# Exploring the need to co-create treatment plans alongside people with schizophrenia: findings from a modified Delphi process

Silvana Galderisi<sup>1</sup>, Davi Kaur<sup>2</sup>, Péter Kéri<sup>3</sup>, Stephen R Marder<sup>4</sup>, Tina Matthews-Hayes<sup>5</sup>, Sabine Müller<sup>6</sup>, Dainius Pavalkis<sup>7</sup>, John Saunders<sup>8</sup>, Tomiki Sumiyoshi<sup>9</sup>, Fiona Nolan<sup>10</sup>

¹The University of Campania "Luigi Vanvitelli", Naples, Italy; <sup>2</sup>Caregiver, Antwerp, Belgium; <sup>4</sup>Semel Institute for Neuroscience and Human Behavior, UCLA, and the VA Desert Pacific Mental Illness Research, Education and Clinical Center, Los Angeles, CA, USA; Seaside Behavioural Centre, Virginia Beach, VA, USA; Charite – Universitätsmedizin Berlin, Germany; Lithuanian University of Health Sciences, Kaunas, Lithuania; <sup>8</sup>EUFAMI, Brussels, Belgium; <sup>9</sup>National Center of Neurology and Psychiatry, Tokyo, Japan; <sup>10</sup>Anglia Ruskin University, Chelmsford, UK

#### **BACKGROUND**

 People with schizophrenia need to be able to access multidisciplinary care and wider social support to take full advantage of advances in treatment. Mental health nurses will play an important role in ensuring that progress translates into improved care for people with schizophrenia.

#### What is schizophrenia?

- Schizophrenia is a severe mental disorder characterised by hallucinations, delusions, disorganised thinking, lack of motivation, loss of interest in everyday activities, social isolation, paucity of speech, and difficulties with attention and expressing emotions.
- It is estimated that schizophrenia directly affects at least 24 million people worldwide, and twice as many are indirectly affected by it (e.g. as caregivers).1
- It is typically diagnosed in adolescence or early adulthood and may affect a person's wellbeing throughout life, their employment status and their ability to live independently (Figure 1).
- With appropriate care and support, people can recover and live within the community, with up to 50% of individuals potentially having a good outcome.<sup>2,3</sup>

#### Symptoms of schizophrenia

- The schizophrenia spectrum typically manifests in 'positive' symptoms, such as delusions or hallucinations, 'negative' symptoms that describe a lack of motivation or a loss of emotional expression, and impaired cognitive functioning (**Figure 2**).<sup>4–6</sup>
- Guidelines for diagnosing schizophrenia include confirmation of various symptoms over time.<sup>7-9</sup>

### AIM

 To produce actionable global recommendations to support and improve the lives of people with schizophrenia.

#### **METHODS**

- Legal texts, policy documents and grey and scientific literature on schizophrenia that was published between 2014 and 2023 were reviewed on the topics of pathogenesis, diagnosis, treatment, adherence and impact, and the key findings were summarised.
- Experts on schizophrenia, including policymakers, members of patient advocacy groups, people with schizophrenia, caregivers and academics, were consulted. Two workshops were held to discuss and finalise the policy recommendations.

## **RESULTS**

 Two key areas in need of policy change identified by our expert panel were optimising schizophrenia treatment itself and seeking to go beyond treatment when planning care. Specialist nurses will have a vital role in translating progress in treatment approaches into positive outcomes for people with schizophrenia.

