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Posted Date: 21 June 2023

doi: 10.20944/preprints202306.1434.v1

Keywords: chronic disease; self-management; elder patients; qualitative study doi:10.20944/preprints202306.1434.v1

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Abstract: Living with a chronic disease involves a variety of daily life limitations that severely affect people in their daily life. Identifying and promoting self-management strategies may improve health outcomes and increase patients' autonomy. The purpose of the present study was to explore the perceived limitations and self-management strategies of elder patients suffering from chronic diseases. An inductive content analysis was applied, with a purposive sampling of 21 patients living with chronic conditions. Data was collected through semi-structured interviews. Two main-categories were emerged from content analysis, namely "Limitations of daily life" and "Disease Management". Physical restrictions and negative feelings were referred to as daily burdens, while scheduling and self-care, supporting environment and technology were related to disease management. Information, training and provision of digital literacy may increase patients' self-efficacy in managing their chronic condition.

Keywords: chronic disease; self-management; elder patients; qualitative study

Introduction

In the 21st century, non-communicable diseases (NCDs) cause approximately 41 million deaths each year, equivalent to around 71% of all deaths globally [1]. According to the World Health Organization, although longevity increased globally by ≥6 years in 2019 on average, compared with 2000, only 5 of those additional years were lived in good health; people are living longer but with more disability [2]. Cardiovascular diseases, cancers, respiratory diseases, and diabetes account for over 80% of all premature NCD deaths in ages between 30 and 69 years [3]. The increasing burden of NCDs, such as chronic obstructive pulmonary disease (COPD), heart failure (HF) and diabetes mellitus type 2 (DM 2) has made their prevention and management a global priority. However, managing the needs of these long-term health conditions adds a substantial load to an already overstretched healthcare system that is struggling to cope with the demands of acute care, exacerbated by the COVID-19 pandemic [4].

In addition, chronic diseases may pose a variety of challenges in humans' lives by causing functional disabilities, life style changes and social and family restrains [5]. For example, COPD patients experience severe fatigue and higher rates of anxiety and depression while early-morning and night-time COPD symptoms result in deterioration of patients' quality of life [6–9]. This chronic condition has significant adverse effects on patients' physical status, as it is a common use of pneumonia, pulmonary hypertension, and cardiovascular disease. To a further extend, the patients' psychosocial well-being, the family relationships and the social life are severely challenged [10].

Similarly, patients suffering from other chronic conditions such as HF and DM2 appear to experience great physical and social problems, impairment, susceptibility to infection and impotence [11,12]. Reed et al., [13] referred to the complexity of the care and treatment, the number of health resources required and the high morbidity rates for individuals suffering from chronic conditions such as HF.

Self-management has been reported as a key factor for patients suffering from chronic conditions [10,14,15]. Self-management requires a dynamic, interactive, and daily process in which the individuals are engaged to better cope with chronic disease [16]. This process has several advantages for the chronic patients, as it leads to appropriate life style changes, improved capacity of managing the symptoms of the disease, reduced physical and psychosocial effects caused by the disease and better treatment [17]. Self-management behaviours may also help patients to slow down the progression of the disease and prevent hospitalizations, particularly during the stable period [18].

However, despite decades of evidence on the needs and the limitations experienced by the chronic patients and the benefits of self-management approach, these issues remain relatively under-utilized and under-investigated. Therefore, exploring the patients' views on perceived limitations, needs and self-management strategies of individuals suffering from chronic diseases, is one of the most important research priorities.

Aim

The aim of the present study was to explore the views on daily life limitations and self-management strategies of individuals suffering from chronic diseases.

Methodology

Design

A qualitative research design based on inductive content analysis approach was applied. Qualitative research methods are recommended for investigating human perceptions, feelings and experiences [19]. They are frequently used for exploring complex phenomena which are underexplored and praised for providing wealth of data and in depth understanding of the subjects under investigation [20]. Inductive content analysis is a systematic and objective method that can be used by the qualitative researcher to gain a thorough understanding of the data and to methodically reduce a big volume of textual data into a clear, short summary of key findings [20]. Utilisation of inductive content analysis is recommended when prior knowledge of the subject under investigation is limited or incomplete [21]. As such inductive content analysis was considered to be the best method for the current study.

