

Psychological intervention for people with Intellectual Disability, their caregiver and healthcare professionals during the COVID-19 pandemic

Marinella Zingale¹, Santina Città¹, Giovanni Belfiore¹,
Angelica Carrubba¹, Flaviana Elia¹, Giovanna Mascali¹, Vita Mongelli¹,
Paola Occhipinti¹, Enrica Pettinato¹, Marilena Recupero¹,
Damiana Schillaci¹, Giovanna Sciacca¹, Valentina Sirni¹,
Anna M. Torrisi¹, Grazia Trubia¹, Anna M. N. Vasta¹,
Tommasa Zagaria¹ & Serafino Buono¹

Abstract

The health emergency we are all experiencing as a consequence of the SARS-Cov2 pandemic, the stressors and all their related factors have strongly influenced the psychological and physical well-being of people with Intellectual Disability (ID), their families and the health care professionals who are daily involved in their care. The containment measures applied have changed the normal rhythms of life and routines, leading to a negative impact on quality of life. The aim of this paper is to present a psychological intervention model and the specific activities addressed for this population, their family and the health care professionals involved in their care and rehabilitation, in order to reduce the impact of the pandemic on their quality of life and to prevent the onset of any psychopathological disorders.

Keywords: Covid-19; Psychological intervention; Rehabilitation; Intellectual Disability; Family; Health care professionals.

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¹ Unit of Psychology, Oasi Research Institute –IRCCS, Troina, Italy.

Correspondence to: Marinella Zingale, UOC of Psychology, IRCCS Oasi Maria SS., Via Conte Ruggero 73, 94018 Troina, Italy. E-mail: mzingale@oasi.en.it.

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1. Introduction

Following the rapid spread of the Sars-Cov-2 virus in Italy and in other countries of the world, the healthcare facilities found themselves to face a true emergency linked to the management of the health and psychological aspects associated with the Covid-19 epidemic. This extraordinary event has inevitably led to an exponential increase in mental health needs. Studies conducted on survivors of health emergencies related to other viruses (e.g. SARS) or traumatic events, supported the idea of the presence of a high rate of major depressive and post-traumatic stress disorders in adults, children and in healthcare professionals (Hawryluck, Gold, Robinson, Pogorski, Galea, & Styra, 2004; Liu, Kakade, Fuller, Fan, Fang, Kong *et al.*, 2012; Sprang & Silman, 2013; Carmassi, Gesi, Corsi, Cremonese, Bertelloni, Massimetti *et al.*, 2018). The results also showed that prolonged exposure to stressful situations could have negative consequences on cognitive functioning, in particular to attention and memory functions (McEwen, 1999).

The emotional and cognitive vulnerability of fragile populations seems to be significantly affected by any emergency condition; therefore, individuals with Intellectual Disability (ID) may present greater difficulties in the adaptation to the rapid and drastic changes in their lifestyles.

It is also necessary to consider that people with ID have a higher prevalence of comorbidities, including physical impairments (2.5 times more compared to general population) which can represent a significant risk factor for the development of serious forms of Covid-19 (SIDiN, 2020). Furthermore, this population is more likely to develop psychopathological disorders due to a greater psychic vulnerability (3-4 times more than in general population) as reported in DSM-5 (APA, 2013).

People with ID and their family often have to cope with environmental (lack of information, inaccessibility to healthcare services), institutional (lack of specific treatment protocols) and attitudinal barriers (prejudices, stigma and discrimination) which could prevent them from accessing the healthcare services essential to reduce personal and social risks linked to the epidemic (SIDiN, 2020), thus causing them stress. In the case of people with ID admitted to healthcare facilities, the measures taken to contain the epidemic, as underlined by Duan and Zu (2020), significantly reduce the possibility of maintaining and/or guaranteeing the intervention of the health professionals (i.e. psychologists, psychiatrists, mental health and

rehabilitation practitioners), resulting in the suspension of rehabilitation and psychological support.

Changes in usual routines can fuel uncertainty (Huremović, 2019) and emotions like fear, anger and frustration, cause a sense of unease (Brooks, Webster, Smith, Woodland, Wessely, Greenberg *et al.*, 2020; Qiu, Shen, Zhao, Wang, Xie, & Xu, 2020), encourage the onset of inappropriate behavior and, in some cases, cause loss of the hardly acquired self-determination and autonomies.

Therefore, the management of this type of patients in situations of emergency and uncertainty (such as the one we are experiencing) becomes complex from an organizational and practical point of view, either at home or in specialized healthcare facilities.

