



Αυτοδιαχείριση του Long-COVID. Αξιολόγηση σωματικών, ψυχολογικών και κοινωνικών αναγκών για παροχή κοινοτικής φροντίδας υγείας

Τσιρμπίνη Νίνα¹, Βλάχου Χρυσή², Αργυριάδη Αγάθη³, Αργυριάδης Αλέξανδρος⁴

1. Νοσηλεύτρια, MSc, Πανεπιστήμιο Frederick, Κύπρος
2. Συνεργαζόμενο Ακαδημαϊκό Προσωπικό, Πανεπιστήμιο Frederick, Κύπρος
3. Λέκτορας Ψυχολογίας, Πανεπιστήμιο Frederick, Κύπρος
4. Επίκουρος Καθηγητής, Πανεπιστήμιο Frederick, Κύπρος

ΠΕΡΙΛΗΨΗ

Εισαγωγή: Η παγκόσμια έξαρση του ιού SARS-CoV-2 και η επακόλουθη πανδημία COVID-19 έχουν οδηγήσει σε ποικίλες προκλήσεις για την υγεία σε παγκόσμια βάση. Μεταξύ των αναδυόμενων ανησυχιών είναι και το σύνδρομο Long COVID-19, το οποίο παρουσιάζει επίμονα συμπτώματα και επιπτώσεις ακόμη και μετά την αρχική ανάρρωση από την οξεία φάση της νόσου.

Σκοπός: Η παρούσα εργασία παρουσιάζει μια εις βάθος μελέτη περίπτωσης της οικογένειας X, μιας ελληνικής οικογένειας που αντιμετωπίζει τις προκλήσεις του Long COVID-19, ενός συνδρόμου επακόλουθου της μόλυνσης από SARS-CoV-2. Η μελέτη διερευνά τις σωματικές, ψυχολογικές και κοινωνικές επιπτώσεις του Long COVID-19 στην οικογένεια και τον τρόπο αυτοδιαχείρισής της.

Μέθοδος: Η μέθοδος μελέτης περίπτωσης που χρησιμοποιήθηκε σε αυτήν την έρευνα περιλαμβάνει μια εις βάθος διερεύνηση μιας οικογένειας, παρέχοντας λεπτομερή κατανόηση των εμπειριών και των προκλήσεων που σχετίζονται με το Long COVID-19. Αυτή η ποιοτική προσέγγιση επιτρέπει την εξερεύνηση των εμπειριών της οικογένειας ως προ τον τρόπο διαχείρισης της ασθένειας.

Αποτελέσματα: Τα ευρήματα αναδεικνύουν τη σημαντική επιβάρυνση της οικογένειας λόγω της εμφάνισης του συνδρόμου σε ένα από τα μέλη της, καθώς και δυσκολίες στην επίλυση προβλημάτων μέσω της συνεργασίας, της αποτελεσματικής επικοινωνίας και των ισχυρών συναισθηματικών δεσμών των μελών της.

Συμπεράσματα: Συμπερασματικά, τονίζεται η ανάγκη σχεδιασμού ενός ολοκληρωμένου, πολύπλευρου σχεδίου φροντίδας προσαρμοσμένου στις μοναδικές ανάγκες και δυνάμεις της οικογένειας και σκιαγραφεί πιθανές προκλήσεις στην εφαρμογή του, με σκοπό την ευρύτερη χρήση του στην κοινότητα.

Λέξεις Κλειδιά: Long-COVID-19, αυτοδιαχείριση νόσου, προκλήσεις υγείας, δυναμική της οικογένειας.

Υπεύθυνος αλληλογραφίας: Αλέξανδρος Αργυριάδης, Κύπρος. Email: hsc.arg@frederick.ac.cy

Self-Management of Long – COVID. Assessment of individual and family physical, mental and social needs for community health care

Tsirmpini Nina¹, Vlachou Chrisi², Argyriadi Agathi³, Argyriadis Alexandros⁴

1. Msc student in Community Healthcare, Department of Nursing, Frederick University, Cyprus
2. Collaborating Academic Staff Frederick University, Cyprus
3. Lecturer, Department of Psychology Frederick University, Cyprus
4. Assistant Professor, Department of Nursing, Frederick University, Cyprus

ABSTRACT

Background: The global outbreak of the SARS-CoV-2 virus and the subsequent COVID-19 pandemic have led to various health challenges worldwide. Among the emerging concerns is the condition known as Long COVID-19, which presents persistent symptoms and effects even after the initial recovery from the acute phase of the illness.

