COVID

Review

COVID-19 Pandemic: Brief Overview of the Consequences on Family Informal Caregiving

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Abstract: Background and aim of the work: The COVID-19 pandemic has deeply affected the quality of people's social life, strongly impacting family dynamics, too, not only in the harshest periods of the pandemic but also afterwards. Pandemic-related measures led to a 'stay-at-home' approach that increased the mental and physical burdens of family caregivers, irrespective of whether they were living together with the person they were caring for or not. In this paper, we provide an overview of the impact that the COVID-19 pandemic had on family relationships and dynamics, as well as on family caregivers' mental burden, and outline how this developed. Methods: We collected relevant info by searching the PubMed/Medline database with appropriate keywords. The search was performed up to 28 February 2023. This paper is reported in line with PRISMA guidance. Results: Given the recent onset of the issue, the number of relevant papers was limited. However, the additional burden that the pandemic has caused worldwide to informal caregivers clearly emerges. Conclusions: The worldwide impact of the pandemic on informal caregiving is assessed, and recommendations on how the issue can be handled are briefly sketched, too.

Keywords: home caregiving; long COVID caregiving; COVID-19 impact; carer

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Citation: Serafini, A.; Peralta, G.; Martucci, P.; Tagliaferro, A.; Hutchinson, A.; Barbetta, C. COVID-19 Pandemic: Brief Overview of the Consequences on Family Informal Caregiving. *COVID* **2023**, *3*, 381–391. https://doi.org/10.3390/covid3030028

Academic Editors: Letizia Materassi, Andrea Guazzini, Mirko Duradoni, Guglielmo Bonaccorsi and Chiara Lorini

Received: 5 February 2023
Revised: 7 March 2023
Accepted: 9 March 2023
Published: 11 March 2023

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1. Introduction

Over the past decades, family organization has radically altered. Technological and societal changes led to new models of cohabitation and living, with more focus on individuals and less on families. At the same time, new achievements of medicine led to an increase in the number of people to be taken care of, both the elderly and those affected by chronic diseases. The caregiver, i.e., the one who takes care, is a family member who free of charge, and by virtue of the emotional bond that binds him/her to the cared person, takes care of and assists in the daily life of a sick or/and disabled relative who is not self-sufficient on a part-time or full-time basis.

Taking care of a family member is a multifaceted issue that involves the well-being of the family caregiver, support from other family members, budget issues and good quality private and public services. Finally, although the sacrifice of the individual for the well-being of the beloved is highly valued, the burden on the caregiver is often overlooked in society. Non-remunerated caregivers have always been the backbone of long-term home caregiving in chronic diseases. In summary, caring for a family member requires the caregiver to have an ability to adapt which is far more challenging than in previous decades when the social structures were more secure, and the pandemic has added to this distress. The last available reports before the COVID-19 pandemic show that roughly

9% (approx. 5 million) of the adults in the United Kingdom and almost 16% (approx. 40 million) of the adults in USA benefited from unpaid care [1,2]. In Europe (data from 2018), the amount of people over 18 years of age providing informal care at least once a week ranged prior to the pandemic from 10% in Romania to 30% in Greece [3]. Caregivers have become more and more involved in providing care, leading to define a few items as compulsory for their well-being: recognition of their role, financial support, health and well-being, information, work, and formation [4]. Social and family dynamics have been deeply affected and even shattered by the COVID-19 pandemic. The sudden emergence of the pandemic has added a huge strain for patients and families as physiological aging and need of care required a balancing between biological risk and care. The COVID-19 pandemic turned out to be a worldwide tragedy like other dreadful events affecting the human species, either self-inflicted such as world wars and genocides or inflicted by nature such as earthquakes, tsunami, and pandemics. However, because of the sudden spread of the pandemic and of today's interconnected world, the consequences have been far more impactful on our lives. This is even more true for developed countries that have been safe from wars and genocides since the second world war.

The impact of the pandemic on the social and family structures has been multifaceted because of the widespread diffusion of the virus and the real-time worldwide news. A huge number of people died, and the survivors of the disease are still affected physically, mentally and in their relationships, and many of them have yet to fully recover because of long COVID. Before large-scale vaccinations became available for medical care, economies and social life were deeply affected. Medicine, nowadays heading toward a personalized approach, had the main objective of protecting the community and not the individual during the pandemic [5]. Huge limitations to social interaction and mobility were set in place, also affecting economies, and leading to a shrinkage in the Gross National Product of most countries.

