

BUONA PRASSI – BEST PRACTICES

FAMILIES WITH YOUNG PEOPLE WITH PROFOUND
INTELLECTUAL AND MULTIPLE DISABILITIES:
CRISIS OR REBIRTH?

FAMIGLIE CON GIOVANI CON PROFONDE DISABILITÀ
INTELLETTUALI E MULTIPLE:
CRISI O RINASCITA?

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The Coronavirus disease outbreak, which we are currently still experiencing, has led several individuals to a period of isolation at home or in quarantine. This article raises the question of what impact this situation has had on families with people with diseases or disability. Furthermore, in terms of Quality of Life, there is a close relationship between the Quality of Life of the young person with disabilities and his/her family: the lower level of Quality of Life of the young person corresponds to a significant decrease in the Quality of Life of their family. In this last direction, researches focus on the impact in terms of Quality of Life, in relation to the burden of assistance and care required by the functioning profile of the person with disabilities. In this case, many scholars relate the Quality of Life of families to the presence or absence of adequate socio-health policies, resources and services aimed at providing forms of support for the family. Specifically, the presence of a person with PIMD requires all family members to adopt a daily answer to the extended and generalised needs of assistance, which often remain stable throughout all the lifespan, making parental and caregiving tasks particularly demanding. The

interest of our research is to highlight the critical aspects of the new life contexts that affect families with young people with PIMD, in order to implement new research paths aimed to collect data and on new support needs.

L'epidemia di Coronavirus, che attualmente stiamo ancora vivendo, ha portato diversi individui a un periodo di isolamento domiciliare o in quarantena. Questo articolo solleva la questione dell'impatto che questa situazione ha avuto sulle famiglie con persone con malattie o disabilità. Inoltre, in termini di Qualità della Vita, esiste una stretta relazione tra la Qualità della Vita del giovane con disabilità e la sua famiglia: livelli più bassi di Qualità della Vita del giovane corrispondono a una significativa diminuzione della Qualità della Vita della sua famiglia. In quest'ultima direzione, le ricerche si focalizzano sull'impatto in termini di Qualità della Vita, in relazione al carico assistenziale richiesto dal profilo di funzionamento della persona con disabilità. In questo caso, molti studiosi mettono in relazione la Qualità della Vita delle famiglie con la presenza o assenza di adeguate politiche socio-sanitarie, risorse e servizi volti a fornire forme di sostegno alla famiglia. In particolare, la presenza di una persona con Disabilità Intellettive Profonde e Multiple (PIMD) richiede a tutti i familiari di adottare una risposta quotidiana ai bisogni assistenziali estesi e generalizzati, che spesso rimangono stabili per tutto l'arco della vita, rendendo particolarmente impegnativi i compiti genitoriali e assistenziali. L'interesse della nostra ricerca è evidenziare le criticità dei nuovi contesti di vita che colpiscono le famiglie con giovani con PIMD, al fine di implementare nuovi percorsi di ricerca finalizzati alla raccolta di dati e sui nuovi bisogni di supporto.

1. Introduction: the pandemic and "submerged" families

The pandemic has had a significant psychological impact on all of us (Biffi & Galimberti, 2021; Bocci, 2021; Brook et al., 2020; Di Giandomenico, Marchetti, Fontanesi & Verrocchio,

2020) and as we have demonstrated in our previous research (Giaconi, Socci, Fidanza, Del Bianco, D'Angelo & Capellini, 2020; Giaconi, Del Bianco, Socci, Severini & D'Angelo, 2021) even more for people who already presented states of illness or disability and for their families, the impact was not only pedagogical but also due to the lack of a series of services and supports that had to guarantee the rights of care and protection (Giaconi et al., 2020; 2021). Even under the best of circumstances, caregiving can be challenging. Usually, a family member who takes care of loved ones in difficulty, if not properly supported through the appropriate economic and social policies (Istat, 2019), are prone to experiencing emotional distress, financial hardship, and physical strain (Greenberg, Wallick & Brown, 2020). For many family caregivers, the pandemic is adding complications.

