This webinar will be recorded
“EURORDIS Outlined Position Paper”

Webinar, 10.07.2024
Welcome!
We will be starting shortly...

Mute your microphones when not speaking

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Raise your hand if you wish to speak & use chat box for Q&A and comments
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Opening Remarks

Kirsten Johnson, Fragile X International & EURORDIS Board of Directors
EURORDIS Position Paper on Mental Health

Matt Bolz-Johnson, EURORDIS
UN General Assembly Resolution on Addressing the challenges of persons living with a rare disease and their families:

10. Urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers. A/RES/76/132

World Health Organisation, 2022:

The World Health Organization (WHO) recognized “people with an existing health condition” as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women (WHO 2022).

European Union, 2023:

- Mental health is now being recognized as a public health priority in the European Union, notably in Commission President von der Leyen’s State of the Union speech at the European Parliament on the 14 September 2022.

- The new Commission Communication on a Comprehensive Approach to Mental Health was published on 7 June 2023.
UN GA Resolution A/RES/76/132 (2021)

UN urges Member States to implement psychosocial support programmes for PLWRD

European: visibility of rare diseases in mental health policy, call for a more inclusive approach of all populations in vulnerable situations and dedicated actions.

National: visibility of mental health in rare disease national plans and strategies specifically to establish psychosocial support programmes through “psychologically informed medical care.”

Recommendations

Common Needs in Uncommon Conditions

- Psychologically informed medical care
- Need for information and practice support
- Empathic communication
- Coping with uncertainty
- Social support
- Family focused care
- Interdisciplinary care & psychological support

Model for Psychosocial Care should strengthen the resources and resilience of everyone affected by rare conditions.

Integrated approach in all interactions with healthcare professional as well as include psychologists in core team.

Reference:
Smits RM et al. 2022 Common needs in uncommon conditions: a qualitative study to explore the need for care in pediatric patients with rare diseases.
Schröder HM. Et al. 2019. Psychosocial Care in Paediatric Oncology and Haematology.
Our key ask is that people living with a rare diseases are recognised as a population living in vulnerable situations, due to the multiple intersectional needs, requiring specific attention in the new Communication.
European Recommendations

Call on the European Commission to better prevent and protect mental health problems and reduce further exclusion and marginalisation of the most vulnerable members of society, by recognising the 30M persons living with a rare condition in the European Union as a population living in vulnerable situations and taking action to address these high unmet needs.

SPECIFICALLY

✓ Be inclusive of all populations in vulnerable situations (including rare conditions) in the actions to implement the Comprehensive Approach to Mental Health.

✓ Translate the implementation of the Comprehensive Approach into a dedicated Flagship Initiative with supporting actions and adequate financial support for all vulnerable groups, including rare conditions and improve access to psychological support.

✓ Allocate funding for a Mental Health & Wellbeing Toolkit for Populations in Vulnerable Situations in order to build the capacities and empowerment of these groups to become mentally healthy communities.
National Recommendations

Call on EU Member States to honour the United Nations General Assembly Resolution’s (A/RES/76/132) call for the development of effective programmes and national strategies to promote mental health and psychosocial support for persons living with a rare condition, and to coordinate EU action to develop and promote policies and programmes that enhance the wellbeing of their families and caregivers.

SPECIFICALLY

✓ Increase and include the visibility of mental health in the revision of Rare Disease National Plans & Strategies and commit to action to address the unmet mental health needs of PLWRD and their families.

✓ Integrate psychological support as an integral standard of holistic care, by incorporating psychosocial personnel as core members of the medical team, and through enhancing medical care to be psychologically informed.

✓ Recognise and support patient organisations to provide community and peer support, and access to trusted information, as the foundation of psychosocial care, enabling earlier detection and access to preventative support.