Relational dynamics of individuals and families have been deeply affected as well. Those family members who had the role of caregivers were forced to face a dilemma: was it possible to maintain the same level of caregiving while avoiding transmitting the virus and putting their own life and the life of the cared person in danger? To tackle this new communication, tools were used, leading to a different dynamic in the relations between people and their family caregivers, where caregiving in person was prevented. The need for increased support for caregivers was not met as the pandemic led to the reduction or even closure of support services for them, increasing their isolation, feelings of abandonment and stress [6]. Economic issues often became relevant, and the overall burden worsened caregiver quality of life and eventually led a number of them toward depression. In particular, as the age of the cared one increases, the weight and responsibilities of a family caregiver of an elderly person will consequently increase. The health, well-being and daily life of closely related people who take on a great deal of responsibility can be significantly impacted.

Given all preceding considerations, we realized that the issue of how family caregiving needs to be adapted to the post-pandemic era is of critical relevance in post-pandemic societies worldwide. We carried out the present review on how the pandemic affected family caregiving dynamics, and the review provides an outline for future social and caregiving scenarios.

2. Methods

This review is focused on providing a brief overview of the issue and to show that the issue is a worldwide one. As our aim was to show the worldwide relevance of the issue and the main features of the problem, in the present report, we focused on providing a broad perspective and not a local in-depth analysis. We were looking for the most relevant papers; hence, we limited our search to the richest database in the field, i.e., PubMed/Medline. Several keywords were used either alone or in combination, such as: carers, distress, lockdown, pandemic, relatives, restrictions, fear, and COVID-19. In addition, we scavenged

the internet with search engines to find reports of interest that were not available through the database. The last search was carried out on 28 February 2023. Through PubMed, we found 270 citations. In total, 141 of them were excluded because they were dealing with subjects not of interest (nursing homes, telemedicine, professional caregivers . . .) or because more recent papers dealing with the same subject from the same perspective (country and pathology) were available. From the remaining 129, we selected a subset of 25 (reported below) which were instrumental to highlight how worldwide the issue is and to describe the difficulties of family carergivers. Among the remaining, we selected the 30 that more exhaustively cover the various aspects of the issue in order to provide a complete overview.

In order to provide a comparison with the situation of caregivers prior to the pandemic, we carried out a search with similar keywords, obviously excluding those pandemic-related. However, as the scope of the present paper is focused on the pandemic effect, we reported on just a few of such papers to allow a meaningful comparison.

3. COVID-19 and Family Caregiving

Family caregivers are a fundamental pillar of every National Health Service. Family caregivers are "family members, friends and neighbors who look after others who need help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support" [6]. Nowadays, family caregivers provide from 70 to 90% of the care required by children or by adults that are not hosted in dedicated residences and are affected by chronic conditions or frailty [7]. Despite the social relevance of caregivers, an increasing number of caregivers find it more and more difficult to carry out their tasks, as providing care affects the caregiver's health and well-being (depression, anxiety, restrictions to social life), and addressing such issues has not been among the priorities of health systems [7]. Nevertheless, a strong call for governments to improve support for family caregivers from all points of view (financial, practical, emotional) has been issued [8,9]. The pandemic has in fact heavily affected caregivers as their physical and mental resources were drained and their social and personal lives weakened because of an increase in distress and isolation.

The world has faced the pandemic in an adaptative way. In Europe's 'stay-at-home' policies, physical distancing and travel restrictions were implemented [10]. Such policies, aimed at reducing the spread of the virus, have heavily impacted social relationships and family dynamics. The first national lockdowns led to an increased burden and subsequent distress for family caregivers [9]. The stay-at-home policy led family caregivers to reduce face-to-face interactions, whilst the need for social distancing led to the closure of day centers and respite facilities leaving family caregivers on their own. In addition to pre-pandemic caregiving, many people were forced to become an almost overnight caregiver for their beloved with no training. In a framework of social disruption, the anguish related to the pandemic was amplified by the fear of inadequacy and of transmitting the virus to their beloved. Technology was used to overcome at least partially the social distancing and keep in contact with loved ones. However, while smartphone use and acceptance were widespread, the negative correlation of computer use with age restricted its impact [11]. Travel restrictions and 'stay-at-home' policies made migrant care workers unable to carry on their domiciliary care work, heavily impacting their incomes [12].

