to obtain. On top of it, numerous ethical responsibilities can also override the

concept of autonomy. For instance, if it is endangering the society and public health during disease outbreaks. In such cases, mandatory testing and treatment are important. Nevertheless, therapeutic benefits can also be a reason to revoke the necessity to get informed consent from patients. In this situation, physicians would always protect the patient's health rather than respecting the patient's autonomy [16].

Then, if autonomy is still compulsory in emergency situations, is it possible for a patient to make a decision to accept or refuse the treatment or any other medical interventions? In the worst case, can others sign a consent form on behalf of the patient? As stated in the Code of Medical Ethics, when a patient could not make a decision, then the physician is responsible to choose the relevant or suitable person to make the decision on behalf of the patient¹⁶. The representative can be the patient's family members, legal guardian or any individual appointed by the patient earlier. The appointed surrogate should be explained well about the medical interventions and help to make a wise decision. Appointed surrogate should make a decision according to the patient's best interest and the urgency of treatment for current health conditions [23]. Respecting patient autonomy means physicians should bear in mind that they must respect the patient's decision as well as her/his family's decision even if the decision overrides the patient's own [24]. A study about who should receive medical information and make medical decisions, showed that 78% of respondents mentioned that it is essential for patients, their families and also their physicians to join together to treat a patient [25]. According to the World Medical Association (WMA), in emergency situations or in the case of absent legal representatives, physicians should decide what would be the best for the patient and proceed with the treatment in order to save the patient's life [26]. Patient's freedom to make their own decisions is the important challenge to health care providers who were practicing paternalism or known as paternalism since years ago [20]. It has been practiced traditionally by the physicians, where doctors will be responsible in making decisions on behalf of the patients according to the patients' needs, although he/she can make his/her decisions by own [27]. Croatia and other countries still accept paternalism or in other words they are willing to waive their autonomy and expect doctors to make decisions for them. They are giving more importance to paternalism and beneficence compared to autonomy. However, the concept of paternalism should not be dropped completely but it has to be modified [28]. Also, the concept of paternalism is still followed by some of the physicians as well as patients' families in the aspect of beneficence in few countries like the United State, Canada and Asia. In such communities, a patient's family or family representative will be the decision maker on behalf of the patient. This is because they consider family's autonomy is much more necessary and essential in managing a patient [29].

An intervention without valid consent can only be accepted in cases where there is no other better option like during a pandemic when it is necessary to further investigate the patient in order to find out the cause of the disease. Health care workers or the authority have to get involved in patient's autonomy in compulsory screening, treatment, isolation, quarantine, cases surveillance and informing it to the authority during a pandemic. Even though it may infringe on basic human rights, on the other hand it is useful to treat the patient and secure the society from any harm [30,31]. Apart from this, physicians should also explain clearly to the patient regarding the test, procedures, including the result, confidentiality, diagnosis and whether the sample collected will be used for any other reasons like research [32]. Prescribing medication in certain cases can be clinically and ethically challenging. In conditions where approved therapies are considered as ineffective or no approved therapies to treat due to the patient's medical condition, physicians should treat the patient in off-label ways. In such cases, physicians must explain about the different treatment approaches and get the patient's consent.

Patient autonomy during quarantine and surveillance

During pandemic, a person should get quarantine if infected or got contact with infected case. Should the person voluntarily get him/herself to quarantine? Morally, it is their responsibility to protect others from getting infected. In cases such as SARS, H1N1 influenza and Ebola virus disease, mandatory isolation and quarantine have been enforced. Forcing an unwilling person to do something for their own good or known as "Beneficial coercion Paternalism" is deemed to be inappropriate in medical ethics. Having said that, this should be implicated in emergency situations to reduce the risk for the society as well as the person who is reluctant to do so. Similarly, it is applied in cases of mandatory vaccination and treatment during emergencies involving pandemic disease. Informed consent is only required minimally in surveillance during medical disasters like pandemic diseases. An individual can't refuse to take part in surveillance since it is officially conducted by the government. For example, in case of pandemic, the health ministry or any health authorities might gather patients' medical information from the particular hospitals without getting the consent from patients³¹. Even informed consent is not mandatory in executing surveillance, as health care providers they should be responsible by providing clear details to the participants. This is one of the ways of respecting and gaining trust and support from society [33]. Language and cultural differences are other challenges facing the patients in understanding the information given by the health care workers to make an important decision independently [34].