✓ Support new and targeted medical training to strengthen cross-specialty training, for all professionals to better understand the relationship between physical and mental health, and specifically for mental health practitioners to become more ‘rare aware’ and medical and nursing care practitioners to become ‘mental health’ aware.
**Development Process**

**Q1-2 2023**
- Gathering Evidence
- Submitted Response for the Call for Evidence on RD & MH
-Submitted a Poster of a Concrete Action
- EMM2023 Satellite Workshop on Mental Wellbeing

**Q1 2024**
Draft Outline Position Paper
Feedback from:
- EURORDIS Mental Health Partnership Network
- Council of National Alliances
- EURORDIS Board of Directors & Team

**Q3-4 2023**
- Published Full Response on the new Communication
- Contribution to MEP Own Initiative (INI) Report
- EP Policy Event on People in Vulnerable Situations

**Q2 2024**
- “What psychosocial care looks like for PLWRD” Webinar
- WG1 Advocacy Sub-Group co-created the “blueprint for psychosocial care for PLWRD”
- Final version completed.
Blueprint for Psychosocial Care
Blueprint for Psychosocial Care

Impact of Rare Diseases on Mental Health & Wellbeing

54% people living with a rare disease declare that the rare disease caused or amplified isolation from friends and family.

(Juggling life and care Survey, 2019)

Emotional Wellbeing

>90% of PLWRD surveyed felt worried, anxious, stressed and/or depressed.

19% had suicidal thoughts.

( Spencer-Tansley 2022)

Financial Independence

7/10 PLWRD have reduced or stopped professional activity due to their own or their family members’ disease.

(Courtier et al. 2017)

Access Support, Faster Diagnosis

Average time to diagnosis of 3.8 Yrs. vs 5.1 Yrs.

PLWRD whose needs for psychological support were met accessed a diagnosis faster.

EUR. RB Survey on Diagnosis, 2022

Holistic Care

50-85% of PLWRD were not offered or received sufficient psychological support in an Expert Centre.

(Courtier et al. 2017; Nunn et al. 2017)
Stressors Associated with Rarity

Progressive, degenerative, disabling and frequently life-threatening conditions.

Diagnostic Odyssey
- Lengthy/traumatic diagnosis odyssey (consult x5 doctors, av. 5 years).
  - History of misdiagnosis (av. x3).
- Poor communication of diagnosis > Reduced trust in HCP's.

Complex interacting emotional and physical symptoms
- High impact of mental health aspects of a rare condition.
- High logistical burden of frequent hospital appointments.
- Extremely intensive tests and treatment. Medical trauma and impact on physical, social and development

Living with uncertainty
- Multiple uncertainties – prognosis and future increases anxiety.
- Low disease awareness among professionals / public, increases isolation and frustration.

Stress & Strain on Relationships
- Stress and strain on family life / couple relationships
- Impact of genetic inheritance on identity, and life choices
- Increased grief and loss
Domains for Psychosocial Care

Pillar 1: Holistic Care

Pillar 2: Prevention

Pillar 3: Family Orientation

Pillar 4: Person-Centred

Pillar 5: Resource Orientation

Pillar 6: Supportive Therapy

Pillar 7: Orientation towards the Rare Disease Journey

Pillar 8: Interdisciplinary Cooperation
Psychosocial care is concerned with the psychological and emotional wellbeing of the patient and their family/carers, and may encompass issues around self-esteem, insights into adaptation to the illness and its consequences, communication, social functioning, and relationships. (Onyeka TC et al., 2010).

Psychosocial care is conducted in cooperation with the medical treatment team and emphasises supporting the resources of the patient and family throughout the course of the disease, during therapy and follow-up care. The basis for psychosocial care rests upon a supportive and informative relationship with the affected individual, family and social environment.

It is oriented towards the physical, emotional, social and developmental potential of the affected child, adolescent or adult, as well as their social environment, and takes into account individual styles and capacities to cope and adjust (Schröder et al., 2008).
Pillar 1: Holistic Care

1. The primary aim of psychosocial care is to identify the psychosocial implications of living with a rare disease, which are often complex, chronic, multisystemic conditions, and the impact of treatment (or lack of treatment), which can result in acute and chronic psychological stress and mental health issues for patients, family members and caregivers.

2. A case manager should be appointed to coordinate care and mitigate the stress factors associated with uncoordinated care, consultations and treatments, and provide timely access to psychosocial support.