Such issues are not limited to a few countries, but are worldwide ones as the COVID-19 pandemic had a disrupting worldwide impact. We quote here a number of papers (one per country) to witness how widespread the feeling is that there is a need to counter the impact that the pandemic had on the mental status of the caregivers. Reports came from the Americas (Bolivia [13], Brazil [14], Canada [15], Chile [16], Latin America [17], USA [18]), Africa (Kenya [19], Nigeria [20]), Asia (China [21], Hong Kong [22], India [23], Japan [24], Malaysia [25], Palestine [26], Taiwan [27]), and Europe (Finland [28], Germany [29], Greece [30], Italy [31], Netherland [32], Poland [33], Serbia [34], Spain [35], Turkey [36], UK [37]). Although caregiving for many different pathologies was investigated (diabetes [14],

stroke [21], nephritis [23], cancer [29,31,32], SLA [35]), the main focus in the literature has been on caregivers providing care to children with mental disorders [13,15,19,26,27,34,36] and old people with pathologies such as dementia [16,18,20,22,28,30,33].

Despite these growing issues, the focus of the media and governments during the pandemic was on the spread of the virus, the increasing casualties and on the urgent need to develop new drugs and vaccines. Only marginal attention was devoted to the impact of the pandemic on families and on caregivers, even though they were more and more prone to many problems: anxiety, sleep disturbances, weight gain, distress/stress due to caregiving, increase in alcohol drinking, and struggle to access social support. Family caregivers have been affected not only by governmental policies that have limited their caring activities as described above but also by the fear and anxiety of being infected by the virus or transmitting it to their beloved. In the United Kingdom, social isolation increased, and routine activities have been disrupted, leading to tough challenges for caregivers. In total, 72% of them stated that their mental health worsened because of the lack of a break from caregiving and 78% reported high levels of fatigue and exhaustion [4]. About one-third of caregivers felt unable to handle their caregiving role, and only 14% had faith that the external support available before the pandemic would be provided in the future [4]. A study focused on caregivers reported how necessary it was to provide timely information and advice on the handling of the funerals during the pandemic [38].

Several issues are responsible for the increased stress on caregivers due to the pandemic: reduced support network, social isolation, increased daily challenges, lack of information, and concerns for their own health and well-being [39]. However, it has been recently pointed out that the impact of COVID-19 pandemic on family caregivers has been largely overlooked [4]. Issues such as the limited or even non-existent access to health services, hospitals and medical clinics forced people to become overnight caregivers and provide home care to people affected by COVID-19. In most cases, the caregivers were close family members [40]. Although non-professional caregivers were widespread in society, the impact of the COVID-19 pandemic on their experiences and health have attracted little interest [41]. Very little information is available about the impact of the pandemic on caregivers, and therefore, the most effective measures to support them are yet to be defined.

The levels of stress and the burden due to providing care for family members and caregivers have increased considerably, and it has often been necessary to resort to therapeutic adaptations such as the use and abuse of benzodiazepines to manage anxiety, which is not always in agreement and synergy with the doctors. Among the causes of such a situation are the changes in daily routines of life, the impossibility of resorting to strategies to control behavioral manifestations of stress by appropriate actions (e.g., going out for a walk), and the prolonged isolation imposed by the pandemic. It has been highlighted, however, that family caregivers have been more heavily negatively affected by the pandemic than non-caregivers. They were in fact more likely to take extra precautions to avoid becoming sick or infecting their beloved. They were also more likely than non-caregivers to experience social isolation, anxiety and depression, fatigue, sleep disturbances and financial hardship. Family and friends who provide regular care for a sick or dependent individual ("caregivers") are at increased risk of health-related socioeconomic vulnerabilities (HRSVs). The pandemic increased risk of incident and worsening in HRSVs among women caregivers compared with non-caregivers [42]. According to caregivers, the pandemic has increased their responsibilities and made caring more difficult emotionally, physically, and financially. This was largely due to the disruption in access to care for both them and their beloved, and the resulting lifestyle adjustments have led to the reported increases in worry, fear, depression, and anxiety [43].

The comparison of the brief summaries of two surveys carried out in Perou (Table 1, [40]) and in Italy (Table 2, [44]) clearly show, as outlined above, that the impact of the pandemic on family caregiving is a worldwide issue, irrespective of economical wealth and social habits.