Although the professionals working with ID patients are used at managing the peculiar health and well-being aspects of this fragile individuals, this extraordinary event has made them facing new challenges (i.e. anxiety, fear and warning caused by possible infections).

Research studies performed on healthcare professionals have shown that emotional experiences, such as the fear of being infected and/or spreading the infection, feelings of frustration and concerns related to the lack of sufficient/important information (Brooks *et al.*, 2020) can interfere with the psychological well-being of the operators themselves and with the quality of the services provided. In stressful situations, in fact, concentration is limited, the ability to tolerate doubt is reduced, irritability increases, often making it difficult to act and decide effectively and quickly (Maslach & Leiter, 2016) and activating, in some cases, maladaptive, ineffective and potentially harmful behaviors (excessive search for information, circumvention or impulsive decision-making processes) (Carleton, Mulvogue, Thibodeau, McCabe, Antony, & Asmundson, 2012; Pawluk & Koerner, 2013).

The stress condition can also be exacerbated by the structural contingencies of the context (e.g. availability of adequate protective personal equipment, management of work shifts, collaboration among colleagues, specific attention to procedural rules, etc.) which can limit the sense of "control" of the events (Liu, Yang, Zhang, Xiang, Liu, Hu *et al.*, 2020). Further, professionals often experience a sort of dynamic conflict between their sense of duty (which would lead them to guarantee patients the most appropriate care), and instinctual mechanisms of avoidance and escape from the "context/contagion" with consequent feelings of frustration, anger and fear (Robertson, Hershenfield, Grace, & Stewart, 2004).

However, research has highlighted that internal and external variables affecting any individual, such as awareness of one's sense of self-efficacy and the use of stable external relational support systems (e.g. familiar and friendly comfort and support systems), contribute to increase coping capacity in dealing with events (Alexander, 2020; Bansal, Bingemann, Greenhawt, Mosnaim, Nanda, Oppenheimer *et al.*, 2020).

Therefore, in order to contain the impact of the epidemic and prevent the onset of psychopathological disorders, with consequent maladaptive behaviors and a wider range of emotional disorders, rapid responses and psychological interventions are necessary for people with DI, their families and healthcare professionals (Orrù, Ciacchini, Gemignani, & Conversano, 2020).

With respect to the above mentioned factors, psychological intervention provides the appropriate "tools" to assess the potential risk factors that lead to maladaptive psychological responses. In addition, it can help to manage feelings of fear and anxiety, panic, boredom, frustration and intolerance to uncertainty.

A number of national and international associations have been sharing guidelines to deal with the immediate emergency (IASC, 2020; SIDiN, 2020) which are addressed to family members or operators dealing with people with ID, thus confirming the importance of an adequate psychological support. Indeed, many healthcare facilities around the world have implemented online counseling and support services, through social media, e-mails or phone calls to promote psychological support to people in need (Chen, Liang, Li, Guo, Fei, Wang *et al.*, 2020; Han, Zhang, Kong, Li, & Yang, 2020).

The purpose of this brief article is to propose a psychological intervention model that can be applied to healthcare facilities dealing with the assistance, care and rehabilitation of people with ID and their families, such as Oasi Research Institute - IRCCS (Troina, Italy).

2. Intervention description

The proposed model for the management of people with ID is divided into different phases, each of which includes specific activities and interventions.

The first phase is aimed at managing the emergency with the identification and activation of the most appropriate user-oriented healthcare pathways and activities. This phase primarily involves clinicians, nurses and

social-health operators. Mental health professionals, such as psychologists, can be involved through telemedicine systems (telephone/online platforms), to provide psychological support for healthcare professionals, patients and their families.

After the initial phase, it is possible to program and re-activate multidisciplinary services aimed at: 1) implementing guidelines to respond to the needs of psychological/physical well-being of people directly and indirectly affected by Covid-19; 2) identifying and/or preparing questionnaires on quality of life, mental health and psychopathological risk factors addressed to people with ID, their families and healthcare operators in order to detect specific needs and design tailored intervention plans; 3) planning and implementing adequate procedures and rapid responses to support patients, their families and the operators of the facility, by intensifying and expanding the various methods of psychological, rehabilitation and educational intervention, in order to reduce the psychological consequences deriving from forced quarantine or linked to a difficult work setting in an emergency.