Aim: This paper presents an in-depth case study of the X family, a Greek family facing the challenges of Long COVID-19, a syndrome sequel to SARS-CoV-2 infection. The study explores the physical, psychological, and social effects of Long COVID-19 on the family as well as its self-management.

Method: The case study method employed in this research involves an intensive investigation of a single-family unit, providing a detailed understanding of their experiences and challenges related to Long COVID-19. This qualitative

approach allows for a holistic exploration of the subject, capturing the intricate nuances of the family's journey through Long COVID-19.

Results: The findings highlight the significant burden on the family due to the occurrence of the syndrome in one of its members, as well as the resolution of problems through cooperation, effective communication, and the strong emotional bonds of its members.

Conclusions: In conclusion, it emphasizes the need to design a comprehensive, multifaceted plan of care tailored to the unique needs and strengths of the family and outlines potential challenges in its implementation, with a view to its wider use in the community.

Keywords: Long COVID-19, family impact, case study, health challenges, family dynamics.

Corresponding Author: *Alexandros Argyriadis, 7 Yianni Frederickou, Nicosia, Cyprus. Email: hsc.arg@frederick.ac.cy*

INTRODUCTION

The term "Post-COVID-19 syndrome" encompasses the persistence of symptoms or the emergence of new symptoms for more than 12 weeks following the acute phase of a SARS-CoV-2 infection, without any other diagnosable cause (NICE, WHO). Symptoms and complications span a wide spectrum, affecting various body systems such as the respiratory, cardiovascular, renal, nervous, and gastrointestinal systems, among others, often resulting in a considerable decline in an individual's quality of life. Among the most prevalent symptoms are fatigue/weakness, shortness of breath, arthromyalgia, restlessness, depression, sleep disturbances, impaired concentration, and memory loss¹⁻⁴.

Over the past five years, research on Long COVID-19 has expanded significantly due to the worldwide impact of the COVID-19 pandemic. A substantial portion of this research aims to comprehend the array of symptoms, potential underlying mechanisms, and risk factors associated with the

development of Long COVID-19⁵⁻¹². Several studies have concentrated on exploring the link between vaccination against the specific virus and the occurrence and severity of Long COVID-19¹³⁻¹⁷.

Lastly, a considerable body of research is dedicated to strategies for managing Long COVID-19 and facilitating patient rehabilitation, with a pronounced emphasis on a multidisciplinary approach¹⁸⁻²¹.

Despite the considerable amount of research on Long COVID-19, many gaps remain. Long-term studies are needed to predict the clinical presentation and progression of individuals affected by Long COVID-19. Additionally, further research is required to uncover the biological mechanisms underlying the diverse range of symptoms, with potential to inform the development of targeted and personalized therapeutic approaches. Moreover, a comprehensive examination of the long-term impact of Long COVID-19 on the immediate environment and caregivers of affected individuals is necessary. Exploring the role of



patients' families in managing this specific syndrome is also worth investigating. Notably, much of the existing research has been conducted in high-income countries, possibly constraining the applicability of findings⁵. There exists an opportunity to investigate the effects and management of Long COVID-19 within varying socio-cultural and economic contexts, particularly in low and middle-income countries like Greece^{12,22}.

Material and Methods

The qualitative case study method was selected for this study due to its suitability for the research topic. Keeping this in consideration, the researchers opted for this approach because their primary objective was anthropological. A 'case study' can pertain to an individual case or a small group involving people, events, or facets of a subject or issue. It is categorized as a qualitative research method as it doesn't intend to involve a large number of participants, collect data from a diverse or representative sample, or generalize its findings. This method bears resemblance to ethnographic research. Its main value lies in the volume of data amassed, achievable only through meticulous observation, documentation, and subsequent analysis. Although typically devoid of an initial hypothesis, data analysis might engender the formulation of one or two

hypotheses, prompting further exploration through alternative research methods²³.

The present study aimed to investigate the psychological and social effects of Long COVID-19 on individual family members as well as the entire family unit, along with exploring potential treatment mechanisms.

Data Collection Process

To gather data for this study, an unstructured interview format was employed. This approach was well-suited for investigating this particular case, as interviews can function as the sole or predominant method in a case study. In this instance, a semi-structured interview style was adopted, utilizing predetermined questions that allowed interviewers flexibility in their interactions.