Informed consent for medical research during pandemic



Informed consent is a fundamental patient autonomy and an important aspect in respecting a patient's refusal in any unnecessary investigations, treatment or even research during a pandemic [35]. Informed consent should be legally and ethically necessary before conducting research during disease outbreaks. Researchers should get informed consent from the patients or participants or even from the appointed proxy decision-makers before conducting a research during a pandemic [36]. On top of that, each participant in a research should take part voluntarily where there must be informed consent and complete explanation given to them such as the reason of the research, details of the procedures, expected risks and benefits, and not forgotten his/her autonomy on participating in the research. Meaning that each participant has the rights to accept, refuse or withdraw from the research anytime [37]. On the other hand, the Department of Health and Human Services has concluded that the requirement of getting informed consent in a research can be omitted if the possibilities of risk to the participants are considered being less or no risk at all and if it is appeared to be troublesome in obtaining consent [38]. Researchers can conduct the research without informed consent and the waiving of the consent does not affect the participants' rights, as long as they have sufficient idea on what they are going to do. In such a situation, researchers should clearly show the importance of the research, the balance between risk and benefits. Based on Canadian Institutes of Health Research, researchers are legally allowed to omit informed consent under specific circumstances. There are few other examples of research that informed consent can be omitted. If the research induces, emergency situations like disease outbreaks, if the patient is unconscious, and no appointed representative to make decisions beside, nature of research or the types, such as retrospective data collection and observational epidemiological research based on the complete data set from a wide range of communities can be one of the reasons for informed consent to be waived [39]. Conducting research during disaster-like disease outbreaks is considered as improper but this can be prevented if researchers manage to balance between the importance of research and people's participation [40]. During emergency or disease outbreaks, researchers should bear in mind that participants' expectations might be higher and this can lead to unwanted issues. Researchers should highlight more on balancing between the number of participants and obtainable benefits to the communities [41]. Is informed consent and research important during disease outbreaks? Different studies show different points of view. It depends on the researchers, how they conduct the research. A study shows that research on identifying the virus during SARS outbreak was one of the contributions to control the disease from getting spread widely [42]. Informed consent for any research during medical disasters is important, although it can surpass or even worsen the end result.

Limitations to patient privacy during pandemic

Patients' information and details regarding their health condition and patient's personal information are highly private and confidential which is between the doctor and patient. However, during an outbreak, this information may be disclosed to the public health in order for them to take appropriate measures to reduce the disease spread and the emergence of new disease cases, but there is no evidence to disclose these information's to the public [43,44].

On a physician's perspective, it is believed that when the patients get to know that their personal information is being shared with the public health department, these patients may no longer be willing to give any information regarding their health condition due to lack of trust [45]. There is a noticeable change in attitude between patients towards doctors in order for them to maintain their privacy. They do this by being dishonest to the doctors regarding their current and past medical condition, buying medications over the counter for self-treatment at home, seeking multiple doctors to get a solution for a single problem that is by not disclosing numerous information regarding their health condition to a single doctor and asking the doctor not to record certain health conditions that they are suffering in the patients Bed Head Ticket (BHT) records. This can later lead to numerous problems and confusions to the public health when the review each case to find risk factors and cause of a pandemic outbreak [46]. In an event of a pandemic, it is vital to allow patient's identity information to be shared with the public health when necessary without delay as it is important for them to take appropriate measures in reducing the spread of the pandemic. This personal information is to be kept within the public health department and not to be revealed to the public. In any event, whereby the information is needed to be shared with the public, it should be in an anonymous manner such that patient's data is de-identified [47]. Patients are not asked for consent or permission before the physician discloses their personal information to the public health, instead they are just informed so accordance to law (Section 60 of the UK's Health and Social Care Act 2001). This is crucial as the public health department can take necessary measures such as contact tracing, disease notification, and disease control measures as to protect the community from the infectious disease during a pandemic crisis. This is ethical as it would benefit the community by helping them take appropriate early measures such as social distancing, isolation and wearing personal protective equipment's [48].

Physician refusal of duty of care

It has been noted that during pandemics, the second most affected group is the healthcare workers. During 1918, the Spanish Flu has robbed 600 doctors whereas the SARS pandemic has 813 doctor's