Table 1. Summary of the outcome of the survey carried out in Perou [40].

Gender	76.3% females
Location	50.8% in the capital (Lima)
Level of education	74% high
Vaccinated against COVID	84.8%
Stable work	83.6%
Stable familiar ties	56% married, 56.2% with kids
Reported quality-of-life	80.1% poor
Psychological well-being	82.7% poor
Reported depression	86.4% mild, 13% severe

Table 2. Summary of the outcome of the 'Caregivers after the pandemic' survey carried out in northern Italy [44].

Gender	85% females (age average: 57 y)
Job issues	6% lost the job, 1/4 reduced working hours or suspended activity
Additional burden	45% of caregivers had an increase in their workload, 52% an increased need for support
Lacking info	88% of the caregivers look for proper info and training on how to assist a person in distress
Lacking support	73% ask for services delivering home support
Psychological aid	51% is looking for a psychological support at home

The European Social Survey [45] has collected data from 20 countries, reporting that 34.3% of the adults of age between 25 and 75 have provided care, some of them (7.6%) for more than 11 hours per week. In all European Union countries, the vast majority of family caregivers are females, even in those countries in which gender parity is more rooted in the social life such as Sweden and the UK. Most female caregivers are in the age group 50–59 years. Females have a 33% larger probability of being involved in caregiving and a 60% larger likelihood of providing care for more than 11 hours per week [42]. This caregiving is provided in addition to other responsibilities at family and working levels, despite the warning issued by the United Nations that the ability of women to run multiple roles is not without limits and therefore promoting gender equality among the Sustainable Development Goals [46]. The COVID-19 pandemic has enlarged the disparity between females and males in family caregiving [29]. We can easily imagine how much the difficulties for these women have increased during the various phases of the COVID-19 pandemic: they have continued to take care of their loved ones despite the closure of daily care centers, rehabilitation facilities, the complex situations of nursing homes and the interruption of relationships, working without babysitters or supporting caregivers. The problems to be faced hugely increased during the pandemic and especially during the various lockdowns, with no previous experience to support choices. In Italy, the "Time to Care" project underlined how their situation needs attention and support. The study included 100 caregivers, 85% females (age average: 57 y). Analysis of job issues showed that 6% lost their job, while about 25% of sample reduced working hours or suspended activity in order to provide care. It is notable that 88% of caregivers, having to switch from daily working activities to care without having a proper training, performed personal research to address daily issues. Home support requests also increased up to 73% compared to the pre-pandemic period. The overall increased burden is stigmatized by a 51% increase in requests for psychological support. Overall data of this survey demonstrate that during the lockdown and pandemic periods, the caregivers would have certainly needed more

support and help to overcome difficulties whose perceived load increased day by day. The situation relating to the support needed by caregivers is currently underestimated, and an intervention by legislators in this regard and greater awareness on the part of the entire community in recognizing the utility and importance of the caregiver role is desirable.

4. Long COVID Caregiving

About one-quarter of those affected by COVID-19 still have symptoms after one month, and one-tenth has yet to fully recover after 12 weeks [47]. This debilitating status is known as either "long COVID" or "post-COVID syndrome" and patients affected by it are termed COVID-19 long haulers [48]. Long COVID has an impact on the ability of patients to recover their pre-disease lifestyle. Difficulties arise in tackling duties connected to work and school. Social life is also heavily affected, and long COVID impacts on the economy of families and society [49]. The clinical picture is diverse among the patients, as up to 200 different symptoms have been reported, including: fatigue, chest pain, headache, dyspnea, anosmia, fever, brain fog and tachycardia. Long COVID patients often require caregiving, which is provided by family caregivers, and yet long COVID caregiving support is still not considered as an issue by many health services. Patients may find it difficult to reconnect with their families or friends during and after the trauma of their illness. Many of these patients have experienced the stigma of having tested positive or may have missed funerals while isolated or hospitalized. They may also struggle with survivor's guilt or guilt about infecting other people. An illness such as long COVID can also intensify existing problems within families. In recent years there have been numerous cases of people who, after recovering from COVID-19, have found the continuation of different health problems, even after some time. In many cases, these are disorders that can prevent the person who suffers them from returning to normal daily life. Long COVID affects not only medicine and science but all spheres of society: the COVID-19 pandemic has created an extended period of disruption in peoples' lives and has resulted in long-term changes in everyday life [50].

