Ensuring Care Continuity in Extreme Crises: A Participatory Action Research Approach

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Abstract

The Lebanese healthcare system has been facing major challenges due to an unprecedented financial crisis, socio-political instability, and the COVID-19 pandemic. This study aims to examine the impact of overlapping major crises on care continuity and to propose IT-based solutions to address current challenges and build future resilience. To this end, we adopted a participatory action research approach and conducted a two-phase qualitative study – six semi-structured interviews followed by three future workshops with local stakeholders including physicians and interns practicing in Lebanon. Through the interviews, we identified the primary consequences of the crises and the ways they impacted the continuity of care. We also identified adaptation mechanisms used by physicians and patients to ensure continuity of care. Through the future workshops, we identified various IT-based solutions that could be implemented to tackle existing challenges and support local adaptation attempts.

Keywords:

Continuity of Care, Action Research, Participatory Design

Introduction

Recently, Lebanon has been facing major challenges that threatened the continuity of care of many of its citizens. In 2019, the country witnessed nationwide anti-government protests. These protests were followed by a major economic crisis, in which the country's currency depreciated by almost 227 percent in a matter of months, triggering waves of hyperinflation [1]. In 2020, an estimated 50 percent of Lebanon's population, or some 3.5 million, were potentially living below the poverty line and under conditions of food shortages and widespread unemployment [2]. These economic hardships affected the affordability of healthcare which is largely provided by the private sector and financed through out-of-pocket expenditures [3].

On March 2020, the spread of COVID-19 was described as a pandemic by the World Health Organization, adding another significant threat to Lebanon's vulnerable climate. Not only is this pandemic the current and largest danger to public health, but it also has a huge economic effect, heightening Lebanon's existing problems. At the social and economic levels, drastic steps have been taken, including lockdowns with the closing of major towns, the ban on foreign travel, the confinement of people to their homes, and school closures. Furthermore, tighter health care policies have been introduced, such as the cessation of all non-urgent elective procedures and the limitation of inpatient and outpatient treatment to seriously ill patients, in order to prevent wasting medical resources while increasing emergency care capacity and limiting the spread of this virus.

Another major crisis took place on the 4th of August, 2020, when a massive explosion happened in the port of Beirut--the capital of Lebanon--which killed more than 200 people, left

more than 6000 wounded, and caused catastrophic and widespread damage--including the collapse of hospitals and the decimation of medical supplies [4]. This blast left the health care system and already vulnerable patients in a state of shock and added new challenges [5]. Short after the explosion, the International Rescue Committee announced that the rates of COVID-19 infections in Lebanon had risen by 220 per cent [6].

To sum up, the Lebanese population and health care system have been facing immense new stresses as a result of the unprecedented financial crisis, socio-political instability, and the current COVID-19 pandemic. With a lack of reliable future expectations and a continuous state of chaos, both patients and health care providers are trying to adapt and ensure, to their best, a continuity of care. In the current state of affairs, solutions based on evidence from the field and on an understanding of current practices and constraints may prove valuable.

To these ends, we adopt a participatory action research approach [7] where we aim to include local stakeholders in a process of research that could eventually lead to social action. By doing so, we seek to transform the current reality into an aspired one through the simultaneous process of doing research and taking action. As a first step, we examine the impact of overlapping major crises on the continuity of care. Then, using the evidence that we collect, we propose IT-based solutions that could address current challenges and build future resilience.

Methods

This work consisted of a two-phase qualitative study – six semi-structured interviews that were thematically analyzed, followed by three future workshops. The aim of the interviews and subsequent analysis was to assess the impact of the overlapping crises on the continuity of care while the aim of the workshops was to propose information technology (IT)-based solutions to address current challenges and build future resilience.

Figure 1 shows a diagram of our methodology with goals, tools, and participant details shown for each step. The following subsections provide details on how each step was conducted.

Semi-Structured Interviews

We conducted semi-structured interviews with six Lebanese physicians from different specialties (Dermatology, Endocrinology, Nephrology, Neurology, Obstetrics and Gynecology and Urology). In the interviews, we asked them about the impact of the economic crisis, the COVID-19 pandemic and the social and political instability in Lebanon on the continuity of care of their patients. The interviews were conducted face to face or online depending on the physician's preference and took approximately 15 to 30 minutes. The interviews were thematically analyzed by 2 researchers following the six-phase guide of Braun and Clarke [8]. The analysis resulted in a list of themes describing the impact of the collapsing economy, the pandemic and the social instability on the continuity of care in the country.

