

SCHIZOPHRENIA'S PATIENT JOURNEY: A PARTICIPATORY MODEL

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Background

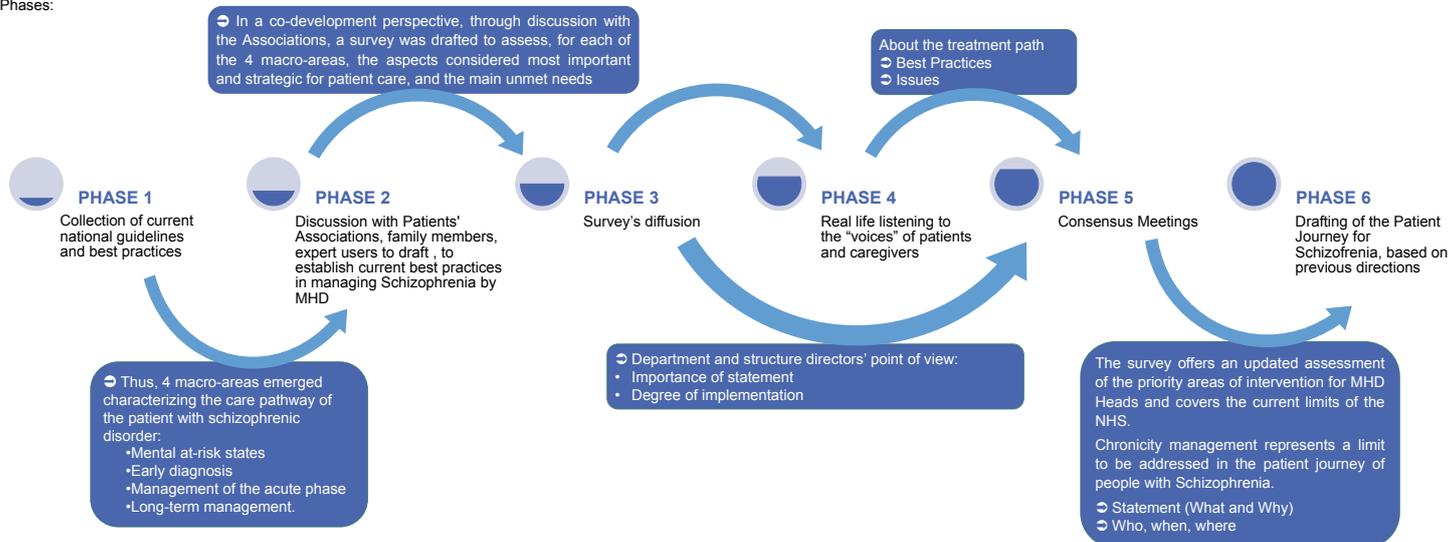
Schizophrenia is a severe mental disorder that seems to present with a variable but chronic course in up to 60% cases, negatively affecting quality of life and psychosocial functioning.

Continuity of care between the purely clinical management and the more rehabilitative-socializing one is of primary importance for the care of the patient with Schizophrenia.

However, the existence of different resources and regulations in the regions and the lack of a single patient budget that encompasses both health and care interventions mean that the network of Services ends up being too unbalanced towards health care.

Methodology

6 Phases:



Survey

Survey study aims to share evidence-based information and real-life experiences, examining the needs of patients during their care path, and identifying gaps and areas for improvement.

The survey comprised items for each area of interest, asking for the degree of agreement or disagreement on the importance of the statements and on their concrete implementation (fig.1).

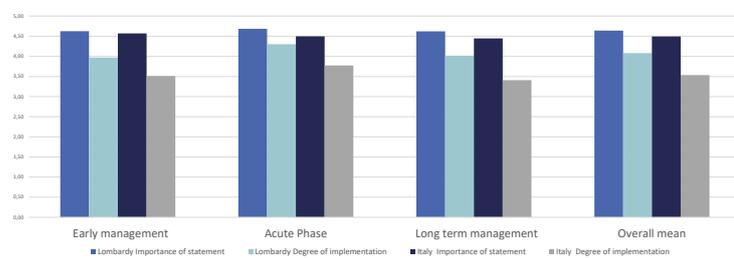
It was sent to Mental Health Organizational Units in the Lombardy in 2021 and extended to national level in 2022; the questionnaires were administered through an online platform using the CAWI method, with closed and open questions.

Sample

Lombardy survey: 25 Complex Structure Heads

Italy: 38 department directors and 22 structure directors, with a national coverage of 80%.

Fig. 1 Survey results



Objectives

To plan a patient journey for schizophrenia:

- Including both care and management, in response to the complexity of the disorder, aiming to achieve recovery for these patients.
- Resulting from a participatory process, that would highlight both consensus with respect to best practices in the management of schizophrenia by Departments of Mental Health (MHD), as well as gaps and critical issues.

Results

The results indicate a larger gap in the long-term management phase, where main differences were in taking care of family members, home interventions, psychoeducational/psychotherapeutic interventions. Important gaps were seen also for pharmacological restraint, collaboration with General Practitioner and regarding the role of experts in peer support and in multi-professional teams of care. As for the national survey, criticalities emerged in the early management phase, again linked to the possibility of home interventions, and to child neuropsychiatry protocols.