A limited number of published studies have focused on the quality of life of caregivers of long COVID patients despite their pivotal role in tackling the heavy limitations that long COVID places on patients' lives. Caring for a long COVID patient is stressful for caregivers due to (i) the continuous feeling of inadequacy, (ii) the uncertainty for the evolution of the disease, still largely unknown, and (iii) the daily fatigue, due to the depressive symptomatology and physical limitations [8]. Therefore, the family dynamic is altered, hindering the ability to handle crisis and conflicts and even reducing the ability to provide emotional support and care. A cross-sectional study was carried out in Peru involving 730 family caregivers who had a high level of education, were largely vaccinated against COVID-19, had stable work and insurance, and stable familial ties. Nevertheless, the vast majority reported poor quality of life (80.1%) and poor psychological (82.7%) and spiritual (61.7%) well-being. Over 85% of the family caregivers reported mild depression, and over one in ten reported severe depression [40].

While numerous scientists around the world are at work searching for the causes of and possible remedies for long COVID, little has been achieved to guarantee support and assistance to those who live with this syndrome, including those who care for them and who find it difficult to carry out the normal daily activities. Long COVID impacts many adults and not only children and the elderly, who are considered weaker and therefore more vulnerable in the face of disorders related to the disease. In some sense, their situation is more critical, as being of working age, they risk losing their productivity due to long COVID. Psychologists could help people with long COVID manage better and also help caregivers protect their family relationships and avoid their caregiving role interrupting their roles as spouse, child, parent, and sibling.

5. Discussion and Recommendations

The COVID-19 pandemic has shed a harsh light on the need for strong healthcare systems and on what may happen when they are institutionally and, more broadly, societally

neglected. In Western countries (Europe, Northern America), caregivers play a key role in the society. This role is however often downplayed, because caregiving is so widespread and yet barely visible as it is almost always conducted in house, and as such, it becomes almost invisible at the society level. In such a framework, figuring out what is best to do for caregivers' day-to-day well-being is a significant effort. What it is like to be a caregiver and take care of someone else? What is their actual subjective experience, and how does actual practice differ in terms of prescriptions? What can constitute a phenomenology of care beyond the specificities of the different professions [51]? The COVID-19 pandemic has increased the need for long-term health care, evidencing and exacerbating the problems of the home care provided by non-professional caregivers (most of them family caregivers). However, the focus has been on people living and working in nursing homes that have been plagued by an abnormal death toll, and there is currently very limited knowledge of the impact of the pandemic on family dynamics and caregivers. This has hindered the development of appropriate policies to tackle such issues, despite the problem of family caregivers being a widespread and sensitive one that was critical even before the onset of the pandemic. Family caregivers were burdened by the responsibility of providing proper care, by the fear about their own health and by economic issues.

The COVID-19 pandemic has heavily impacted all aspects of our lives, including family caregiving. Many caregivers that were already providing care have been forced to act in person, boosting their unease and distress. Others were overnight obliged to become family caregivers, which is a role to be played without previous training. The COVID-19 pandemic has highlighted the need to recognize the lack of autonomy in self caring as a social risk, urging the governments to recognize the rights of such people, encompassing the Long-Term Care (LTC) in the health services. This will consequently reduce the burden, stress, and distress of family and informal caregivers. This is even more necessary as the pandemic has highlighted the pre-existing limits of social welfare services all around Europe. LTC Services must refocus and reorganize to provide proper support to informal and family caregivers focused to properly train them and provide them with an appropriate continuous support. This will limit their caregiving burden, reduce their psychological burnout and limit the impact on their health and well-being. As far as Long COVID is concerned, the support to family caregivers by LTC services is even more critical, as the disease is not yet fully understood and there might be a need to tailor the care to the individual affected. As empathy from the caregiver plays a pivotal role in patient recovery, providing proper support focused on promoting family caregivers' emotional and psychological well-being and improving their quality-of-life is fundamental. The experience acquired about family caregiving during the pandemic should lead to an improved approach to home care by healthcare professionals. Most healthcare professionals receive both initial theoretical and practical education (internships, simulations, etc.), and many of them undergo further training throughout their careers. However, more often than not, there is little room for gaining lived experience in care situations, whether it is the experience of the patient or that of the caregiver. Anthropologist Byron Good has examined how caregivers welcome (or not) the patient experience [51]: caregivers often understand the psychological impact of the illness (such as frustration, disappointment and stress) and the accompanying medical explanations. His work on teaching health professionals shows how medical students at the university develop their listening styles, particularly with respect to patient voices and illness narratives, and their attitudes over the years.

