



Considering Parents of Malignant ill Children in COVID-19 Health Crisis

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Keywords

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Abstract

Aim: Parents of children suffering from malignant diseases indubitably represent a very dainty population, underrepresented in psychosocial research. It is common for these parents to move to the hospital wards in order to support their children, which causes an unnatural cut in their lifeline, in addition to coping with terrifying diagnosis. Coping with a child’s malignant disease includes a continuous feeling of fear and concern, and change in the overall family dynamics, but also the cessation of daily life activities, even outside the context of a global pandemic, some pre-COVID research had shown. COVID-19 brought some additional challenges. In order to protect children’s fragile physical state, parents were obliged to adapt to new rules and distance from the others even more. At the same time, their fears and worries grew only bigger and coping mechanisms were seriously limited. **Subjects and Methods:** In this paper we investigate parental experiences and needs during COVID-19 crisis. Semi-structured in-depth interviews were conducted with ten mothers with experience of children’s in-patient treatment before and during pandemics. **Results:** According to main findings, theoretic

cal model of parental adjustment and wellbeing in health crisis is proposed. **Conclusion:** Results imply the necessity to consider parental psychological wellbeing in order to support them and their children, especially when additional stressful and/or traumatic experiences emerge, and treat them as especially vulnerable group in research and practice.

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Introduction

According to Croatian Institute of Public Health, 120-150 children are yearly diagnosed with malignant disease in Croatia [1]. Coping with a child’s malignant disease includes a continuous feeling of fear and concern on the part of the parents and a change in the overall family dynamics, but also the cessation of daily life activities, both for the parent and the child, even outside the context of a global pandemic [2]. Treatment of paediatric oncological and haematological patients is a long-term process and includes invasive tests, procedures and therapy that carry numerous severe side effects and significantly affect the quality of life [2].

Children with malignant diseases were designated as clinically extremely vulnerable if they were to contract SARS-CoV-2 due to immune suppression in the early

phase of the COVID-19 pandemic. A lot of recommendations for their special care were issued [3]:

- Apply physical isolation for all children with malignant diseases who are currently undergoing treatment. This includes confinement at home between treatments and single-room admission during hospital stay when possible.
- Outpatient visits should be limited and other means of communication should be prioritized.
- Screen patients who present symptoms suggestive of the infection. This screening must be done regardless of the structure - paediatric, general hospitals or oncology and haematology centres.
- Limit access to paediatric wards and clinic spaces to one parent only.
- In these areas promote, respect and enforce social distancing rules; at least 6 ft. between individuals, and no grouping.

It is obvious that recommendations listed affect psychosocial life as much as they are beneficial to somatic health, even though it is not emphasized.

The emergence of the COVID-19 health crisis has suddenly brought demanding accompanying factors that require parents of children with malignant diseases to further adapt. Beside of many additional information and intensified care related to child protection and health impacts, there are also feelings of loneliness, isolation and separation from their families. According to the few previous researches worldwide, parents of children suffering from malignant diseases are currently facing additional challenges and sources of stress [2].

The aim of this study was to deeply investigate the experiences of parents of children with malignant disease due to the COVID-19 health crisis and the specific needs to help and improve the quality of life.

Subjects and Methods

Semi-structured interviews were conducted with ten mothers of children with malignant diseases (age 2-16) involved in active treatment at the Department of Haematology and Oncology „Dr. Mladen Čepulić” at the Clinic for Children’s Diseases Zagreb in 2021 (during COVID pandemic in Croatia). Eight of them have other children at home. Criteria in selecting research subjects were: parents who have experience of children’s treatment both before and during the pandemic; and parents of children with solid tumours (N = 8) or haematological diseases (N = 2) [1,2]. It is important to enhance that parents stay full time with their children in hospitals and it is most common they are mothers, which is represented in this

sample. Ethic board permission was successfully obtained. All parents on the ward (fitting criteria at the moment) recruited were willing to participate. Interviews were structured into five main themes: general information, pre-COVID in-patient care experiences, current in-patient care experiences, main concerns and troubles and COVID period related needs. They were conducted by same psychologist that works at the Clinic and lasted 45 to 70 minutes (M = 55 minutes). Questions were wide open, e.g. “Please tell me all about your experience with your child’s treatment before COVID”, with slight encouragements when needed, e.g. “Tell me more about that”.

