PROJECT MENCAP

2025

TRANSFORMING VOICES INTO DATA: PRELIMINARY EVIDENCE ON CARE, RIGHTS, AND INEQUALITIES IN BIPOLAR DISORDER IN ITALY

ASSOCIAZIONE ITALIANA BIPOLARI

REPORT

Associazione Italiana Bipolari

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Questo report è disponibile in due lingue: italiano e inglese. La versione italiana é stata pubblicata separatamente.

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Acknowledgements

This report is the result of a structured collective effort, developed within the research, data collection, communication, and institutional activities of the **Italian Bipolar Association (AIBP)** and the European Network for Bipolar (ENB). The contents presented derive from multiple distinct but interconnected projects, coordinated within an overarching strategy of monitoring, advocacy, and bottom-up evidence generation. **Overall coordination of the report, as well as final drafting and editing, were carried out by Eleonora Caiazza,** *MSc Clinical Neurodevelopmental Sciences (King's College London), Vice President and co-founder of the Italian Bipolar Association (AIBP), and President and co-founder of the European Network for Bipolar (ENB).* She is responsible for the association's institutional work, public campaigns, and data collection and analysis activities. The campaign **"Bipolar Disorder: Below the Tip of the Iceberg"** and the project **"Body, Stability, and Integrated Care"** were developed through the association's social media channels. For these projects, the *Public Relations* and *Social Media* team is gratefully acknowledged for its central role in the design of the information campaigns, data collection, and dissemination of content, activities that developed over the course of several months, and the results of which are analysed in the present report. The project **"Real Access to Care: Mapping Mental Health Services"** was made possible by the work of the *Hospital Contacts* team, which conducted a systematic, region-based mapping of mental health services. This activity was carried out over a two-year period through direct contact with facilities and services, and represents one of the first bottom-up mappings of psychiatric care provision in Italy.

The **National Survey on Malpractices in Psychiatric Patient Care** and its study protocol were developed within the framework of the MENCAP Project by a team composed of:
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Noera Azimi, *Assistant Psychologist, MSc Clinical Neurodevelopmental Sciences, King's College London.* The team contributed to the development of the questionnaire, the study protocol, and the methodological and statistical framework of the survey, ensuring scientific rigour, ethical coherence, and attention to data governance aspects.

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The paradox of a care system that drives patients away

Imagine seeking help because you are unwell, only to realise that what is happening now matters less than what is already written in your medical record. Symptoms are interpreted through the lens of a previous diagnosis; questions are limited, and further exploration even more so. Instead of a thorough assessment, there is a sense that conclusions have already been drawn. This is not an isolated experience: *58% of respondents report feeling that evaluations of their health were based exclusively on their prior clinical history rather than on a comprehensive assessment of their current situation.*

At the same time, care pathways appear confusing and fragmented. Professionals do not communicate with one another, guidance is unclear, and no one truly explains what the next steps should be. *A lack of coordination between care providers is reported by 46.6% of participants, while 44.8% indicate insufficient information about available services.* In psychiatry—where care should integrate biological, psychological, and social dimensions—this fragmentation carries even greater consequences. **As a result, people begin to postpone or avoid seeking care, not because they feel better, but out of fear of being dismissed or of receiving inadequate treatment.** *Indeed, 45% report having delayed or avoided care due to concerns about the quality of treatment.* **This is the paradox: a system designed to provide care ultimately drives people away, worsening individual suffering and, over time, increasing the clinical and social burden of care itself.**

> **Imagine being expected to follow important instructions written in small print, hastily provided, while being told that "there is no time to explain."**

You are prescribed a pharmacological treatment without truly knowing what to expect: how it may make you feel, whether it will sedate you, alter your body or your mind, how long you will need to take it, or what will happen if it does not work. You follow the instructions either because you trust the clinician or because you feel you have no real alternatives. Yet without genuine understanding, it becomes difficult to adhere to treatment, to ask questions, or to report side effects. *Thirty-eight per cent of patients report having received treatments or diagnostic tests without any explanation of their necessity, and 59% felt pressured to accept care or medication they were not comfortable with. In many cases, care is reduced to medication alone (50%), with alternative options not discussed (39%). Consent may be obtained, but it often remains purely formal.*

When people do not understand their care, the clinical relationship itself weakens. *Sixty-one per cent of respondents report poor listening or a lack of empathy from healthcare professionals, while 41% describe feeling treated more as a collection of symptoms than as a person. In more than one third of cases, individuals' experiences were questioned or minimised. This is compounded by the absence of clear information about what will happen after treatment, reported by 70% of respondents, and by the lack of structured emotional support, which 58.5% report not having received.* **The paradox is clear: without communication, listening, and genuinely informed consent, even available treatments become harder to follow and less effective, turning the clinical relationship from a tool for care into a source of distance.**

Not knowing you have rights means being unable to exercise them.