Context and Participants

Individuals suffering from chronic conditions consisted the study population. In particular, the chronic diseases which were selected to be included in this specific study were those that according to the relevant literature cause major functional disabilities and require significant changes and adaptation in daily living. In this respect and considering the high prevalence rate and the severity of the chronic conditions, [1] patients with DM2, COPD and HF constituted the study population. A purposive sampling strategy was used to recruit potential participants. The outpatient's department of a tertiary general hospital (S1) and two rural health care centres (S2 and S3), within the region of Crete island were the involved study sites. Individuals ≥ 60 years old, living with DM2, COPD and HF for at least two years, were invited to participate in the study. This time frame was deemed crucial for the research participants to thoroughly discuss their experiences and perceptions on self-management strategies regarding their illness. Recruitment of study participants took place by two members of the research team who advertised the study via social media and within the involved Organisations' sites. Twenty-one individuals participated in the study. Demographic data of the participants are listed in Table 1.

Data Collection

Semi-structured interviews were conducted online for data collection purposes. When in-depth information on a person's experience is needed, this type of interview is recommended as, it enables the study participants to spontaneously and thoroughly respond to complex questions and to provide thus a plethora of information [22]. Interviews were carried face to face in a location selected by the participants. A researcher who was well educated in interviewing procedures, conducted all the interviews. Throughout the interviewing process the participants were encouraged to provide the most rich and complete information possible, while closed-ended or leading questions were avoided. The interview guide included one open-ended question that invited the participants to describe: *how it is living with DM2/COPD/HF*?

Additional open-ended questions were used whenever necessary focusing on the following issues:

1. Problems caused by the disease in daily life.
2. Ways of managing the disease.
4. Suggestions for better disease management.
5. Overall perceived assessment of the participant's quality of life.

Each interview lasted from 15 to 25 minutes. In total, 21 interviews were conducted. The "information power," technique which determines the sample size based on the sample specificity, the volume of data collected and the quality of the dialogue was followed to establish data saturation [23]. After completing each interview, data was converted into a textual format so that the analysis phase can be applied. For the purpose of accurately conveying the meaning of the text in the English language, a backward-translation technique was adopted [24].

Data Analysis

Following the model of Elo and Kyngas [25], three stages of the inductive content analysis approach—preparation, organisation, and reporting—were used in the current study. According to this model, words and sentences of the interviews' text were comprised the units of analysis. The context of the interviews was thoroughly examined, to obtain in depth understanding of the collected data. Further to this, main categories and subcategories were emerged through open coding and abstraction of data. Findings were reported in the form of participants' quotations. In this way research evidence was presented and substantiated with the most indicative text extracts.

Ethics

This study was a part of a broader research Project entitled "Empowered: Complete, smart personal autonomous living assistant for the elderly". This Project was approved and co - funded by the «RESEARCH - CREATE - INNOVATE» Operational Programme Competitiveness, Entrepreneurship and Innovation 2014-2020 (EPAnEK) (Ref. No 5070922/29-9-2020 and Ref. No approval from Hellenic Mediterranean University 74/θ.21/18.11/2020). For the present part of the research an informed consent form was signed before conducting each interview. Relevant information on participant anonymity and confidentiality was provided. The voluntary nature of the study and a participant's right to withdraw from the study at any time without any consequences were discussed. Before each interview, permission was granted by the participants for tape recording. Personal data were protected throughout the study, and code numbers were given to participants for preserving anonymity. Interview extracts were used in order to illustrate the presentation of the findings, without including any identifying information.

Credibility of Research

Analyst triangulation was one of the strategies used to ensure the trustworthiness of the study. A second analyst was engaged to review the findings of the study and to identify possible inconsistencies in terms of coding and category formulation. Furthermore, the involvement of the two analysts provided the opportunity to explore in detail potentially different views and concepts, to resolve divergences and improve thus the reliability of the findings. Reflexivity and reflexive notes were used by the researcher throughout the research process for exploring and acknowledging personal assumptions, biases and values, and identify how subjective responses and relationships with the study participants may influence the decision making throughout the research. COREQ guidelines were used to report our qualitative findings [26].

Findings

Twenty one (21) individuals suffering from with chronic health conditions such DM2 (No of participants: 7), COPD (No of participants: 6) and HF (No of participants: 8), participated in the present study. Participants' age ranged from 60 to 85 years. The vast majority of the participants were married, while half of them had relatively low level of education (below high school) and a poor or moderate financial status. On the scale of perceived knowledge regarding the disease, most scored above average, with six patients scoring excellent or almost excellent (grades 9 and 10) regardless of education level. Participants' demographics are listed in Table 1.