Data Analysis

The interview material was then transcribed by an independent researcher. Interpretative phenomenological analysis of the content (IPA) was applied, using the Atlas.ti research software. Each transcript was read several times. After that answers were summarized and a preliminary interpretation of results was obtained. Then the categorization of answers was conducted and main themes were identified. These themes were divided into meaningful clusters. Original transcripts were consulted during the process, in order to authenticate the foundations of themes and clusters of answers obtained from the participants. Each transcript was coded following defined themes and clusters, with minor changes of the names of themes and the introduction of new themes. Finally, all transcripts were coded again, following the final list of themes and clusters. The credibility of the analysis was ensured by two independent professionals working according to the same principles. Their disagreements were discussed and supervised by an independent researcher specialized in qualitative analyses.

Results

The presentation of results is organized according to the six themes that emerged:

- a. Additional sources of stress related to physical health protection

All the parents included reported increased fear and sense of responsibility in child protection from COVID-19 virus, which led to somewhat unreasonable and potentially harmful behaviour.

“Every time I come from the store, I spray everything with disinfectant - sticks, chips... I wash all the bags. We are so burdened by pandemic.”

“I’m afraid to go to the store. When I come to the apartment, I take off all my clothes and throw them in the laundry. I could be carrying anything in clothes, in my hair or on my hands.”

“I didn’t go out to take out the garbage without a mask and gloves. My hands were burned of washing and wounds began to form.”

Some described the struggle between these fears and protective urges on one hand, and desire to socialize on the other.

"I'm worried about whether he will survive or not, because COVID is high-risk for him, so I'm afraid of what life will look like when we go out. I want to protect him, and yet not put us in isolation from everyone."

"I am distant from people. Imagine you wave at everyone; you must not speak because of fear of getting infected. And still, you miss your life."

For some, certain protective hospital rules were not logically clear or perceived as meaningful.

"My child and I used to have over 30 nasal swabs in a month. I don't understand the rule by which we get tested before some examination, then we lie in the hospital all the time and don't go out, and then tomorrow we get tested again."

b. Increased experience of isolation, loneliness, lack of social support due to epidemiological guidelines and rules.

In contrast to pre-pandemic period, parents were not allowed to socialize with each other, which had been a great supportive tool, both practically and emotionally, and they have terribly missed it.

"Before the pandemic we were helping each other. For example, one of the two parents in the room would have looked after both of the children, and the other one could have relaxed a bit. Now that is impossible, there is no rest, no pause."

"I couldn't go out and cry, if anything else, or share with only people who could have understood – the other parents."

Some of them developed anxiety issues related to sense of captivity, which have manifested both psychologically and physiologically. Parents were lacking chances to physically move and release some energy.

"The inability to move around the hospital is like a lump in your throat, like someone is choking you."

"One day I was sitting, stiff, and I was feeling as I was in jail."

"We put it together in one room for a month and a half. The thought that you are closed, that you can't go out creates anxiety. Sometimes you feel like you're going to suffocate."

"Now that we are allowed to pick up food down in front of the hospital, I only use the stairs because I really miss some physical activity. My body is restless because I can't do anything."

c. Difficulties in managing parenting of other children, worrying for the spouse.

Parents report difficulties in balancing their care for the ill child with their marital and parental role regarding other children, which leads to worry and other unpleasant emotions, and is worsened by lack of physical contact and timeline unpredictability.

"It was very difficult for my husband for the first two months because he had to continue with his usual activities while being with us in his mind all the time and could not visit. I worried about him."

"It's very difficult for everyone. Now that visits have been banned, I remember one visit while it was raining. My daughter and I were at the hospital window, and my husband and other daughter were downstairs under an umbrella on their cell phones with us."

"It is very difficult for the younger daughter because we will not be with her for her birthday. Those days that are very important to our family, it's all gone now."