Pillar 2: Prevention

3. Early preventative support should be aimed at reducing psychosocial risk factors and safeguarding the mental health and wellbeing of the person living with a rare disease and their family. Such support should aim to prevent or reduce social isolation, financial hardship, and the overall uncertainty, stress and anxiety associated with the rare disease journey.

4. Psychosocial care should have a low threshold for accessing psychosocial assessment support and be tailored to meet the needs of the people living with a rare or undiagnosed condition and their families.

5. Medical care should include regular and routine assessment and early detection for psychological stressors and include measures to prevent the deterioration of mental health of the person affected by a rare disease as well as all family members.
Standards for Psychosocial Care (II)

Pillar 3: Family Orientation

6. Families of PLWRD are the primary source of support for coping with the rare disease. Assessing the ability of parents and/or the caregiver and support system to cope with the demands and uncertainties of living with a rare disease and providing robust psychosocial support can optimise the resources of the family to provide emotional support, security and protection.

7. Psychosocial care should encompass the provision of timely information, advice and interventions aimed at optimising resilience, coping strategies and stress management as well as reducing the uncertainties experienced by the family.

Pillar 4: Person-Centred

8. Psychosocial support and guidance should be tailored to the specific needs and circumstances of an individual, as well as their family members, informed by the specifications and course of the disease and treatment. At each consultation or intervention, members of the medical team should allow time to enquire how the individual and family are coping with the rare or undiagnosed condition and treatment.

9. Information regarding the disease and treatment should be offered both during and after disclosure of the diagnosis, complementing the information and advice provided by the medical team and signposting for support when needed.
Standards for Psychosocial Care (III)

Pillar 5: Resource Orientation

10. Psychosocial care aims to promote functional coping mechanisms in PLWRD and families, strengthening resistance to psychological stress factors associated with rare or undiagnosed conditions and associated treatments.

11. Psychosocial care should leverage the individual abilities and skills of the individual and their family, promoting personal resources such as self-esteem, self-efficacy, optimism, hope and resilience, to help PWLRD and their families cope with living with a rare or undiagnosed disease.

12. Healthcare professionals should share information with the family on the local support groups and/or referrals to appropriate patient organisations that can provide peer and community support as well as access to trusted information.

Pillar 6: Supportive Therapy

13. Psychosocial care should provide supportive care, oriented towards the course of the disease through the diagnostic process and treatment. Monitoring of psychosocial needs should be a standard part of every consultation and provide advice and support throughout the whole course of the disease.

14. Psychosocial care requires sufficient time during consultations to build trusting relationships with the PLWRD and their family and to optimise support and resources.
Pillar 7: Orientation towards the Rare Disease Journey

15. Psychosocial care should start when a rare disease is first suspected, as this can reduce the time to diagnosis, and should continue throughout the entire course of the disease. Wider-family counselling should be offered in cases with a genetic diagnosis.

16. Accurate diagnosis empowers families to strengthen their resources by connecting with a patient community and accessing peer support.

17. Healthcare professionals should be trained to ensure that the presentation of significant, life-changing news is conducted in an appropriate and sensitive manner. Follow-up consultations should be scheduled within a month of a confirmed clinical and/or genetic rare condition diagnosis, with regular follow-up consultations scheduled annually thereafter.

Pillar 8: Interdisciplinary Cooperation

18. Psychosocial care is an integrated component of medical care, requiring close interdisciplinary cooperation with the medical, nursing and social team members.

19. The psychosocial team should be led by a psychologist or clinical psychologist, nurse-specialist, with an educator and social worker, both with an additional psychotherapy qualification, and be supported by a genetic counsellor, music and art therapist, a psychotherapist and a psychiatrist.

20. The medical team members should be trained to provide psychologically informed medical care to detect underlying unmet needs early and to communicate in a sensitive manner; conversely, the psychosocial care team should be trained to be ‘rare aware’ to understand the common challenges rare diseases pose for affected individuals and their families.
Best Practice on Psychosocial Care

Daniel Theisen, Director at Alliance Nationale Maladies Rares (ALAN)
Questions & Answers

Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches
Final & Closing Remarks
Satisfaction Survey for the webinar

https://form.jotform.com/241852997297375
THANK YOU