Both the regional and national dimensions' results are clear and seem to follow the same direction.

Need for reinforcement of:

- late diagnosis and assessment through the use of validated and internationally widespread assessment tools;
- cooperation aimed at prevention and care with GPs and free-choice Paediatricians;
- multidisciplinary interventions in the patient's life environment and interventions aimed at family members;
- strengthening psychotherapy, psycho-educational, psychosocial interventions;
- again, the need to pay more attention to family members;
- it is necessary to improve patient care and ensure hospital-territory continuity;
- there is a need to strengthen team-based approaches for joint hospital-territory care (e.g.: general practitioner, community nurse, addiction services, third sector for social interventions, schooling and/or job placement);
- stronger promotion of peer support groups.

Fig. 2 Projects and protocols with GPs aimed at prevention (National Level)

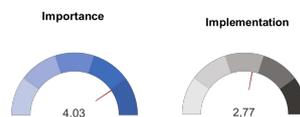


Fig. 3 Home interventions (National Level)



LIMITATIONS

The survey involved only specialists in adult psychiatry, but not child neuropsychiatrists, GPs and other mental health workers, so it does not cover the views of all the stakeholders involved in this complex field.

CONCLUSIONS

The present survey, co-designed by clinicians, expert patients, and caregivers, offers an updated evaluation of the areas of intervention of priority importance for the patient journey of schizophrenia in MHS, also covering the current critical issues. Particularly, the moment of transition from child to adult services in the early phase of the disorder and the management of chronicity represent unmet needs to which a response is needed to improve the patient journey of people living with schizophrenia.

REFERENCES

- Capasso-Litazar A, Gutierrez-Maldonado J, Miranda-Castillo C. Quality of life in caregivers of patients with schizophrenia: a literature review. *Health Qual Life Outcomes*. 2009 Sep; 7:84.
- Fiorillo A, Barlati S, Bellomo A, Corvetti G, Nicolò G, Sampogna G, et al. The role of shared decision-making in improving adherence to pharmacological treatments in patients with schizophrenia: a clinical review. *Ann Gen Psychiatry*. 2020 Aug; 5:19.
- Fleischhaker WW, Arango C, Arned P, Barnes TRE, Carpenter W, Duckworth K, et al. Schizophrenia—time to commit to policy change. *Schizophr Bull*. 2014 Apr; 40 Suppl 3(Suppl 3): S165-94.
- Galdieri S, Rosa MA, Girardi P, Anzorelli M, Caporinello B, Angiola E, et al. Schizophrenia and "narrower needs": From diagnosis to care in Italy. *Eur Psychiatry*. 2020 Mar; 63(1): e26.
- Galdieri S, Kaiser S, Bitter I, Nordentoft M, Macci A, Saba M, et al. EPA Guidelines on Treatment of Negative Symptoms in Schizophrenia. *Eur Psychiatry*. 2021 Mar; 17: 64: 1-56.
- Klanwin DN, Dixon L, Caregiver burden, family treatment approaches and service use in families of patients with schizophrenia. *Int J Psychiatry Relat Sci*. 2005;42(1):15-22.
- Julian S, Johnson M, McKenna P. Schizophrenia. *Lancet*. 2022; 399(10231): 473-86.
- Lora A, Mozzani E, Ibrahim B, Soranna D, Corrao G. Routine quality care assessment of schizophrenic disorders using information system. *Int J for Quality in Health Care*. 2016; 1-6.
- Murray CE, Lopez AD, Organization WH, Bank W. Health HS of P. The Global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020: summary / edited by Christopher J. L. Murray, Alan D. Lopez [Internet]. Geneva PP: Geneva: World Health Organization; 1996. (Global burden of disease and injury series, volume 1).
- Percudani M, Cerati G, Petrovich L, Vita A. *La Psichiatria Di Comunità in Lombardia: Il Piano Regionale per La Salute Mentale Lombardo e La Sua Linea Di Attuazione (2004-2012)*. McGraw-Hill; 2013. ISBN 9788836664.
- Pedroni F, Riddle A, et al. Protocol for the development of guidance for stakeholder engagement in health and healthcare guideline development and implementation. *Systematic Reviews*, vol. 9, n. 21, 2020.
- Shafiq A, Deroi T. Meta-analysis of the positive and Negative Syndrome Scale (PANSS) factor structure. *J Psychiatr Res*. 2019 Aug; 115: 13-20. 10.1016/j.jpsychres.2019.05.008.
- Shahry R, Aguping YB. Peer Support in Mental Health. *Literature Review*. JMBR Ment Health, vol.7(6), 2020.
- Van E, Finken T, et al. Evaluating the "return on patient engagement initiatives" in medicines research and development: A literature review. *Health Expectations*, vol. 23, n. 1, 2020, pp. 5-18.
- Vita A, Barlati S, Bellomo A, Poli PF, Masi G, Nobili L, et al. Patterns of Care for Adolescent With Schizophrenia: A Delphi-Based Consensus Study. *Front psychiatry [Internet]*. 2022 Mar; 30: 13:844098.