"Separation is too difficult. You are here with the child that needs you the most now. Your heart breaks when this other child calls and says: 'Mom, I don't know how to do the math / mom when will you come home / you only love my sister'."

"The younger daughter is very attached to me, often when we talk, she is crying and she can't calm down because she doesn't know when we will go home and be together again. It is harder if there is no psychical contact for God knows how long."

d. Difficult coping with the loss of at least part of the usual everyday activities.

Participants were deprived of basic everyday activities both for them and their children, such as socializing, cooking, doing laundry, cooling the water etc., that of course added to burden of most the routines and structure being lost.

"It was much better and easier before COVID. There was a different atmosphere, we could go out, do the laundry, make a meal, drink coffee."

"There were babysitters, there was school, children had more hobbies, socializing and content."

"Before, at least you could have cooked a soup, made pasta or brought some of your own food from the refrigerator that your child liked to eat."

"It was summer, and we have only been drinking warm water and warm juices for a month because of the COVID restrictions."

e. Feeling of pronounced dependence on others.

Parents described their pronounced dependence on other people, mostly nurses and NGO volunteers, which made some feel embarrassed and more helpless.

"I felt embarrassed to give someone from the NGO my dirty underwear to wash, but there was no other way."

"Every day at noon we had an opportunity for someone to exchange things for us from the 'outside world'. But the problem was everyone was working at the time, so we had to rely on strangers' good will."

"I have to praise the nurses who have always helped us, but it was hard for me to keep asking and asking them something –

to bring us our things from the fridge, to go downstairs to get the food we ordered, and so on. I felt helpless.”

“When nothing was allowed, the nurses went to buy and make things for me. Everyone who could have helped us, got everything we needed, but I wanted to do it myself.”

f. Need for information, understanding and enhanced psychosocial support.

Most parents’ anxiety increased due to confusion in information regarding COVID and epidemiological measures.

“There should be a flyer for new parents. There are parents who don’t have a clue what to do here, especially in COVID.”

“I called the epidemiologist, our doctor at home, here at the hospital... Wherever I could get some information, I asked for it, but it was not clear.”

Their need to be considered and understood grew, and yet could not have been prioritized in pandemic state.

“It would have been good for us if we had the opportunity to exercise a little somewhere, talk to other parents or have any content. I know children are the priority, but I wonder if anyone thought about us as their main support.”

“I need someone to listen to me, for example I can let it all out to the psychologist, get information on how to deal with the child, how to explain about the hair loss (...), just that someone comes to the room and greets you, these are important things and there should be more of those opportunities.”

Discussion

The aim of this study was to deeply investigate the experiences of parents of children with malignant disease due to the COVID-19 health crisis and the specific needs to help and improve the quality of life. Through in-depth semi-structured interviews some interesting findings emerged.

Firstly, some additional sources of stress related to the protection from COVID-19 virus were identified, such as increased fear and sense of responsibility in child protection from COVID-19 virus at the same time as desire to socialize. That ambivalence was perceived to cause additional anxiety and less reasonable behaviour, which increased the ambivalence itself over again. Frustration was then sometimes projected on *un-logical* and constantly changing hospital rules. Ambivalence is common in situations of great emotional value, in which there is rarely simple or correct solution – having one often means losing the other and the individual has troubles coping [4]. In prolonged and intense sense of ambivalence, individuals often project their discomfort and inability to cope to someone or somewhat greater, such as God, destiny, society or in this case – the hospital

they otherwise describe great experiences with [5]. Thus, it is not unusual for parents in high stress situation of their children’s malignant disease to have this type of emotions and coping difficulties in case of even greater stress such as COVID-19 paired to the original one.

Beside of being the parent of seriously ill child, these parents have more than one social role they value. Most of them have other children and spouses, let alone their career-related roles, and they felt cut off of the rest of their lives, ones outside the hospital walls. As expected, feelings of worry and guilt towards other important family members weighted their psychological adjustment. All of that was worsened by lack of physical contact and timeline unpredictability. Social isolation, that this group experiences even outside of the pandemics, in lockdown period profoundly deepened. According to research, social isolation is highly predictive for many adverse mental health outcomes, so resilience building and coping strategies are of great importance in these circumstances [6].