The perspective introduced has been the focus of several investigations, in fact by searching in the databases of Scopus, Wiley, Eric for the keywords Covid-19, people with disabilities or diseases and caregivers, different studies can be traced between March and April 2020. These investigations allow to shed light on the pedagogical criticalities before Covid-19 and during the pandemic as they have significantly impacted the daily life of people with disabilities and their families, marked by the closure of social and health services and the interruption of home care (Phillips et al., 2020). Therefore, the pandemic and the transformations of contexts and relationships have had a significant impact on the perception of the Quality of Life of people with disabilities and families themselves, especially caregivers (D'Angelo, 2020; Giaconi et al., 2020, 2021). Criticalities emerge especially in the management of the daily routine of people with intellectual disabilities (Hassiotis et al., 2020; Courtenay, Perera, 2020; Phillips et al., 2020) or with Autism Spectrum Disorders (Colizzi, Sironi, Antonini, Ciceri, Bovo & Zoccante, 2020; Lee et al., 2020; Eshraghi et al., 2020) highlighting a strong impact on the stress levels of family caregivers, compared to family members who have other disabilities (Narzisi, 2020).

From the reconstruction of literature (D'Angelo, 2020; Giaconi, 2015; Giaconi et al., 2020; 2021; Greenberg et al., 2020; Prasad et al., 2020; Vaitheswaran, Lakshminarayanan, Ramanujam, Sargunan & Venkatesan, 2020), the impact of caregiving stress on caregiver mental and physical health can be considered a strict emergency because it is grafted onto an already present critical condition. Social-distancing efforts and fears for Covid-19 infections increase the levels of caregiver stress, asking to formulate new answers to their need for support, requiring them a different and new type of commitment both in time and skills terms. Socio-educational and health services have been very often suspended or activated at a distance and family caregivers have had to face a new and unexpected load of care. Also, the socio-economic conditions of families with people with disabilities or with disabling diseases, was already precarious (Istat, 2019), and the need to face new management of the daily routine, which often requires carrying out care tasks previously arranged by professional figures, must be addressed. Caregivers of people with neurodegenerative diseases, for example, felt inadequate to nursing care and felt distressed for not having been able to fulfil the last wishes of their beloved ones (Greenberg et al., 2020; Prasad et al., 2020; Vaitheswaran et al., 2020).

In brief, family or informal caregivers are considered essential support for people with disabilities, addictions, mental health, and chronic diseases, so much so that they are key figures of European and Italian social welfare care (Giaconi et al., 2020; 2021; Greenberg et al., 2020). They are called to demanding tasks and the Covid-19 pandemic amplifies the daily challenges caregivers face.

Our reflection will focus on the family caregivers of people with complex disabilities, or Profound Multiple Disabilities (PIMD), since, as we are going to see, they could be considered among the people most at risk of burnout due to the consequences linked to the lockdown.

The health conditions and the existing distance between the functioning and the contexts' (WHO, 2001) of people with PIMD requests already high hours of care and as long as re-

strictions and protocols were refined during the pandemic, it is necessary to investigate how this decision affected the caregiving tasks and the well-being of caregivers themselves (Kent, Ornstein & Dionne-Odom, 2020).

As underlined by Schalock and Verdugo Alonso (2006) a positive quality of life should be the result of the policies and services, implemented in favour of people and their families. The Quality of Life of family caregivers is linked with the Quality of Life of the person, especially if he/she has intellectual disabilities. Specifically, the presence of a person with PIMD requires to all family members to adopt a daily answer to the extended and generalised needs of assistance, which often remain stable throughout all the lifespan, making parental and caregiving tasks particularly demanding.

In this direction, the interest of our research is to highlight the critical aspects of the new life contexts that affect families with young people with PIMD, in order to implement new research paths aimed to collect data and find new support needs. Therefore, in this paper, we would like not only to deepen these pedagogical criticalities and how they have been faced today in the post-pandemic period, but to focus into an initial assessment that allows us to reflect on the meaning of the call of this journal in reference to families with young people with disabilities, and, specifically, with Profound Intellectual and Multiple Disabilities. As we are going to see in the next section, we will argue that what we will present as a weakness represents a resource for rethinking social welfare.

2. The delicate life path of families with members with PIMD in the present context

Recent scientific literature within the scientific community of Special Pedagogy (Caldin & Giaconi, 2021a; 2021b), has highlighted the transformations of the family with children with disabilities between the past, present and future, with particular attention to the take in charge, which today more than ever is invoked

to safeguard, safeguard and strengthen the texture of exchanges (affective, relational, intellectual, values) within society itself. We believe that putting the family with children with disabilities at the centre of a pedagogical reflection and, as we will see in this paragraph with young people with PIMD disabilities, allows us to express and capitalise on the ability of the family, or rather of families, to be able to overcome disturbances. of the crisis maintaining its generative pregnancy, first of all, of affections, emotions, feelings, relationships which in turn are the foundation of thoughts, ideas, values.

As we have seen in the previous section, the impact of the epidemic and the consequential social-distance condition has been violent for all people and families, especially the ones who have to face challenges in caregiving of their beloved ones. Despite the critical and delicate life condition of family caregivers of people with PIMD during this global pandemic the situation was largely invisible in media reports and in the scientific literature.