Table 1. Demographic characteristics of participants with Diabetes Mellitus (DM), Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure (HF).

Participants' code	Sex	Age	Marital status	Education	Financial status	Disease	Years since the first diagnosis	Perceived knowledge regarding the disease (from 1 to 10 – 1=none and 10= excellent)	Study Site
R1	Male	61	Single	University	Good	DM	6	9	S2
R2	Female	85	Married	High school	Poor	DM	40	7	S2
R3	Female	60	Married	University	Very good	DM	23	8	S1
R4	Female	75	Married	Primary school	Moderate	DM	15	1	S1
R5	Male	62	Married	University	Good	DM	6	6	S1
R6	Male	81	Married	Secondary school	Good	DM	20	7	S1
R7	Female	81	Married	Primary school	Good	DM	10	1	S3
R8	Male	76	Married	Primary school	Moderate	COPD	13	9	S3
R9	Female	84	Married	Primary school	Moderate	COPD	3	10	S1
R10	Male	85	Married	University	Moderate	COPD	20	7	S1
R11	Male	84	Married	Primary school	Good	COPD	18	5	S2
R12	Male	79	Married	Secondary school	Moderate	COPD	19	7	S1
R13	Female	61	Married	University	Moderate	COPD	7	7	S1

R14	Female	62	Married	University	Moderate	HF	5	9	S2
R15	Male	81	Married	Primary school	Good	HF	15	7	S1
R16	Female	79	Married	Primary school	Moderate	HF	19	9	S1
R17	Male	60	Married	Primary school	Poor	HF	10	7	S3
R18	Male	60	Married	High school	Poor	HF	20	6	S3
R19	Male	60	Married	High school	Poor	HF	10	6	S3
R20	Female	60	Divorced	University	Good	HF	5	6	S1
R21	Male	69	Married	High school	Good	HF	15	9	S2

The content analysis led to the formulation of two main categories, namely "Limitations of Daily Life" and "Disease Management". Five subcategories were formed and assigned respectively to each main category (Table 2).

Table 2. Main categories and subcategories.

MAIN CATEGORIES	**LIMITATIONS OF DAILY LIFE**	**DISEASE MANAGEMENT**
SUBCATEGORIES	1a. Physical Restrictions	2a. Daily planning and Self-Care
	1b. Negative Feelings	2b. Supportive Environment
		2c. Use of technology

1. LIMITATIONS OF DAILY LIFE

Individuals living with chronic health conditions reported a variety of problems caused by their disease and affecting their daily lives. Analysis of the data revealed two subcategories which were assimilated to the first main category namely: a) Physical restrictions and b) Negative feelings.

1a. Physical restrictions

In the first subcategory called "Physical Restrictions", the participants referred to the physical constraints that the chronic disease caused in their daily life. In particular, DM2 individuals reported restrictions on diet, mobility, family and work obligations (R6). Variations in their physical condition and abnormal blood sugar levels appear to greatly limit daily tasks and the ability of the individuals to cope with household activities (R7). Discomfort was caused by the lack of knowledge regarding the proper management of the disease symptoms at a daily basis (R2). The COPD participants referred to issues such as shortness of breath, continuous need of oxygen, restricted mobility and fatigue (R8, R9), while respondents suffering from HF reported that symptoms of the disease and constant fatigue due to the abnormal heart rate severely constrain their lives (R16). In addition to that, comorbidities seem to worsen the individuals' health status and limit their autonomy (R21).

1b. Negative feelings

Regarding the subcategory "Negative Feelings", the participants referred to fear, anxiety and stress as the dominant feelings experienced throughout the course of their disease.

These feelings are related to the symptoms caused by their health condition, the course of the chronic disease and its complications (R3). The lack of knowledge and skills regarding the management of the disease, the limitation of autonomy and the dependence on others seem to maximize the tension and the negative feelings experienced by the respondents (R2). Uncertainty, psychological burden and grief are caused by the bad physical condition and the severity of the illness (R20). The inability to sufficiently cope with professional responsibilities appear to cause additional stress for the chronic patients (R14) and deteriorate even more their physical condition. Participants seem to experience a continuous struggle and tension not only to cope with the activities of daily living, but to keep on living (R13).