If one tries to look for resilience and coping tips in crisis, it is highly plausible that social support, routines, structure and common activities would be recommended [7,8]. Parents from our sample have experienced a paradox – almost all the coping and resilience building advices their psychological adjustment would have benefit from were not allowed due to physical health protection. In contrast to pre-pandemic period, parents were

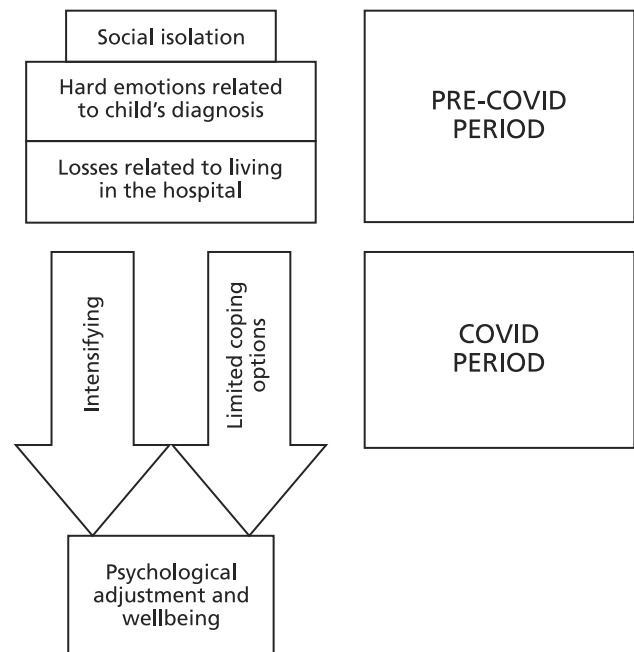


Figure 1. Proposed theoretical model of additional parental vulnerability in health crisis

not allowed to socialize with each other, which was a great supportive tool they have terribly missed. Some of them developed anxiety issues related to sense of captivity, both psychologically and physiologically, since there were to stay in their rooms only. That way they could not cook, cool the water or wash their own clothes, so some felt additional helplessness and dependence, the exact opposite of what they would have emotionally needed in that period.

According to findings discussed, a theoretical model of additional parental vulnerability in health crisis can be proposed (Figure 1). According to this model, hard emotions related to child's diagnosis (e.g., fear, anger, worrying), social isolation and numerous other personal losses related to moving to the hospital (such as cut in other aspects of their lives – both family and work related), that have been present even before the pandemics, tend to intensify in COVID-19 period. At the same time, coping options (such as maintaining routines, activities, socializing) are much limited, affecting psychological adjustment and wellbeing negatively.

When asked about useful resources and suggestions, parents emphasize information and support. With complete understanding of priorities in health-related crisis on malignant illness hospital ward, parents feel they could have got even more of that, and they are probably right. It was almost impossible to balance all the relevant aspects of the COVID-19 situation, since it was highly unpredictable and new. Anyhow, for any further similar situations, we should highly value experiences obtained this far. COVID-19 is not officially beaten and other health crises are not impossible to expect in the future.

On some aspects of the model presented one can have little or no influence. But when considering lim-

ited coping strategies, professionals can and need to buffer the crisis effects as much as possible. Parental needs must be considered in guidelines and practice for both parental and children's sake. Any sense of structure and routines, any possibilities for physical activities, regular information sharing, psychoeducation and normalization, as well as empowering support and socialization possibilities within some epidemiological frame would probably bring a lot better adjustment and cooperability. There is a necessity to consider parental psychological wellbeing in order to support them and their children, especially when additional stressful and/or traumatic experiences emerge, and treat them as especially vulnerable group, as they are, furthermore in research and practice.

The authors strongly encourage further research in this field, testing and complementing the model proposed. For purposes of this paper's goal and national overall number of parents that fit the sample criteria, methodology and sampling can be considered satisfying. However, if possible, quantitative and combined methods, as well as broader sample size from different hospitals, would highly contribute and enhance the strength of conclusions drawn and suggestions set based on the results of this paper.

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Conflict of interest

None to declare.

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