deaths from 8437 infected patients [49,50]. With this alarming rate of infectious and mortality? Is it reasonable for a doctor to refuse to treat? Is it ethical or justified for a physician to abandon their patient in crisis in order to save themselves or their family? Do physicians truly have a moral obligation to treat during the times of pandemic? To what extent should a doctor risk his or her own life? In what way would doctors be compensated for putting their lives on the line? According to the American Medical Association (AMA)'s code (1847), patient's welfare should be prioritized even if, in exchange, the physician's health may deteriorate. This was a standard ethical practice in the year 1918, this form of thought was prescribed in the doctors are expected to resume their provision care to patients without minding the risk of their health in pandemic crisis [51]. Some believed that healthcare workers must have a strong ethical obligation to serve and accept hardship as it has been made known of the risk or dangers in their profession when embarked in their career [52]. An example could be given is when a firefighter that refuses to enter a burning home while wearing full-protective gear is unacceptable as a treating physician who refuses to treat a patient during pandemic when they have been protected by Personal Protective Equipment (PPE) [53]. Without doubt that morbidity and lethality of an infectious disease will inadvertently affect a healthcare worker in their willingness to treat as an example that apart from the first cases in Vietnam, all of the people who died were doctors and nurses [54]. A striking number of 2% of treating physicians in South Africa had passed in the midst of the Pandemic occurring in 1918-19. In the United States, a random sample study was done among the physicians in regards to their readiness to work in a devastating and likely lethal infectious disease and it was found that 40% of them were willing to put themselves on the bay to contract themselves in order to save lives [55]. What if a healthcare worker refuses to treat a pandemic? To say that a healthcare professional refuses to give treatment solely because it is a pandemic would be generalizing when there are a number of factors contributing to this refusal. It is acceptable for nurses to dismiss their duty during a pandemic, this was stated by a professor in nursing in the United States [56]. It has been argued that the AMA codes do not gauge the physician to act during a pandemic and the code published in 1847 could be view as unclear on the risk that has to be taken by the physician during a pandemic [57]. hence many of these physicians may fear for their own health as well as may have increase in anxiety while treating patients in a highly infectious pandemic while indirectly brings a dispute to a prima facie obligation towards their non-clinical moral obligation (towards their spouse or children) [58]. In the tandem of this reasoning, a study that was conducted in the Midlands, United Kingdom shown that 74.1% who agreed with the statement "my main responsibility is to myself and my family" were female respondents and this could be traced back to

the misogynistic characterises of the medicine field in whereby the field was served by men whose main task is to provide income whereas the female nurses were to leave the profession once they tie a knot hence there are conflicts in moral obligation) [59]. In the spectrum of Non-maleficence as one of the ethical pillars in the medicine, it is true that one who refuses to treat a patient in hope to prevent further spread of the disease in the name of minimising the risk to other patients or staff members are justified⁶⁰ and a similar finding was found in in a study conducted in Japan inquiring healthcare personnel on the reason why they would not serve during pandemic is that they believe their family might contract the disease through them 54.5%, followed that they might become affected 49.5%, they will have to care for their family members 27.5%, and they are not specialist 27.0% and lastly they have inadequate energy to serve 24%. The second last is evident by physicians who believed that they would not likely treat patients with avian influenza because they believe that their speciality (obstetrics, surgery or rehabilitative medicine) does not involve managing pandemic. But in the same study, about 10% of medical professionals will not perform their duties in time of pandemic, about 20% would perform their duty as usual and 30% will perform their duty but not treating pandemic patients and 40% needed some conditions to be met. Of course, while bearing in mind if a physician refuses a patient, this will plant a seed in the latter to not trust in medical professionals, loss of status and may inadvertently harm other healthcare workers so what is the way to overcome this dilemma? A balancing test should be done when there is a pandemic on determining the risk of a new pathogen is "significant" by the means of medical evidence and consensus of the actual risk; the risk is not to be determined by the physician's own assumption and the physician should not withdraw his care for the patient however, a physician may refer his patient to another expertise who is well-equipped in knowledge to treat the patient. From another point of view, regarding the anxiety that a physician may face during a pandemic, if anxiety is the main cause for a healthcare worker's absenteeism, it should be approached with a manner that does not penalise the said worker but rather persuasion should be instilled⁶⁰. Some incentives can be applied during pandemics to promote more physicians to treat their patients during pandemic and this could be inclusive of (1) Personal Protective Equipment made available (2) Providing vaccine and chemoprophylaxis (3) Infection control and protective equipment are given training to medical workers (4) Giving them psychological support and environment (5) Allowing to take leave for emergency plans (6) Compensating their transportation to work (7) Providing lodging (8) Compensating the workers in terms of financial for their risk and extra hours (9) Benefits are given for sickness and death benefits (10) Standards of care and liability protection is given (11) Triage teams that are

independent and objective-wise. There are few who agreed that healthcare workers who refused to work during pandemic are punishable and could be answerable to law followed by 18.3% believed that individuals who do not work during pandemic should be disciplined but a majority of number (29.8%) thought they should lose their wage. On regards to the ones who worked during the pandemic, many respondents believed that they should be gaining reward in the form of special priority if they were to be infected by the pandemic virus (80.5%) and some believed they should be reimbursed financially [60-63].

Ultimately, the matter of human resources should be discussed among physicians and its governing body in determining what are the limits while treating in pandemic that may threaten the physicians' own lives as they too have the right unto their health.

Conclusion

Preservation of patient autonomy during pandemics is greatly challenged for the safe of the community that make it necessary to have on spot regulations and observations to keep the ethical medical practice. Regarding patient consent during pandemic, it is concluded that it is essential patient right that can be delegated to the physician during pandemic for the both patient and community safety. Regarding the patient confidentiality, it is concluded that it should be kept in all situations even if information has to be reported to the health authorities but this never to allow bridging the patient confidentiality to the public.

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