Sampling

The participants on this case study was the Family X that comprises five members: Mr. and Mrs. X, both in their 60s, their adult children Maria and Dimitris, aged 32 and 28 respectively, and their 6-year-old daughter Elena. Mr. X is an engineer, while Mrs. X is a teacher. Maria and Dimitris have both completed university studies in business and IT, respectively, and are employed in their respective fields.

Research Procedure

The research process adhered to guidelines established in 2008 by the Greek Ministry of Education and Religions to conduct effective interviews. Consequently, researchers commenced by elucidating the interview's objective, confirming the confidentiality of personal data, and obtaining consent for recording the session. Subsequently, an initial rapport-building phase was initiated to establish a comfortable atmosphere for the interviewee. Following this, the core set of questions was introduced. Throughout the procedure, a serene ambiance was maintained to alleviate any potential interview-induced stress. Ultimately, the interview concluded with researchers expressing gratitude to the interviewee for their time and insights. The session lasted an hour and necessitated the physical presence of the participant. With explicit permission from the participant, comprehensive notes were compiled, and the interview was audio-recorded.

Data Collection

Five one-hour sessions were conducted at the participants' residence in a suitable and private setting, ensuring an uninterrupted exchange. The semi-structured interviews commenced with open-ended inquiries about the patient's emotions, experiences, and concerns related to the illness. The patient and a close family member were both present during the interviews. Audio recording was

utilized to faithfully capture spoken responses as well as emotional nuances. Additionally, demographic details and a family lineage were documented.

Data Analysis

Thematic analysis, a technique frequently employed in qualitative research, was utilized to uncover patterns within the data, particularly in less-explored domains. Unlike relying on preconceived concepts, this method allows participants' responses to guide the development of knowledge. The data analysis served as the foundation for nursing assessment and the formulation of a nursing care plan in accordance with the nursing process. This plan aims to identify current and anticipated needs or risks, while also serving as a means of communication among healthcare providers.

Validity and Reliability

Ensuring the research's validity and reliability necessitated evaluating the appropriateness of the approach for the research questions and engaging with other experts. Moreover, re-administering the interview with the same individual could yield similar results. Questions were meticulously constructed based on the research objectives and global literature. Credibility, transferability, reliability, and confirmability were assessed to ensure a rigorous investigation. These



attributes encompass consistency between the study approach and findings, generalizability, long-term stability of outcomes, and transparency of the research process.

Ethical Considerations

Ethical norms were diligently adhered to throughout the study. Participants provided written and verbal informed consent, confirming their willingness to participate. The researcher documented procedures during interviews through notes, photographs, and audio recordings, all with explicit participant consent. Participants were informed of their right to withdraw from the study at any point. Maintaining participants' anonymity was prioritized by emphasizing confidentiality and data protection.

RESULTS

Family X comprises five members: Mr. and Mrs. X, both in their 60s, their adult children Maria and Dimitris, aged 32 and 28 respectively, and their 6-year-old daughter Elena. Mr. X is an engineer, while Mrs. X is a teacher. Maria and Dimitris have both completed university studies in business and IT, respectively, and are employed in their respective fields.

Residential Environment and Lifestyle

The family resides in Athens, Greece, within a suburban neighborhood characterized by a

Mediterranean climate. Their diet predominantly adheres to traditional Greek cuisine, abundant in fruits, vegetables, fish, and olive oil—mirroring the dietary preferences of most Greek households. Their community is closely-knit, fostering a strong sense of belonging, and the family frequently engages in local events. Additionally, their active involvement in the local Orthodox Christian church guides their conduct based on the principles of compassion, unity, and respect. These values deeply influence interactions within and outside the family, shaping their worldview and significantly influencing their decision-making process.

Psychological and Social Environment

The X family exhibits a robust emotional bond, characterized by love, respect, and mutual support. Shared values and objectives are prevalent among family members. Prior research underscores the significance of these factors in managing chronic illnesses and attaining life satisfaction. Despite the emergence of Long COVID-19 within the family, an active social life has been maintained—both collectively and individually.

Communication within the Family

Effective communication prevails among family members, fostering emotional well-being and facilitating effective issue resolution. This trait has been pivotal in comprehending and addressing the needs of

the affected family member and adapting to the altered circumstances associated with Long COVID-19. This aligns with research indicating that collaborative problem-solving bolsters family resilience and health outcomes.