Nearly one in two people (48%) report not having been informed of their rights, including the right to refuse treatment or to provide genuinely informed consent. In more than one third of cases, decisions are made without the person's active involvement, within a paternalistic framework in which choices are made "for your own good" without explanation or consultation.

This lack of information and participation can quickly translate into a tangible loss of self-determination. *Thirty-seven per cent of patients report being excluded from decision-making processes, while 32.3% describe their psychiatric diagnosis as functioning as a lasting label* that limits both their rights and their credibility. *In nearly 30% of cases, experiences of power imbalance or psychological coercion emerge, and for one in five individuals, treatments occurred without genuine consent,* even when they were formally lawful. These experiences are not confined to exceptional settings: they occur in first-contact services, outpatient clinics, and long-term care contexts, extending to inpatient and crisis-management settings. **The paradox is that paternalistic practices—long considered normal and even protective—are now shown to worsen care outcomes: they undermine self-determination, weaken consent, and ultimately compromise the very protection and effectiveness the system claims to provide.**

When Care Leaves Lasting Marks on Health and Daily Life

Imagine being forced to choose which part of yourself can be allowed to deteriorate: your mental stability, your physical health, your relationships, or your sexual life. Even when a procedure ends or a treatment is changed, the effects do not always stop there. What remains are lasting traces that shape everyday life—often invisible in clinical records, taken for granted as "acceptable," until you are the one who has to live with them every day. Survey responses indicate that, for a significant proportion of people, the experience of care has been associated with substantial consequences for physical and cognitive health.

One third of respondents report persistent cognitive impairment, while one in five describe a permanent physical disability. Others report treatment-induced metabolic conditions, such as diabetes or hypertension, or chronic neurological problems. Even when the harm is not permanent, the impact can be considerable: *more than 40% describe temporary but debilitating side effects, and around 30% report cognitive or motor changes that interfere with daily functioning. More than one in three individuals report a decline in self-esteem or body image, while over a quarter experience a reduction in sexual desire. In one in five cases, social isolation is reported as having worsened or emerged during the course of treatment,* and for some individuals, sexual dysfunctions arise that significantly affect quality of life and intimate relationships.

01. Introduction

Why This Report: The Bottom-Up Model

The Italian Bipolar Association (AIBP) is the first and only national organisation in Italy founded and led by people living with bipolar disorder, with the involvement of family members, healthcare professionals, and activists. AIBP was established in response to a clear gap in the Italian mental health system: the limited recognition of lived experience as a legitimate source of knowledge, the lack of practical support tools, and the exclusion of people with bipolar disorder from decision-making processes, information pathways, and the governance of care.

In the Italian context, *people with bipolar disorder have historically been described through diagnostic categories and clinical frameworks, while remaining largely absent from the definition of care priorities, the evaluation of services, and the production of knowledge about the systems that affect them*. AIBP was created to address this imbalance by recognising lived experience not as a personal or anecdotal contribution, but as a form of knowledge that can inform clinical practice, professional training, and health policy. This principle underpins the association's bottom-up model.

In its day-to-day activities, AIBP gathers hundreds of first-hand accounts, supports individuals across their care journeys, develops tools for prevention and long-term stability, and delivers bottom-up training initiatives grounded in users' real and expressed needs. This positioning allows the association to observe directly what works and what fails within mental health services, not only at the level of clinical care, but also across relational, organisational, and institutional dimensions.

On this basis, data collection is not a separate or abstract exercise for AIBP, but an integral part of its support, advocacy, and engagement with the healthcare system. Collecting data makes it possible to bring together experiences that would otherwise remain fragmented or invisible, and to build a shared evidence base to support dialogue, service improvement, and collective accountability.

01. Introduction

From the First Report to the Second

This field-based work has made a structural gap increasingly clear: in Italy, there is no systematic, independent, or comparable data on people's experiences within psychiatric care pathways. This gap is especially evident in relation to the ethical and relational quality of care, the protection of patients' rights, territorial inequalities, and the impact of malpractice on trust in the healthcare system.