People with PIMD in Italy represent about 2% of the population (D'Angelo, 2020) however very few studies have been conducted concerning the Quality of Life of their caregivers (Luijckx, van der Putten & Vlaskamp, 2019) and, at present, as far as we know, no research has investigated the new needs dictated by the new health emergency.

Leading research on this specific sample has different scientific motivations within Special Education.

The first concerns the need to take charge of families with children with disabilities, a focus explored by several scholars of Special Education (Caldin, Cinotti & Serra, 2017; Giaconi & Del Bianco, 2019; Pavone, 2009), that still needs to be furthered in specific pedagogical issues related to taking charge of young people with PIMD and their families (Goussot, 2011; Luijckx, 2016; Maggiolini, 2011; Nakken & Vlaskamp, 2007).

Secondly, the person with PIMD, as we anticipated in the previous point, presents unique conditions of functioning which require the use of extended supports throughout their life (Granlund et al., 2013). Taking charge of a person with PIMD is,

therefore, a particularly demanding task for all their caregivers (Luijkx et al., 2019). Furthermore, in terms of Quality of Life (Granlund et al., 2013), there is a close relationship between the Quality of Life of the young person with disabilities and his/her family: the lower level of Quality of Life of the young person corresponds to a significant decrease in the Quality of Life of their family (Blacher, 2001; Giaconi, 2015; Nieuwenhuijse, Willems, van Goudoever & Olsman, 2020).

In this last direction, researchers focus on the impact in terms of Quality of Life, in relation to the burden of assistance and care required by the functioning profile of the person with disabilities. In this case, many scholars relate the Quality of Life of families to the presence or absence of adequate socio-health policies, resources and services aimed at providing forms of support for the family (Caldin et al., 2017).

The Quality of Life of family caregivers is linked with the Quality of Life of the person, especially if he/she has intellectual disabilities (Granlund et al., 2013). Specifically, the presence of a person with PIMD requires all family members to adopt a daily answer to the extended and generalised needs of assistance, which often remain stable throughout all the lifespan (Luijkx et al., 2019).

Research highlights how the Quality of Life of family caregivers decreases in relation to different circumstances, for example, the discrepancy between the profile of the person's functioning and the demands of the context (Giaconi, 2015; Grey, Totsika & Hastings, 2018; Negri et al., 2019), the number of difficult situations to deal with (Minnes & Woodford, 2007; Walden, Pistrang & Joice, 2000), the epileptic states (Grey et al., 2018) or feeding problems (Killian et al., 2016). Other research (Sherpa, Kitrungrrote & Sae-Sia, 2018) investigates the changes in the caregivers Quality of Life levels, in relation to the variation of self-determination and autonomy of their child with disabilities (Del Bianco, 2019), or concerning the reduction of his/her social roles, such as the deterioration of the network of interpersonal relationships (Negri et al., 2019). Alongside these dimensions, the

literature examines the aspect related to the family economy, because particular expenses for health care and to guarantee the physical well-being of the person with a disability, the risk to have a negative impact on the general condition of the family unit (Chou, Kröger, Chiao & Pu, 2013). In this direction, and with the same negative impact on the Quality of Life of caregivers is the availability or not of resources (social or professional) for home care or from the so-called “Family Centred Care” or “Family-Centred Services” (Chou, Pu, Kröger & Fu, 2010).

Considering the complexity of the PIMD, about the person needs for continuous care, the frequent presence of problems, such as forms of epilepsy or dysphagia, and the consequential amount of the care hours demanded to family members, several studies (Luijkx et al., 2019; Negri et al., 2019; Tadema & Vlaskamp, 2010) highlight a risk condition for the caregivers. Due to guilt feelings, states of fatigue and frustration, caregivers frequently experienced depression or symptoms attributable to the so-called Burnout Syndrome (Grey et al., 2018). Always within the studies on the psychological impact of the PIMD’s family caregivers, strategies such as coping, positive appraisals, psychological acceptance, internal locus of control, play an important role (Negri et al., 2019) in the promotion of both personal growth and the social inclusion of caregivers and, therefore, to increase their Quality of Life (Grey et al., 2018).