#### Treatment approaches in schizophrenia

#### Antipsychotic medications

- Early introduction of an antipsychotic medication can deliver sustained improvement in symptoms over 5 years;<sup>10</sup> however, medications are usually not given early.
- Maintenance therapy (long-term medication) with antipsychotics has been shown to reduce the risk of relapse and hospitalisations in people with schizophrenia.<sup>11</sup>
- Most available antipsychotic medications address the positive symptoms but have limited efficacy against negative symptoms and cognitive impairment (Table 1).
- This is a major concern because negative symptoms are more closely related to impaired functioning than positive symptoms; negative symptoms constitute a significant barrier to independent living, the ability to work and manage daily activities, and social engagement.4
- Cognitive impairment affects functions such as verbal fluency, memory, attention, processing speed, and decision making; these functions deserve the most urgent priority for the medical treatment of schizophrenia.<sup>5</sup>
- In recent years, advances have been made in identifying new therapeutic targets and brain stimulation interventions. Some of the potential interventions show promise for the treatment of negative symptoms and cognitive impairment.

#### Table 1. Potential benefits and limitations of current antipsychotic medication.

#### **Benefits** Limitations Reduction of positive symptoms Limited efficacy against negative symptoms Treatment of acute episodes

- Reduced risk of relapse
- Provision of stability and a platform for other treatments
- Reduction of aggression and hostility
- Reduced suicidal behaviour
- Inadequate treatment of cognitive
- impairment Troubling side effects or tolerability
- issues
- Low acceptability to some patients Poor adherence
- Negative perceptions

### Psychosocial therapies

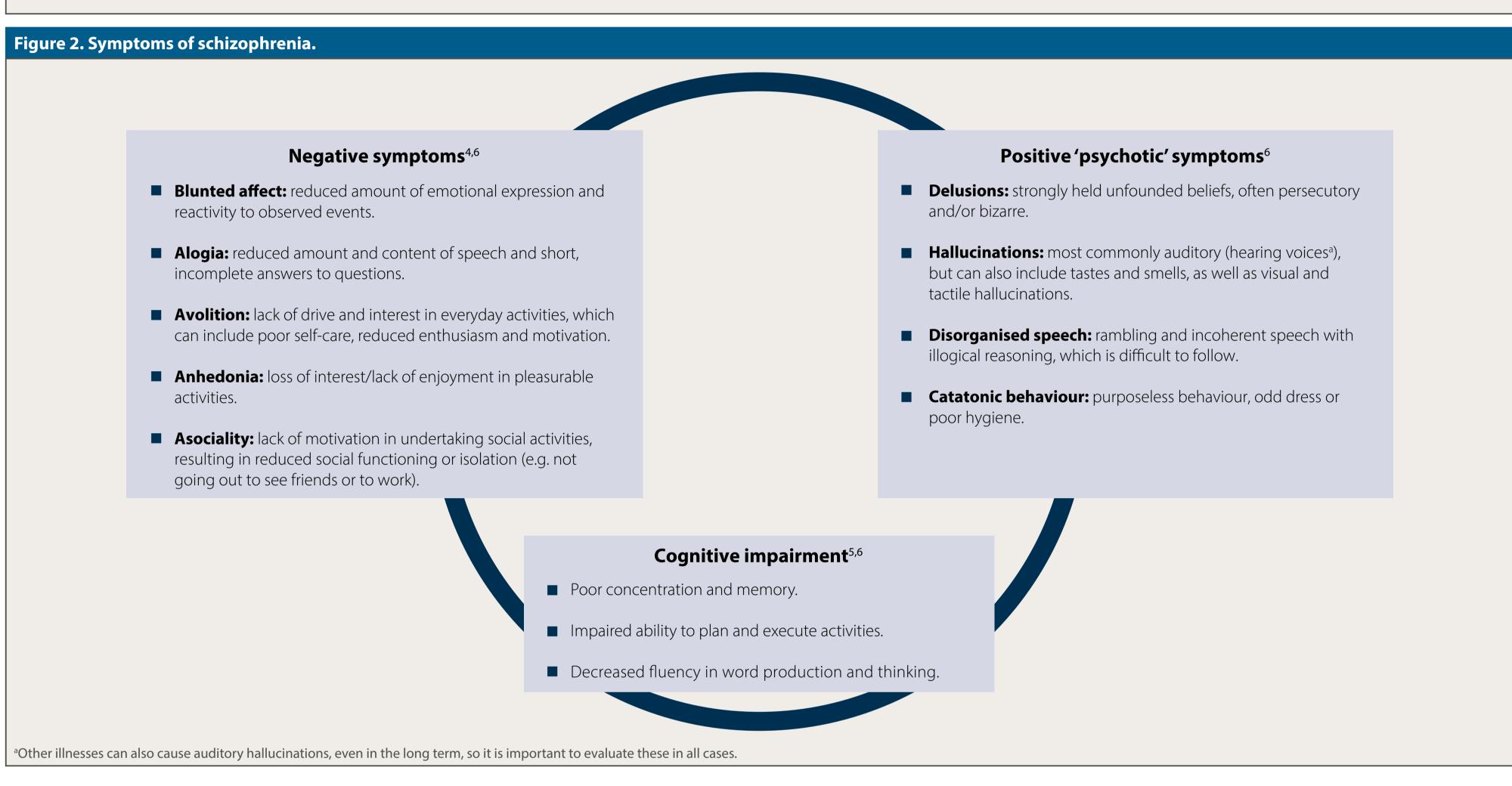
- Psychosocial therapies are aimed at improving the patient's functioning in the community, which can in turn result in clinical improvements, such as a reduction in the number of relapses or hospitalisations.
- Substantial evidence supports the use of different types of psychosocial therapies in schizophrenia, 12-16 including:
  - **cognitive behavioural therapy** for psychosis, a talking therapy that helps people manage their illness by changing the way they think and feel.
  - **cognitive remediation**, to improve aspects of cognition and to develop strategies for coping with cognitive impairment.
  - social skills training.
- Potential benefits of evidence-based approaches are summarised in Table 2.
- Several other approaches also show promise, including cognitive adaptive therapy, healthy lifestyle intervention, interventions targeting older individuals, prodromal stage intervention, social cognition training, and social rehabilitation (Clubhouse Model).