	Phase 1		Phase 2
Methods	Semi-structured interviews	Thematic analysis	Future workshops
Goals	Gather data on the impact of the overlapping crises on the continuity of care	Identify themes describing consequences of the crises and existing adaptation mechanisms	Propose IT-based solutions to address current challenges and build future resilience
Tools	- Face to face or online - 15 to 30 minutes each	6 phases of thematic analysis as described by Braun and Clarke	- 3 phases: Preparation, Critique, and Fantasy - Online using Zoom and Google Jamboard
Participants	6 physicians from different specialties	2 researchers	10 participants split over 3 groups - Group 1: 3 medical interns - Group 2: 3 medical interns - Group 3: 2 physicians + 1 health economist + 1 informatician

Figure 1 Two-phase qualitative study

Future Workshops

A Future workshop is a technique that enables a group of people to develop new ideas or solutions for problems, and can be used as a kind of action research method [9]. Future workshops were previously used as a participatory design tools in healthcare settings [10] and with refugees in Lebanon [11]. When conducting our workshops, we followed these steps:

1. Preparation phase: we introduced the aim of the workshop, its rules and its scheduled course.
2. Critique phase: the participants investigated the problem critically with a visualized brainstorming.
3. Fantasy phase: the participants imagined future possibilities and proposed solutions to achieve them.

Future workshops usually include a 4th step called the "implementation phase" where participants try to implement their ideas by creating action plans. However, since our purpose at this time was to generate ideas for solutions, we stopped our workshops at the fantasy phase.

The workshops were conducted online using Zoom. The facilitator gave out instructions for both groups in the main session and put the groups in breakout rooms to communicate separately when engaging in their group brainstorming and discussions. The participants used Google Jamboard for brainstorming. In the beginning of the critique phase of the workshops, the themes that were identified in the interviews were used to give the participants an overview of the problem space.

We conducted a total of three workshops with a total of 10 participants. For the first two workshops. Six medical interns were recruited and split into two groups with three participants each. Each group generated high level ideas of solutions. In order to translate the high-level ideas into tangible and actionable solutions, we conducted a third workshop with four participants including 2 physicians, a health economist, and a health informatician. This workshop used the results of the first two workshops as a starting point and was mainly aimed at generating tangible solutions.

Results

We first present the results of the thematic analysis in terms of themes relating the impact of the overlapping crises on the continuity of care. Then, we present the results of the workshops in terms of solutions that could alleviate the situation by tackling existing challenges and supporting local adaptation attempts.

Themes from the Semi-Structured Interviews

Our analysis of the interviews resulted in 16 themes. The themes fall into 3 main categories: (1) primary consequences of the overlap of major crises, (2) secondary consequences of the overlap of major crises on the continuity of care and (3) adaptation methods used by physicians and patients. Themes and their supporting quotes are shown in Table 1.

Table 1– The impact of the overlapping crises on the continuity of care

Theme	Supporting quotes
Primary consequences	
Decrease in purchasing power	"With the extreme poverty in Lebanon, the patients have other priorities such as feeding their children, so I guess that we will see a decrease in the demand."
Rising healthcare costs	"We had problems with the drugs. Some were out of stock. Some were becoming very expensive. And because of that, we had a delay in the disease management."
Fear of COVID-19 contamination	"In the first wave, the patients were mainly afraid of coming to the hospital and clinics so they postponed their follow-up for months. However, in the second wave, the main problem was that patients tested positive, postponing their appointment for 3-4 weeks."
Hindered geographical access	"During the revolution, we had some problems with the closure of roads. But it was a temporary problem and it affected mainly the patients that live in other regions, far from the hospital or clinic."
Feeling of insecurity	"Some patients that used to come from other regions now prefer to change to a doctor in their region."

Damaged home and healthcare centers	"Patients affected by the Beirut blast postponed their follow-up because their main priorities were to reconstruct their houses and recover from their physical damages."
Record immigration	"Many patients required a last follow-up before immigrating from Lebanon. The flow of immigration began with the economic crisis but escalated quickly after the 4th of August explosion."
	"Also, many physicians are now immigrating."
Consequences on the continuity of care	
Postponement and cancellation of follow ups	"My patients weren't coming for their follow up on time. They increased the time between their regular follow-ups."
Disproportionate effects on certain population	"The most affected patients were patients with low socio-economic status."
	"The patients who are suffering from pathologies that are known to be risk factors for COVID-19 severity such as cancer, diabetes, etc. are more afraid to follow-up, thus more affected."
Increase in healthcare demands from expats	"We noticed an increase in Lebanese expats patients that live and work abroad. They are mainly here […] because with the devaluation of the Lebanese pound, it is now much cheaper for them."
Advancement of scheduled procedures	"We had some Lebanese citizens that advanced their scheduled [procedures], because they are afraid that the devaluation of the Lebanese pound will make it more expensive and out of their reach."
Delay in disease management	"One patient did his cystoscopy 1 year later instead of every 3 months, thus we caught the recurrence at an advanced stage."
Adaptation mechanisms	
Increased use of generic and cheaper drugs	"We switched to other drugs that are available and cheaper, so we lost quality of the products that we use."
Prioritization of healthcare needs	"I limited my face-to-face consultations to seriously ill patients."
Increased demand for affordable services	"Patients started asking me if they can follow up in a Non-Governmental Organization primary health care center where I go. There, there is no consultation fee."
Rapid adoption of telemedicine	"I used to do a little bit of telemedicine, but with the pandemic I am using it officially on a platform where the patient can pay and share the paraclinical exams."