Way of Living

The X family places paramount importance on maintaining a healthy lifestyle. They adhere to a Mediterranean diet, engage in regular physical exercise, and undergo routine preventive health examinations, aligning with recommendations for promoting overall well-being. In response to the emergence of Long COVID-19 within their household, they have adapted their habits and overall lifestyle to accommodate the new circumstances, particularly to support the affected family member. Their adjustments encompass modified levels of physical activity, increased intervals of rest, and an enhanced dietary approach aimed at bolstering their immune systems.

Patient History

The principal challenge confronting the X family revolves around Mr. X encounter with Long COVID-19, which has profoundly impacted his quality of life and prompted changes in the daily routines and responsibilities of other family members. Mr. Papadopoulos contracted the virus in his workplace in July 2020. While exhibiting mild upper respiratory symptoms for the initial

twenty-four hours, his health rapidly deteriorated thereafter. Consequently, hospitalization was imperative, leading to subsequent ICU admission where he remained intubated for two weeks. Following a month-long hospital stay, he returned home visibly plagued by depression.

Chronic Symptoms and Their Management

Even three years subsequent to this ordeal, Mr. Papadopoulos continues to grapple with a range of symptoms typical of Long COVID-19 patients: persistent severe myalgias, fatigue, arrhythmias, intermittent severe cough, and shortness of breath. Addressing these symptoms, the family adheres to contemporary clinical recommendations encompassing adequate rest, a balanced diet, regular medical supervision, and moderate exercise within manageable thresholds. All family members have tailored their routines to create a supportive framework for the afflicted individual, necessitating the redistribution of roles and responsibilities within the family structure.

DISCUSSION

The psychological repercussions of Long COVID-19 on the X family are substantial. The sufferer endures the immediate psychological impact of the disease, grappling with uncertainty, apprehension, and fear—common emotional responses to the unpredictable trajectory of Long COVID-19,



shared by numerous patients²⁹. The myalgias and intense fatigue inherent to the condition impinge on his occupational performance and participation in family activities, consequently evoking sentiments of frustration and despondency.

Other family members have also felt the effects. Mrs. X contends with the stress and anxiety stemming from caring for a chronically ill loved one, a phenomenon extensively documented in the literature¹⁴. Maria and Dimitris assume active roles in caregiving and supporting their mother, taking on responsibilities formerly held by their father. This transition has induced alterations in their routines and elevated stress levels. Even Elena, the youngest member, is not immune, expressing concerns and confusion regarding her grandfather's condition.

The family's robust emotional bonds have been pivotal in addressing the challenges posed by Long COVID-19, augmenting resilience and adaptability as underscored by existing literature¹⁵. Effective communication and collaborative problem-solving were instrumental in their ability to acclimate to the novel reality, exemplifying flexibility in the face of change. This adaptive approach contributes positively to the family's health and resilience¹⁷.

The family's belief system, rooted in their Greek Orthodox faith, serves as a wellspring

of strength and optimism amidst uncertainty. Faith often serves as a vital resource for individuals and families during health crises²². The psychological impact of Long COVID-19, both on patients and their families, constitutes a burgeoning area of research. Studies underscore the emotional weight linked with the uncertainty and unpredictability of the condition²⁵, aligning with Mr. X experiences. The literature on the stress of caregiving for an ailing family member parallels the challenges faced by Mrs. X and her children²⁷.

The X family has a strong emotional relationship that is defined by love, respect, and mutual support. Shared ideals and goals are common among family members. Prior research has shown the importance of these elements in controlling chronic illnesses and achieving life happiness²⁴⁻²⁶.

Family members communicate effectively, which promotes emotional well-being and facilitates effective issue resolution. This feature has been critical in understanding and meeting the requirements of the affected family member, as well as adapting to the new circumstances brought on by Long COVID-19. This is consistent with research showing that collaborative problem-solving improves family resilience and health outcomes^{27,28}.

Assessment of the Family

The X family effectively navigates the challenges associated with Long COVID-19 within a supportive and collaborative familial context. Their resilience in the face of adversity is nurtured by robust emotional connections, effective communication, and shared values. However, the impact of Long COVID-19 introduces notable physical and psychological burdens, necessitating meticulous assessment and supportive interventions.

Mr. X's Medical Needs

Regular medical follow-up is essential for managing Mr. X's Long COVID-19 symptoms. While the family's lifestyle and dietary choices are generally health-conscious, potential adjustments should be considered to accommodate Mr. X fluctuating energy levels and evolving nutritional requirements.