Previous studies (McCann, Bull & Winzenberg, 2012) had shown how the dimensions of the Quality of Live (Giacconi, 2015; Schalock & Verdugo Alonso, 2006) that are at risk in the life of the caregiver are those of free time (Luijkx et al., 2016) and friendly interactions. Concerning the free time, comparative studies (Luijkx et al., 2016) between mothers and fathers of children with PIMD and mothers and fathers of typically developing children the amount of care time (housework and care and supervision of their children and free time), show a significant difference. Having to dedicate more time to care activities, in the daily lives of parents of children with PIMD there is a significant reduction

of the time spent on both housework and leisure activities, in the latter case, with a significant impact on personal well-being.

Also, in studies on families with children with PIMD, investigations are focused on the role of siblings as the main caregiver when parents become elderly or die (Luijkx et al., 2016). According to research conducted on the roles assumed by brothers and sisters, they are often the main components of the social network of their siblings with PIMD and the primary actors of their leisure time planning. Siblings also assume, during the lifetime of their brothers and sisters with PIMD, functions of protection and legal representation, becoming, very often, the true referents and coordinators of the network of formal and informal services. Siblings experience, therefore, numerous and important roles, which can vary during the lifespan of people with disabilities and who invest their own life plans. The investigation focus shifts, also in this case, towards the analysis of the reality between Quality of Life of the siblings and the person with PIMD (Hall & Rossetti, 2016).

However, research conducted on the perception of Quality of Life levels of young and adult siblings of people with PIMD is still small, especially with reference to the transition phases, which often correspond to crucial moments of modification of roles and family balance (Giaconi, 2015).

In light of what has been reconstructed, we can guess how much the lockdown and socio-economic changes, imposed by the Covid-19 outbreak, could have affected the Quality of Life of caregivers of people with complex disabilities. The use of a wide formal and informal support network has no more been available as before, due to the social distancing imposed. This required the family caregiver to raise the number of hours of caregiving. As pointed out from different research, higher hours caregivers are prone already to «experiencing emotional distress, financial hardship, and physical strain» (Greenberg et al., 2020, p. 220) and Covid-19 could have magnified these conditions.

As a result of the Covid-19 pandemic, many caregivers may now find themselves providing even more care than previously.

With routine home-care visits disrupted or discontinued, closure of daily service-centres, tube feeding, injections, bedsores' and catheters' care, prevention or management of epileptic seizures may become the responsibility of family caregivers who may not feel adequately prepared to carry out these medical tasks (Greenberg et al., 2020).

To this must be added the difficulty of the caregivers in asking for help and direct support because of the fear of transmission of the virus which could significantly aggravate the already critical health picture of loved ones with PIMD.

The uncertainty linked to future economic and welfare scenarios can only make the condition of social distancing experienced by the caregivers of people with PIMD even more critical. In the lockdown context, the dimensions of free time and friendly interaction, which has already emerged are already at risk in the caregivers of people with PIMD, were adversely affected, further lowering the level of satisfaction perceived for their life and increasing their psychological strain. The emotional and physical repercussions of caregiving for a person with a complex disability during a pandemic, as we have tried to reconstruct based on the criticalities that literature has currently highlighted, can significantly be affected by governments' restrictions.

As reconstructed so far, we want to underline the importance of deepening informal caregivers living conditions during the Covid-19 outbreak. Little is known about how people with PIMD and their caretakers cope during a pandemic, and which are the supports they need in order to experience less stressful conditions. Is it, therefore, of utmost importance, during these unprecedented times, to start new research paths on Covid-19 restrictive measures on the Quality of Life of persons with PIMD and their caregivers, to design new ways of taking charge.

In conclusion, the studies reported in this section show how the life cycle of a family with children with PIMD is full of delicate and sensitive phases both from a pedagogical and economic point of view (Giacconi et al., 2020; 2021), even more so it is state in the period of the pandemic and post-pandemic. This period

also showed, as will be specified in the next paragraph, how the family itself has been a resource for the community, addressing the challenges of daily care and care for their children. However, in order for this resource to be rightly exploited and strengthened, it is necessary to rethink new socio-health models for the proper care of families with children with disabilities throughout their life cycle and in the complex challenge of raising a child with PIMD.

3. New socio-health models for the rebirth of families with PIMD

Attempts to curb Covid-19 have forced countries to be under lockdown, with a strict emphasis on self-isolation and social distancing. The pandemic has created a range of health and social challenges that impact mental health which if prolonged, can be extremely stressful (Brooks et al., 2020). This situation, for families and caregivers, as we have seen, can be greater as the absence of usual formal and informal supports (schools, day services, respite care, friends, other family members) and the presence of new stressors can significantly increase their care burden.

