

Palliative Care in the COVID-19 Pandemic

Briefing Note

Meeting the Palliative Care needs of People with Physical and Intellectual Disabilities

Issue

The Covid-19 pandemic is intensifying existing health system inequities associated with disabilities (UN 2020). Persons with physical and intellectual disabilities, both children and adults, are likely to become more vulnerable due to Covid-19.

Background

One billion people worldwide are living with a disability: 46% are older than 60, and 80% live in a developing country. Palliative care supports the dignity of persons with disabilities, who are often subjected to discrimination, abuse (physical, emotional and sexual) and social exclusion (WHO, 2011). Disability is strongly associated with increased rates of multidimensional poverty, decreased rates of education and employment, and higher medical expenses (Mitra et al., 2013). The pre-pandemic world was already one of isolation for many people with disabilities. (Disability Rights Fund 2020) In many countries persons with disabilities (PWD) do not receive palliative care and health care staff do not understand the need for palliative care for persons with disabilities. Communication difficulties result in undetected pain and failure to report symptoms, leading to deterioration of physical and/or mental health. Spiritual support in palliative care is often neglected in the care of PWD especially those with intellectual or communication disabilities.

Key Facts

- Palliative care is a component of the human right to health, which includes persons with disabilities (General Comment 14 CESCR, para.34)
- Article 25 of the Convention of the Rights of Persons With Disabilities recognizes that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.
- PWD are three times more likely to have another underlying illness than adults without disabilities, increasing their risk to become severely ill (CDC, 2020).
- Personal Protective Equipment can exacerbate communication difficulties for persons with disabilities as they will be unable to lip-read or interpret body language.
- PWD often depend on family or friends to collect money from accounts, increasing the risk of financial abuse. They could be denied food and basic needs if resources become scarce.
- Individuals living in institutions are more likely to contract COVID-19, especially if these facilities are overcrowded and unsanitary. (UN, 2020).
- Certain disabilities cause an increase in sexual needs, intensified in stressful situations. Lockdown and isolation scenarios may increase sexual needs, leading to frustration and aggression.



Current Status

- Resources for treatment of pre-existing conditions have become unavailable or difficult to obtain, aggravating existing conditions;
- Challenges of implementing basic protective measures such as regular hand washing, physical distancing, and inability to access PPE, are putting PWD with underlying medical conditions and co-morbidities at increased risk of serious illness if infected with Covid-19;
- PWD in quarantine are at an increased risk of infection from paid caregivers who use public transport or engage in other social interactions;
- PWD report more physical and emotional stress as a result of difficulties accessing health care and medications;
- PWD in Low-to-Middle-Income Countries (LMICS) or resource limited health systems fear not being able to access intensive care if they become infected with Covid-19 or experience any other health crisis;
- PWD are experiencing more isolation than usual as a result of the pandemic.

Recommendations to UN member states and civil society organisations

- Ensure that governments and agencies are held accountable for the provision of palliative care for PWD during Covid-19 to improve quality of life.
- Ensure those with pre-existing conditions, including those in need of palliative care, continue to receive treatment and support without disruption.
- Train healthcare workers on the holistic needs of persons (children and adults) with disabilities.
- Establish contact between the person with disabilities and primary carers via electronic media if possible.
- Obtain input from primary carers on communication techniques and typical behaviour patterns to enable detection of pain or other health concerns. Use simple and clear language and avoid medical terms as far as possible.
- Ensure adequate communication resources (including braille, sign-language interpreters, communication boards and pictures) where needed.
- Discuss treatment preferences and end of life care – involve primary carers for advance care planning if needed.
- Ensure adequate spiritual and psychosocial support and enable PWD to access mental health services.
- Include PWD in all health care planning, including for Covid-19.
- Integrate education on sexuality and PWD in palliative care programmes
- Ensure that PWD can continue to contribute to society.
- Include access for PWD in all health care facilities.

¹ <https://www.up.ac.za/centre-for-augmentative-alternative-communication>

References

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