Psychological Impact on the Family

Long COVID-19's psychological effects reverberate throughout the entire family. Mr. Papadopoulos contends with uncertainty and limitations brought about by his condition, while Mrs. X and the children shoulder the emotional weight of caregiving and concerns for their loved one's well-being.

Community Support and Connection

The family's ties to the community and robust social connections offer invaluable support. Nevertheless, evaluating the family's effective utilization of this network and potential

benefits from additional community resources is imperative.

Identification of Potential and Existing Issues

Mr. X Long COVID-19 symptoms are already being managed with adaptations to his activity levels. However, considering the unpredictable nature of the disease, further adjustments might be necessary.

The stress and emotional strain stemming from Long COVID-19 represent significant concerns. Prioritizing Mr. X emotional well-being is essential, as feelings of frustration, sadness, and uncertainty could potentially culminate in mental health disorders. The emotional toll on the entire family also warrants attention, given the potential risks to caregivers' well-being.

Alterations in family roles and dynamics, prompted by Long COVID-19, could potentially lead to conflicts or negative sentiments. While the family excels in communication and collaborative problem-solving, these dynamics might evolve under current pressures and emerging challenges.

Lastly, despite the family's strong community network, untapped resources may exist. Local organizations, support groups, or social services could offer additional assistance in practical matters, emotional support, or information.

Design and Implementation of Care Plan



A comprehensive care plan for the X family encompasses the following components.

- **Medical Monitoring:** Ensuring consistent medical evaluation for Mr. Papadopoulos, including tailored symptom management and recognition of potential changes.
- **Psychological Support:** Providing Mr. Papadopoulos access to psychological therapies like cognitive-behavioral therapy. Extending specialized interventions to other family members, such as stress management techniques and counseling sessions, is beneficial.
- **Family Dynamics:** Consideration of family therapy or counseling to address shifting dynamics, facilitate conflict resolution, and strengthen communication.
- **Community Engagement:** Encouraging more effective utilization of community resources, involving connecting with support groups, accessing practical assistance, and participating in community events.

Evaluation of the Care Plan

Evaluation of the care plan must be ongoing and adaptable to evolving family needs. Monitoring Mr. X symptom severity and frequency is crucial. Assessing strategies to manage family stress, emotional well-being, and overall family satisfaction should also be regular practices.

Observing family dynamics is essential, with attention to potential conflicts, changes in

communication patterns, and signs of strain within relationships. The family's interaction with community resources should also be evaluated, considering both the quantity and quality of their engagement.

Limitations and Challenges

Implementing this care plan may encounter several challenges and limitations. Access to necessary resources, such as psychological and non-caregiver support services, might be restricted. The family's willingness to participate in certain plan components, like psychological therapy, could also present obstacles.

Assessment of the Family

The unpredictable nature of Long COVID-19 could also present difficulties. The plan must be flexible and responsive to changes in Mr. X condition, which may require frequent adjustments and ongoing communication with healthcare providers.

Additionally, while the family's strong communication and problem-solving skills are important assets, they may be tested by the constant stress and uncertainty associated with Long COVID-19. Providing support in these areas while respecting family autonomy could be a delicate balance to maintain.

Overall, implementing this care plan requires a patient- and family-centered approach, taking into account the unique strengths and

weaknesses of the X family in their battle with Long COVID-19.

CONCLUSIONS

Learning from the X family's experience with Long COVID-19 has yielded valuable insights into the disease's impact on individuals and families. Like numerous families worldwide, the X family grapples with the challenges of a condition characterized by uncertainty and fluctuating symptoms.

The X family's resilience stems from robust emotional bonds, effective communication, and a cooperative approach to problem-solving. These qualities have bolstered their resilience as they navigate the effects of Long COVID-19. Nonetheless, the disease imposes significant physical and psychological burdens, warranting a comprehensive, multifaceted care plan.

The primary sufferer necessitates ongoing medical care and a tailored symptom management plan. The entire family could benefit from psychological support, given the emotional strain of Long COVID-19 and caregiving responsibilities. Proactive measures to uphold healthy family dynamics and promote effective use of community resources are equally vital components of the care plan.

Implementing and evaluating the care plan may encounter challenges, including resource limitations, reluctance to engage in certain

interventions, and the unpredictable nature of Long COVID-19. Nevertheless, an approach centered on the patient and family, while respecting their autonomy and capitalizing on their strengths, can facilitate the management of these challenges.

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