During this global health emergency, family caregivers, more than ever, are key figures in the support of people with diseases or disabilities, keeping look after their loved ones, with a completely altered usual lifeline and supports. Few studies (Kent et al., 2020; Luijkx et al., 2019) have paid attention to the new needs of caregivers of people with PIMD. Family caregivers continue to deliver care to people with complex disabilities who also are to be ones of the most at risk of dying from Covid-19. As emerged from the reconstruction of the studies on the topic, different levels of analysis can constitute important points of reflection in the organization of supports aimed at ensuring adequate levels of Quality of Life even during this new emergency.

The first level of reflection is the unwanted consequences of social distancing, such as feelings of loneliness or abandonment, in part linked to the closure of services or centres, that can have

negative consequences on the health of the caregivers (Kent et al., 2020). As pointed out by Greenberg and collaborators (2020), loneliness and social isolation can have a significant impact on mental and physical well-being. In this direction, caregivers are encouraged to stay socially engaged with family and friends through the use of social networks, telephone calls and so on. At the same time, the caregivers' reluctance to ask for help by professionals, or other support figures, must be simultaneously noted. As a consequence of the fear and the anticipated sense of guilt for having people in their home who could transmit the Virus (Kent et al., 2020), the family caregiver very often prefers to completely absolve the load of care. In this direction, we believe that the construction of correct information, of educational paths to prevention practices and the delineation of operational guidelines, could be the first response.

The second level of analysis concerns the economic difficulties that many caregivers will face because of Covid-19. Some international studies (Lee et al., 2020) already report some financial strains because of employment loss and medical expenses. In the caregiver's perspective, the work should also be read not only in terms of economic resource but also as a space that guarantees a time away from caring responsibilities that, instead, during the Covid-19 has to be shared with care tasks, in particular in the smart working options (Phillips et al., 2020). As the lines between work and care become increasingly blurred in, carers may be at risk of burnout.

Lastly, «caregivers are now needing to balance an unprecedented landscape of decision making for their care recipients with maintaining current public health safety practice» (Kent et al., 2020, p. 67). They are asked to provide health care usually supplied by professional careers and, at the same time, they have to deal with an unknown future in which everything will have to be rethought.

The studies conducted to date on the theme of caregiving burden during the Covid-19 outbreak have also drawn up some

guidelines for the construction of good practices to put in place during social distancing (Narzisi, 2020).

Particular consideration has been placed on building new access opportunities for caregivers to their support networks in order to safely obtain respite care. In this direction, services have activated new charging methods through the use of technologies (telephone interventions, video calling, online platforms etc.). The use of technology has certainly provided a first useful answer to reorganising services even if the technological divide can represent an important access barrier (Courtenay & Perera, 2020). The reorganisation of services, in the future, will have to proceed according to a plan designed in time and not managed in an emergency. Only in this direction will it be possible to think of more inclusive and quality support trajectories.

Concerning the guidelines, further reflection should be conducted. Due to the pandemic, service operators have faced new difficulties in assisting the person and caregiver, but it remains a central issue the training of operators themselves in communication and relations with them. In our opinion, there are two prospects for development. On the research side, it would be necessary to study the difficulties of the operators (home assistants, professional educators, hospital figures, etc.) in the communication and relations with the caregivers of the people they assist. On the training side, it would be appropriate to think of specific training courses for operators also on this dimension of taking care of caregivers. For this last point, training modules are being tested within the university training courses (for example, the path for professional educators or nurses) or post-graduate updating and improvement courses.

4. Conclusions

The recognized importance of identifying the new needs of caregivers has not found sufficient confirmation in the production of research and studies aimed at detecting the perception and

the impact of government measures on people with PIMD and their caregivers. Although the latter could be considered among the people most at risk of burnout due to the consequences linked to the lockdown, they have not been at the centre of study or research. As we have seen, the impact of caregiving stress on caregiver mental and physical health can be considered a strict emergency because it is grafted onto an already present critical condition.

Future research will have to deepen the social impact that the lockdown has had and will have on the Quality of Life of people with PIMD and their caregivers.

In reference to what has been assumed, during the current Covid-19 emergency, in line with the national measures that have provided the closure of day centres, and considering the difficulties that families have in activating home care with the required safety standards, we believe that it is necessary to investigate the perceptions of the caregivers, to drive future pedagogical intervention and practices.

In this direction, collecting evidence about the caregiver perception will be helpful to empower people with disabilities and their carers to face future outbreaks and confinement.

Questioning and investigating the transformations that families with children with disabilities have experienced, live and will be able to experience, grasping their possibility of being able to overcome the perturbations of the crisis, allows pedagogy to be able to centre their generative significance, starting from the weaving of exchanges (affective, relational, intellectual, values) up to the entire system of needs and supports, necessary to safeguard them and make them ever more solid.

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