Results of the future workshops

Critique Phase

In the beginning of the critique phase, the facilitator presented the results of the interviews. Following the presentation, the workshop participants brainstormed problems that could have contributed to the discontinuity of care during the crises. In this brainstorming session, the participants used knowledge gained through their personal experiences during the crises, in addition to new knowledge that they acquired from the presentation.

After the brainstorming session, the participants were asked to categorize the problems and choose a category to focus on. When choosing the category, the participants were asked to consider the feasibility of tackling the problems and the overall utility of doing so. Groups 1 and 2 found three categories: (a) government related problems, (b) people related problems, (c) policies and organizations related problems. Group 1 chose to focus on policies and organizations related problems while Group 2 chose to focus on people related problems. Figure 2 shows the brainstorming and categorization results of Group 1.
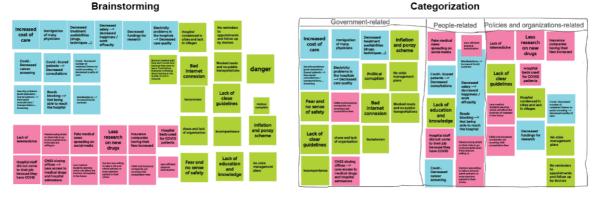

Figure 2 Brainstorming and categorization done by Group 1. Sticky notes of the same color belong to one participant.

Fantasy Phase

Once the groups decided on their categories, they moved to the fantasy phase where they first imagined a utopic situation. Using this vision as a reference, they brainstormed and discussed solutions that could transform the current reality into their imagined utopia. After the initial session, they were asked to focus on 2 or 3 main problems and go more in depth and brainstorm practical solutions that could be eventually implemented.

Group 1 chose to focus on the (i) lack of access to certain drugs and equipment, (ii) disproportionate effects on certain population, and (iii) low adoption of telemedicine. Group 2 chose the (i) spread of fake news and (ii) fear of generic drugs.

The third workshop used the results of the first two workshops as a starting point and translated the ideas that Groups 1 and 2 generated into practical and tangible solutions. Table 2 shows the solutions that were finally proposed.

Table 2– Solutions proposed through the future workshops

Problems	Proposed solutions
Population related	
Spread of fake news	- Identify and prioritize viral fake medical news by infiltrating large What's App groups from different geographical areas and social groups.
	- Flag the fake news on a dedicated social media account and tag relevant organizations to rebut it.
Fear of generic drugs	- Create a public database for locally manufactured generic drugs where patients and doctors can gain information and write reviews of drugs.
Policies and organizations related	
Lack of access to certain drugs and equipment	- Create a platform where locals can connect with expats and request needed medical supplies.
	- Create a platform where people can exchange their unused medical supplies for needed ones.
	- Keep track of major unfulfilled medical needs and encourage local university students to engage in research that could potentially contribute to those needs.
Disproportionate effects on disadvantaged populations	- Publish easily accessible schedules, locations, and fees of free or low costs medical services.
	- Create a database and crowdsource data collection on the use and coverage of low costs medical services.
	- Create a platform for the Lebanese diaspora to sponsor chronic disease patients in the country.
Low adoption of telemedicine	- Equip each rural municipality with a tele-clinic with a high-speed internet connection and a computer for remote teleconsultations.
	- Equip existing mobile clinics with high-speed internet connection and a computer for remote teleconsultations with specialists.

Discussion

An overlap of three major crises paralyzed the Lebanese healthcare system and threatened care continuity. We used a participatory action research approach to come up with solutions that could help ensure care continuity and build future resilience. Using semi-structured interviews and thematic analysis as research methods, we established the problem definition space. These problems were subsequently used as a starting point for future workshops involving local stakeholders—physicians practicing locally during the crisis. Next, we discuss the participants' feedback regarding the workshops, factors that contributed to the success of the workshop, limitations that we experienced, and recommendations for future researchers aiming to adopt participatory action research approaches in similar contexts.