2. *DISEASE MANAGEMENT*

The management of chronic diseases appeared to be a challenge for our participants. Issues involving daily scheduling, self-care, compliance and support were reported. The data analysis led to the formulation of three subcategories fitting under the main category, a) Planning and self-care, b) Supportive environment, and c) Use of technology.

2a. Daily planning and self-care

In the first sub-category called “Planning and self-care” the participants appeared to manage their disease by following a precise daily schedule regarding nutrition, exercise and medication. The concept of self-care was dominant in the participants’ reports (R3, R4). Compliance with medication and following the health providers’ instructions were mentioned by several participants as key-issues for managing their disease in the most appropriate way (R12, R14). By following these actions, the participants appeared to be able to satisfactorily manage their illness and control the symptoms arising from it (R15). Although proper nutrition, compliance with the treatment and communication with the doctor were praised in most cases, the need of more organised support and assistance for effectively managing the disease was also mentioned (R15, R18, R19).

2b. Supportive environment

In the second subcategory called "Supportive environment" the participants referred to the importance of the supportive environment in the effective management of their disease. Family and health professionals, seemed to be key-persons in supporting the individuals suffering from chronic conditions. (R1, R10, R11). Most of the participants seem to be satisfied with the way they manage their disease, while they appear to turn to their doctors for further advice and follow-up (R14). The need for extra support and provision of more specific information about disease management were highlighted by participants with deteriorating health and limited knowledge in managing their disease (R19, R20).

2c. Use of Technology

The participants referred to the use of technology as a means of disease management. Using simple devices, such as a blood pressure monitoring device or the pulse oximeter, for managing their disease and control their diet was mentioned in some cases (R7, R14, R8). Most of the study participants appeared though to be unfamiliar with the use of technology mainly due to a lack of appropriate infrastructure, knowledge and skills. In addition to that, participants of an older age and of a lower educational level do not use technology in managing their disease (R2, R16, R11). It appears though, that many participants use the internet to acquire information about issues related to their illness (R5) and that technology can play a supportive and facilitating role in disease management even at older ages, provided users are properly trained and familiar with the equivalent devices (R20).

Table 3. Indicative quotations from the participants’ interviews.

MAIN CATEGORIES	SUB CATEGORIES	Quotation	Participant
1. LIMITATIONS OF DAILY LIFE	1a. Physical Restrictions	*“I have high blood sugar and sometimes I get hypoglycaemia and this affect everything I do, my family life, my work, my diet”*	*R6*
		“When my blood sugar drops, I cannot walk around the house, I struggle with my daily household tasks”	*R7*
		“I have many problems; heart arrhythmias… it’s a daily burden…and I don’t know where all	*R2*

		these come from…I don't know how to handle that…"	
		"I cannot move fast…I cannot walk up and down the stairs, even getting out of bed is difficult. I have no strength at all..."	*R8*
		"… the oxygen (supply) is always on me, it doesn't come out at all… I am dependent on it and this causes irritation, shortness of breath, and when my heart is affected, the situation becomes more difficult..."	*R9*
		"When I'm very anxious or when I'm tired, my heart rate is affected. I can do the homework but I get tired…it takes me days to clean up the house, I cannot do it as a healthy person does…"	*R16*
		I have a lot of arrhythmias. Now I can't do anything. I can't take the car to go to the health center. I can't even take my medicines because I can't see…"	*R21*
	1b. Negative Feelings	*"The disease is very bad, everything is damaged... the eyes, the vessels, and as time goes by I get more anxious, weaker, I worry so much…I am afraid as my life is getting more difficult."*	*R3*
		"I'm afraid that I might get a hypoglycaemic shock and die. I'm afraid because I'm alone, I can't go anywhere, my children are not around… Most of the times I am not able to get the insulin properly. I don't know how to do it…"	*R2*
		"I can't walk… I can't go anywhere. Especially these days, it's so miserable… with the heat…I don't know if shall be alive tomorrow… I don't know if God let me live or die…"	*R20*
		When I'm upset my heartrate is increasing…it feels like someone punching me in the chest …I have these symptoms at work from the stress…"	*R14*
		"I struggle to walk... to live… I have the C pap all night… it's so difficult"	*R13*
2. DISEASE MANAGEMENT	2a. Daily planning and Self-Care	*"I take care of myself…I have a daily exercise programme, I walk a lot and I check my blood sugar levels several times per day…I am very careful with my diet and with medication"*	*R3*
		"I take my medication, twice a day. I check my blood sugar regularly, morning, noon and night… I strictly follow my programme…"	*R4*
		"I take 18, 19 tablets every day. 8 in the morning, 6 in the afternoon and 3 in the evening. I have a notebook and I keep track of my symptoms every day."	*R12*
		"I check my pulses with the sphygmomanometer and take my medicine. I watch my diet. I	*R14*