Educating healthcare professionals to provide caregiver-centered care is a practical first step in creating a new support system for caregivers through defined and agreed care trajectories. Involving multi-level stakeholders in the educational co-design process can help ensure that the care offered by healthcare professionals is relevant and useful for family caregivers. Regarding the transfer of technical and assistance information that occurs between the professionals and the caregivers, it must be premised that each situation and each person is different from others; therefore, training, even if it follows a standardized line, must be tailored to individuals according to the needs of the persons to whom it is

delivered. A specialized training and a personalized education about caregiving will allow healthcare professionals to achieve a more efficient and effective therapeutic support for each patient and lessen the psychological and mental burden of caregivers.

Another action to be considered concerns the remote support through telehealth and telemedicine systems. Many families were forced to try telehealth for the first time, and they reported positive experiences [52]. This suggest that developing telehealth services, beside minimizing possible disruptions in the event of future emergencies, can provide a timely support to caregivers in difficulty.

Even for the caregivers, illness always entails a loss: the loss of what one was, of what one could do, of what one could still live. Listening to the caregiver's narration of his daily life allows a healthcare professional to collect not only the patient's clinical state but also his sadness, fears and how much these emotional aspects affect the caregiver's state of mind. Therefore, psychoeducational and psychosocial interventions aimed at caregivers are needed to promote an increase in assistance-related skills and contribute to a general improvement in the quality of life of the patient–caregiver team. Telephone interventions and the use of technological devices (e.g., remote monitoring apps) have proven effective in reducing doctor visits and hospitalization. They have shown promising results in promoting knowledge and facilitating the process of home care. The world currently experiences uncertainty about the duration of the COVID-19 pandemic, and its effect on the quality of life of caregivers of patients with disabilities has yet to be understood. The extensive use of technology in this pandemic period must be accompanied by knowledge of the barriers to its use. Identifying and addressing technological barriers will unlock the potential of this modality, both for social connection and for access to supportive resources. Indeed, technology provides real care in the form of telehealth and other assistive technologies. Creating user-friendly guides on the use of technology for different applications could facilitate the use of the platforms and different devices suitable for this type of user.

There is a need for the implementation of patient-centered care, which is a multi-stage process in which healthcare professionals must be integrated. The first step is to ensure that the caregiver, together with the patient, understands the patient's state of health: diagnosis and prognosis, both in the sense of limited life expectancy and as well in the direction of the expected progression. In this path, palliative management must also be well understood according to the modern definition of Simultaneous Care from diagnosis to the "end stage" with "remodulation of care" for the well-being of the patient [53].

6. Conclusions

Under ordinary circumstances, caring is an intense, complex, and potentially stressful undertaking. The pandemic has made an already difficult situation even more complex to handle. There is a worldwide perception that the burden of caregivers has been increased by the pandemic and that new approaches to support the caregivers must be developed, including exploiting modern technology such as telehealth systems.

A "Caregiver-Centered Care" system should be implemented based on the presence of a strongly interacting team of family members and healthcare professionals. This must ensure (i) the follow-up of the patient at home by the National Health System professionals and also (ii) psychological support to the family caregiver(s). This twofold approach will guarantee an optimal quality-of-life of the patient, a lower psychological burden on the caregivers and may reduce hospitalizations of patients that are due to inappropriate caregiving so that health systems resources can be used efficiently.

Author Contributions: Conceptualization: A.S. Literature analysis: A.S., G.P., P.M., A.T., A.H., C.B. Discussion: A.S., G.P., P.M., A.T., A.H. and C.B. Writing—original draft preparation A.S. and A.T. Writing—review and editing G.P., P.M., A.H. and C.B. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Ethical review and approval were waived for this study since the present review is based on already published data.

Informed Consent Statement: Not applicable as the data as this is a review paper that only uses already published info for which the Consent was obtained in the original paper.

Data Availability Statement: As this is a review paper, the data are available through the cited papers.

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

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