#### Management of comorbidities

 Schizophrenia is associated with a substantial burden of physical illness. On average, people with schizophrenia die 15 to 20 years earlier than the general population. 19-23

#### Figure 1. The journey for people with schizophrenia can affect wellbeing throughout life. **Early intervention** • • • • • • • • n pre-psychosis phase to reduce DUP to support early identification FIRST EPISODE OF **PSYCHOSIS NO SYMPTOMS PRE-PSYCHOSIS DIAGNOSIS FIRST TREATMENT**

Psychotic episode duration



#### Table 2. Potential benefits of psychosocial therapies. 14,16-18

Intervention	Potential benefits
Assertive community treatment	<ul> <li>Reduction in rates of homelessness and length of hospital stays</li> </ul>
<ul> <li>Cognitive behavioural therapy for psychosis</li> </ul>	<ul> <li>Decreases in both positive and negative symptoms and mood disturbances, and improved social functioning</li> </ul>
<ul> <li>First episode intervention for psychosis</li> </ul>	<ul> <li>Improvements in quality of life, social functioning and adherence</li> </ul>
<ul><li>Cognitive remediation</li></ul>	<ul><li>Improvements in cognition and psychosocial functioning</li></ul>
Family psychoeducation	<ul> <li>Some improvement in social functioning, and family coping and empowerment</li> </ul>
<ul> <li>Peer support and illness self-management training</li> </ul>	<ul> <li>Enhancement of empowerment and ability to cope with the illness</li> </ul>
Social skills training	<ul><li>Improvements in social functioning</li></ul>
<ul> <li>Supported employment</li> </ul>	<ul> <li>Increases in employment rates, hours worked and wages earned. Gains in self-esteem and quality of life</li> </ul>
<ul> <li>Integrated treatment for coexisting substance abuse disorder</li> </ul>	<ul> <li>Reductions in substance use and arrests; improved functioning</li> </ul>