		generally feel safe on how I manage the situation because I seek my doctor's advice very often. "	
		"I take half my tablets in the morning and in the evening and I control my heart rate. I also take blood pressure pills and I am very cautious with my diet"	*R15*
		"I take my medication, I watch my diet, I don't exercise… but I am fine with it"	*R18*
		"I take my medicines … I watch my diet… we are trying with the doctors to cope with it...I would like though to get some more help"	*R19*
	2b. Supportive Environment	*"My wife and the children support me along with the doctors. Everyone helps as much as they can."*	*R1*
		"The doctor helped me … he gave me an oxygen device and when I get tired I use this device and that helps a lot…. My wife has her own problems but one helps the other."	*R11*
		"I am fine because I have my doctor and often turn to him for further advice".	*R14*
		"…my wife helps me. She has quit her job to take care of me. I am lucky to have my wife".	*R10*
		"Every two or three months I have follow up visits with my doctor… this helps me to manage my condition"	*R17*
		"It would be helpful, if I had more information about my condition and how to manage it as the years go by..."	*R20*
		"I would like more instructions and advice on how to manage my health."	*R19*
	3b. Use of technology	*"I use a device that tells me what to eat, what to do. I use it 3 times a week"*	*R7*
		"I use a blood pressure monitoring device ... I don't use technology extensively...I am not familiar with it."	*R14*
		"I only use the pulse oximeter. Apart from that, I get help and information from others."	*R8*
		"I am not familiar with it; I don't want it. I don't want to use it…it's too much effort… I even gave up on my cell phone. I use only the glucose monitoring device…this is enough for me."	*R2*
		"The truth is that I don't know a lot about these devices...I would like however to learn how I can use them…"	*R20*
		"I don't know how to use these devices… I am not familiar to these…"	*R11*
		"I do not use technology…I cannot use it here in the village"	*R16*
		"I search on the web, mostly about the effects of diabetes in health … just to be informed. When I	*R5*

	don't have anything else to do, I get some information from the internet…"

Discussion

The findings of the present study revealed that people living with chronic health conditions face serious restrictions as they suffer from a variety of problems caused by their disease and severely affect their daily lives.

More specifically, physical restrictions were associated to individuals' dietary habits, mobility, shortness of breath, dyspnoea, permanent use of oxygen devise, abnormal heart rate and fatigue. In addition, the participants referred to the negative feelings experienced due to their chronic illness such as stress, anxiety and fear. The inability to effectively manage their disease and to cope with family and professional obligations were also mentioned.

Research evidence at an international level, agrees with the results of the present study, emphasizing on the impact in patients' daily lives and how this leads to poor quality of life [27]. Sevilla-Cazes et al., [28], stated that people with HF experience negative emotions of hopelessness, frustration and restricted functional status, leading to despair and impairment. Furthermore, HF individuals referred to social and family destruction, fear of dying, sadness and depression [29], while others said that living with a chronic disease such as COPD meant coping with fear, lack of knowledge about the disease and loss of freedom at multiple levels [10].

Similarly, the involvement of healthcare professionals in self-management education was praised as reducing patients' anxiety and supporting successful adaptation to the disease [30]. Understanding the disease, managing symptoms and medication, independence, upholding family and social life and living positively are referred to as support needs and coping strategies to effectively manage the chronic illness [31,32].

In our study, management of the chronic disease, was closely related to daily planning and self-care, supportive environment and use of technology. More specifically, following a precise daily schedule including diet, exercise, medication and doctors' instructions was mentioned as an assisting mechanism for disease management. Even more, family and health professionals, were referred as the key persons in supporting the individuals suffering from chronic conditions.

Similar results are reported in the relevant literature, stating that family's and health professionals' support is crucial for the patients' adaptations in life changes due to the disease. Understanding how patients perceive the disease and how they manage their health condition is a key action for health professionals, in order to develop personalized health care plans and relevant training programmes [10,31,33–35].