Participants in action research projects are treated as co-researchers rather than subjects. Through their involvement and reflections, they engage in a process that changes them and their environment [12]. In our case, participants in both the interviews and workshops were able to deeply reflect on the care continuity problem and reach a deeper understanding of challenges and opportunities for change. In general, they were positive about their participation in the project and acknowledged the topic's relevance as it represents a major challenge that they are currently experiencing. Also, they considered their participation as a contribution that could potentially lead to solutions even though there was a general belief that the problem may be too complex to solve without the involvement of the government or major institutions that can implement top-down solutions. Interestingly, some of the solutions that were proposed were inspired by already existing initiatives that are highly successful and citizen-led. One example is the LibanTROC initiative which started off as a barter platform to become a humanitarian platform with more than 70 thousand followers and tens of humanitarian cases solved every day.

Even though this project was conducted during the COVID-19 quarantine period, we were able to successfully conduct the interviews and workshops using online tools. However, we encountered some limitations when conducting the workshops. First, not all of the workshop participants were familiar with the structure and goals of design workshops. For example, during the brainstorming sessions, some participants were thinking pragmatically and focused on generating quality ideas rather than a large number of ideas. Moreover, the use of Jamboard for the brainstorming sessions allowed all the participants to see each other's sticky notes and limited their available space. These factors may have affected the results of the workshops as they limited the overall creative potential. To address these limitations, the facilitator had to extend the brainstorming sessions, resulting in long workshops which led some participants to lose interest during the fantasy phase. These limitations could be addressed by choosing participants who are familiar with design-thinking approaches or conducting pre-workshop trainings for participants. Moreover, when choosing online tools to conduct the workshops, one needs to consider the effect of these tools on the participants' creativity.

In this part of the project, we mainly involved physicians and medical interns. However, the limitations of involving a limited group of stakeholders were evident after the first two workshops. To address this limitation, we conducted a third workshop that included a mix of other stakeholders—medical, economy, and information technology experts. Future steps will have to include patients, particularly disadvantaged ones, in order to reach a deeper understanding of the problem space and identify adaptation mechanisms that they developed to ensure their care continuity in these crises.

In other respects, the process of action research involves a team whose members iterate through a series of steps starting by fact finding and analyzing, followed by planning, acting, evaluating the result of the action, and reanalyzing to continually adjust as needed [13]. Moreover, future workshops include an implementation phase where action plans are devised to describe steps that could transform the envisioned ideas into reality. However, our workshops ended at the fantasy phase as our goal was to generate ideas for solutions that could be pursued and implemented later on. In order to break the cycle of "producing research with little action," [14] the next step requires the selection of solutions to further pursue, and the creation of a plan of action. The selection of top ideas can be guided by the use of common Multiple Criteria Decision Making (MCDM) methods [15] or approximative utilitarian analysis approaches in analyzing the potential overall impact of implementing these ideas [16]. Once top ideas are selected, their usefulness and feasibility could be initially assessed through prototypes, before moving into the action and evaluation phases where they are implemented, used, and continuously evaluated and refined.

Another aspect to consider, while moving towards the "acting" phase, is the ability to act on the findings generated in the initial phases. This ability to act can be hindered by a lack of necessary endorsements and permissions. In addition, our analysis so far highlighted a potential future challenge that needs to be addressed: a weak internal capacity to act due to the belief that the problem is too big, and requires top-down solutions rather than small scale action research. In fact, both issues are common sanctions that participatory researchers need to obtain in order to yield action and move beyond research [17]. The involvement of a wider array of stakeholders, including ones in decision-making positions, is imperative to our ability to enact solutions and would potentially empower other team members engaged in the action research process. To identify stakeholders with high salience, i.e., ones who possess power, legitimacy, and urgency [18] in relationship to the care continuity crisis, a stakeholder mapping, analysis, and prioritization process is necessary.

Conclusions

The inclusion of stakeholders of the local healthcare system in a participatory action research project resulted in an in-depth understanding of the implications of major overlapping crises on the continuity of care. Our experience suggests that future workshops can be used to elicit locally adapted solutions to increase the resilience of the healthcare system. Our involvement in the process, and reflections on it, highlighted the need to include a wider array of stakeholders, especially ones in decision-making positions, to enable a complete action research process that is capable of action. Future work will aim to include other stakeholder groups and turn the proposed solution ideas into reality.

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