- This burden is the result of a number of factors, including:<sup>21</sup>
- A high frequency of poor health behaviours (e.g. poor diet, poor oral health hygiene, lack of exercise, high rates of smoking, alcohol or substance abuse).
- Under-diagnosis of physical illnesses.<sup>24</sup>
- Decreased access to healthcare compared with the general population; furthermore, when care is provided it is often too late and of poor quality.<sup>22,25</sup> Suicide.
- Self-stigmatisation (people with schizophrenia may be reluctant to seek healthcare
- because they fear prejudice and discrimination). Healthcare professionals, including specialist nurses, should pay more attention to
- treating physical illnesses in people with mental illness.<sup>22</sup>

#### **Recommendations for change**

Specialist nurses play a vital role in the areas of treatment planning that our expert panel highlighted, and our corresponding recommendations are outlined below.

#### A. Optimising schizophrenia treatment

- Ensure direct access to specialist care including psychiatrists, specialist nurses, psychosocial and psychotherapy support, to be delivered through dedicated centres or community services, depending on the country, geographical context and healthcare system.
- 2. Ensure access to multidisciplinary teams who are able to provide comprehensive personal care assessment and personalised/integrated care, as well as wider support plans.
- 3. Create treatment plans in partnership with the patient and their chosen caregiver, to include:
  - i. a care and crisis management plan
  - ii. identification of recovery options, and personal goals for recovery iii. warnings about potential physical and psychological side effects to prevent
  - treatment withdrawal.

## **B. Going beyond treatment**

- 4. Integrate mental health education into all levels of healthcare training, offering additional specialised information for those pursuing mental health careers.
- 5. Prioritise recovery (i.e. the attainment of a more fulfilling and rewarding life) as the primary goal of treatment. 6. Ensure the involvement of people with schizophrenia and their chosen caregivers when deciding on what services are required (e.g. financial security,
- supported housing, contacts with social workers, vocational support and rehabilitation) and how these should be provided. Ensure holistic treatment plans taking into account social support and
- comorbidities.

## **CONCLUSIONS**

- Most currently available antipsychotic medications address positive symptoms but have limited efficacy against negative symptoms and cognitive impairment.
  - Recent therapeutic advances have been made that show promise for the treatment of negative symptoms and cognitive impairment. Current treatment and wider care models must change to take full advantage of these advances for the benefit of people with schizophrenia.
- We developed global policy recommendations to support and improve the lives of people with schizophrenia. In summary:
  - Global policymakers should work to ensure that direct access to specialist care, including specialist nurses, as part of multidisciplinary care teams, is available to people with schizophrenia.
  - These teams should have the skills to provide comprehensive assessments of a person's needs, as well as personalised, integrated, recovery-oriented and trauma-informed care, along with wider support plans.
  - A central aspect of optimising care is the need for care teams to create treatment plans in partnership with the person with schizophrenia and their chosen caregiver.
  - Adoption of these recommendations would contribute to shifting the primary goal of treatment towards **recovery** (i.e. the attainment of a fulfilling life) via holistic treatment plans, which consider social support services and comorbidities.

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#### **Disclosures**

Creation of this poster and the schizophrenia policy report that the poster is based on were undertaken by the Oxford Health Policy Forum (OHPF) in collaboration with the authors. We are also grateful for the support and input of Ruth Bentley, Will Carpenter, Rachael Chandler, Anna Dahlberg, Ronan Doyle, John Findlay, Anja Kare Vedelsby Louise Kimby, Husseini Manji, Christine Marking, Neil More, Lindsay Perera, Millie Ryan, Pontus Strålin, Elizabeth Webb and Kajsa Wilhelmsson.

#### **Funding**

Creation of the schizophrenia policy report that this poster is based on was supported by an independent medical educational grant from Boehringer Ingelheim International GmbH, and an unrestricted educational grant from H.Lundbeck A/S. Neither organisation has had influence on, or input into, the development of the policy report or this poster.

The information presented here is based on the Schizophrenia – Time to Commit to Policy Change 2024 report.