Bernhard et al. [36], report that self-management strategies for individuals with chronic conditions should involve community health care services, social and online resources, and enhanced personal responsibility. The need of educating patients concerning early recognition of disease symptoms and complication is also stated.

Furthermore, developing a self-management support system with the patient-physician collaboration may enhance the individuals' ability to cope with their health problems at a daily basis [37,38]. Emotional support and encouragement, empowerment and independence, an organized daily life and support of family and health professionals at a community level, are considered important dimensions for self-care and for improving the quality of life of patients with chronic diseases [39–41].

Finally, in the present study, the use of technology in disease management seemed to be deteriorated due to the lack of familiarity, knowledge and skills and the old age of the participants. These inhibiting factors were also observed in various other studies, reflecting that the limited knowledge and skills along with aging deteriorate the use of technology in managing the chronic disease and restrict thus self-management strategies for persons with chronic diseases [28,30,31,42].

Despite that, relevant research evidence demonstrates that specific groups of patients (DM and HF) seem to be more familiar with the use of information technologies, such as mobile phones' applications to support self-management and empowered strategies. Those patients held positive attitudes towards using IT for managing their disease and appeared to have high levels of self-efficiency. Relevant studies reveal that technology acts as a safety net for detecting errors, collecting information and managing the disease in an optimal manner [42–49].

Even more, the use of technology by individuals with chronic conditions may assist in changing behavioural patterns, self-regulation of emotions such as anxiety and uncertainty, rehabilitation process, communication with health professionals and promotion of self-awareness [50–53].

Buildings self-care capacities for individuals with chronic diseases is related to improved outcomes and better quality of life [54]. Patient education, information and knowledge are capacities that may alter the patients' behaviour, increase psychological resilience and enhance adherence with treatment process [55]. To a further extent, provision of digital literacy through education, training and community-based support may increase patients' self-efficacy in managing their disease in a more autonomous and efficient manner [56].

Limitations of the study

Participation of chronic patients living in a certain geographical area may consist a study limitation. Furthermore, as the involved participants came mainly from rural provinces, our findings should be interpreted through this limitation. In addition, the culture related to family structure in these areas, which may differ in terms of cohesion from urban areas, should be also considered. The difficulty regarding the technological infrastructure may also be another limitation of our study. Further research in a similar population living in wider geographical areas and in urban areas would enrich the knowledge on the subject under investigation.

Conclusion

Individuals living with chronic conditions consist a vulnerable population group requiring specialized treatment and care. Quality care and empowerment interventions for this population are extremely important for improving their health status and maintain quality of life. Adopting self-management strategies may reduce the limitations of daily life that these people experience and provide an opportunity to obtain a more autonomous life style. Support from health professionals and utilisation of information technology appear to have a positive effect on the empowerment and independent living of people suffering from chronic conditions. However, relevant interventions, for being effective, should be adapted to the needs of the patients and the context in which they live. Tailor-made training, targeted information and organised support from the health care team at the primary level are considered essential factors for empowering these population groups. Further research is recommended aiming at monitoring and investigating the needs of these patients in relation to the use of information technology and developing fitting strategies for self-management and independent living.

Author Contributions: Conceptualization, M.R., A.S. Al.D. and S.K.; methodology, S.K., A.S. and N.R.; validation, Ar.K., A.P. and G.T.; formal analysis, A.T. and G.V.; investigation, A.T.; resources, An.D. and D.K.; data curation, S.K., N.R. and A.S.; writing—original draft preparation, A.S., N.R.; writing—review and editing, M.R., E.T., A.P. and E.K.; visualization, Ar.K.; supervision, M.R., S.K. and A.S.; project administration, Al.D., Ar.K., and M.R.; funding acquisition, Al.D. and M.R.; All authors have read and agreed to the published version of the manuscript.

Funding: This research has been co-financed by the European Regional Development Fund of the European Union and Greek national funds through the Operational Program Competitiveness, Entrepreneurship and Innovation, under the call RESEARCH – CREATE – INNOVATE (project code: T2EDK-00586).

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the Hellenic Mediterranean University Ref. No. of approval 74/θ.21/18.11/2020).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Data generated during the present study are not able to be shared due to issues of subjects’ privacy and confidentiality.

Acknowledgments: Sincere gratitude should be expressed to all participants in this research study.

Conflicts of Interest: The authors declare no conflict of interest.

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