In order to comply with containment measures, the delivery of psychological interventions must be carried out in a smart-working mode with the use of technologies (i.e. telephone, mobile devices, interactive video conferencing, chat and online platforms) which the Italian Ministry of Health (Ministero della Salute, 2020) and the National Board of Italian Psychologists (CNOP, 2017) have been recognized and recommended as the most appropriate instrument to be used during particular epidemic situations. The reference model used to carry out these activities is that of “Oasinet”, the first experimental tele-counseling protocol which was effectively implemented by Oasi and delivered to ID patients and their families in 1999/2000. According to the findings of a research measuring users’ satisfaction, it emerged that 84% of them were highly satisfied of the service provided. Among the main advantages, the users underlined the continuous presence and support of specialists, the reduction in travel to specialized centers and an increase in the adaptive skills of their children (Buono & Città, 2001, 2004, 2007; Buono, Città, & Zagaria, 2001; Buono, Città, Palmigiano, Polizzi, & Savoca, 2004).

The planned intervention covers the following areas:

1. neuropsychological, educational, rehabilitation, and psychological interventions aimed at two types of users: people with DI who have been recently or are still admitted to Oasi;

2. individual or group support, counseling and training activities for families of both hospitalized and discharged people with the aim of providing useful information for the daily management of their children;
3. e-counseling activity (listening, help and taking charge) aimed at emotionally and psychologically supporting the person, increasing his/her well-being and quality of life. This method also implies e-learning practices to promote knowledge based on scientific data related to issues such as concerns and anxiety;
4. e-therapy activities aimed at providing psychotherapy interventions to families, couples, individuals in different phases of their life;
5. support interventions for healthcare professionals aimed at managing stress, improving motivational aspects, and implemented through mindfulness practices for anxiety reduction (Orrù *et al.*, 2020; Bansal *et al.*, 2020);
6. weekly online re-enabling interventions provided by a team of professionals in order to guarantee a multidisciplinary approach.

The activities, in line with what has been already published in literature (Ho, Chee, & Ho, 2020; Liu *et al.*, 2020; Orrù *et al.*, 2020; Zhang, Wu, Zhao, & Zhang, 2020) are shown in Figure 1.

Figure 1 - *Scheme of interventions by type of users*

People with ID

- Administration of a questionnaire to evaluate stress and emotional factors;
 - individual psychological support or individual treatment to improve cognitive and emotional skills;
 - recovery of normal routines by defining an agenda of recreational and occupational activities, suitable for the emergency context and to be carried out with the support of telemedicine;
 - follow-up of the interventions and the scheduled targets;
 - individual interventions (2 or 3 for week) to improve attentions, memory and executive functions, school skills, communication, socialization, daily living skills, emotional skills.
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Families of people with ID

- Administration of a questionnaire to evaluate the following variables: stress factors, emotional well-being needs and supports needed to manage their child in the family context;
- individual psychological support;
- parent training or parent education to allow them to make behavioral observations within their family context and to improve social-communicative and daily living skills;
- parent training to resume normal routines by defining an agenda of recreational and occupational activities, suitable for the emergency context and to be carried out with the support of telemedicine;
- parent training to help the parents to organize family environments according to the activities to be carried out;
- follow-up of the interventions carried out within the family context;
- group psychological interventions to offer educative indications related to the main neurodevelopmental disorders (ID, ADHD, SLD, ASD).

Interventions for healthcare professionals

- Administration of a questionnaire to evaluate the following variables: stress factors, emotional well-being;
 - individual psychological support and psychotherapy;
 - group psychological interventions to reduce stress (e.g. mindfulness, meditation, biofeedback).
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3. Conclusions

The containment measures designed and implemented as a consequence of the spread of the Covid-19 epidemic are proven to be useful to protect people's health and to avoid further contagion. However, as evidenced by the studies published and cited in this brief article, it is essential to reorganize the psychological activities so to ensure that this could be better afforded and tolerated by people with DI, their family and the healthcare professionals who take care of them. The intervention is also necessary to avoid the onset of psychopathological symptoms that could worsen their health conditions and quality of life.

According to the guidelines designed for this population, the main concern is on the management of routines and the emotional aspects within the family context; however there is a need for specific online psychological

support and counseling to family. Since this population needs a multidisciplinary approach (biological, psychological and social), the interventions must be able to meet not only the needs related to their assistance/care, but also to those more closely connected with their psychological/physical well-being and quality of life. Furthermore, intervention shall be provided both to people with ID and their family and to all the careers involved in their assistance. This will avoid or reduce the possible negative epidemic-related consequences on their psychological/physical well-being and allow the reactivation of individual resources and resilience systems. This brief article proposes a model of psychological intervention for people with ID, their families and health care professionals, with a set of activities that can be safely implemented.

The effectiveness of this intervention model shall be verified in the long term, assessing the impact on the health and psychological/physical well-being of the people involved in the care pathways, as well as the quality and satisfaction level.

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