> More than forty years after Law 180/1978, known as the Basaglia Law, the Italian psychiatric reform— inspired by the work of Franco Basaglia and the Democratic Psychiatry movement — marked the dismantling of the asylum-based model and the abolition of the psychiatric hospital as a total institution. It introduced a community-based system of care and redefined the role of hospital psychiatry as a limited, non-segregating intervention formally oriented toward the protection of rights.

Level	What Currently Exists	What Is Missing
Regulatory Framework	Law 180/1978 *(the Basaglia Law)* establishes fundamental principles for the protection of rights and places limits on the most severe and overt violations, such as institutionalisation, arbitrary deprivation of liberty, and involuntary confinement[1].	An updated regulatory framework that recognises and clearly defines forms of harm, abuse, or malpractice that do not stem from institutionalisation, but instead arise from the clinical, organisational, and relational practices of contemporary psychiatric care.
System Implementation	Mental health services organised at the regional level, with territorially differentiated care models.	There is a lack of shared tools and mechanisms to ensure that rights are effectively upheld across the country; fragmentation, regional inequalities, and ongoing barriers to access and continuity of care continue to affect people's everyday lives.

[1] Legge 13 maggio 1978, n. 180 (Accertamenti e trattamenti sanitari volontari e obbligatori), testo integrale vigente, Normativa – Il portale della legge vigente: https://www.normattiva.it/uri-res/N2Ls?urn:nir:stato:legge:1978-05-13;180

[2] SOSPSICHE, Le disparità regionali in psichiatria: un ostacolo alla salute mentale in Italia, 27 giugno 2024. https://www.sospsiche.it/news-fisam/salute-mentale-news-in-dettaglio.html?tx_news_pi1%5Bnews%5D=134519

01. Introduzione

Dal primo report al secondo

Level	What Currently Exists	What Is Missing
Scientific and Institutional Debate	Legal analyses of professional liability and informed consent, empirical studies based on administrative data, and national surveys on experiences within mental health services [4] [5] [6].	There is a lack of systematic and ongoing analysis of **people's lived experiences** within mental health services, particularly in relation to ethical, relational, and communicative aspects, as well as trust in the system. These experiences are still treated as isolated accounts rather than as structural data.
Monitoring	The collection of administrative and clinical data on service access, interventions, and outcomes [5] [6].	Independent national mechanisms to monitor patient experiences, capable of distinguishing between individual episodes and broader, structural patterns of systemic dysfunction.
Recognition of Harm	Legally recognised violations remain largely confined to extreme cases or to narrowly defined, formally categorised situations.	What remains largely unaddressed is the recognition of everyday malpractice, relational violations, and systemic inequalities, which continue to be treated as isolated cases rather than as indicators of structural weaknesses within the system.

[3] Cassano G.B., Sbrana A., Come migliorare e salvaguardare la legge psichiatrica in Italia, Journal of Psychopathology. https://old.jpsychopathol.it/article/come-migliorare-e-salvaguardare-la-legge-psichiatrica-in-italia/

[4] Dalla Balla, F. (2019). I paradigmi normativi dell'amministrazione psichiatrica: servizi territoriali e strumenti per l'autodeterminazione terapeutica a quarant'anni dalla Legge Basaglia. BioLaw Journal, 1(1), 399–432. https://teseo.unitn.it/biolaw/article/view/1334/1336

[5] Lasalvia, A., Bodini, L., Fin, V., et al. (2025). Lived experience in Italian mental health services: A national survey of peer support and co-production practices. BMC Health Services Research, 25, 1235. https://doi.org/10.1186/s12913-025-13407-z

[6] Lorettu, L., Nivoli, A., Milia, P., Depalmas, C., Piu, D., Taras, G., Riondino, L., & Nivoli, G. (2020). La responsabilità professionale in psichiatria: evoluzione e criticità. Rivista di Psichiatria, 55(Suppl. 1), S3–S8. https://www.rivistadipsichiatria.it/archivio/3504/articoli/34899/

01. Introduction

This document is AIBP's second public report and represents a key step in the association's work. While the first report focused mainly on collecting and presenting testimonies—aimed at bearing witness, increasing visibility, and breaking the silence—this second report responds to the need to turn lived experience into structured evidence, without flattening its complexity or reducing it to simple numerical indicators.

This report brings together and provides a coordinated analysis of multiple data sources collected directly by AIBP over recent years, including:

- **a national online survey** on malpractice, inequalities, and rights violations in psychiatric care;
- **a qualitative thematic analysis** based on service users' narratives;
- **data used in clinical and training settings** to support dialogue and comparison with mental health professionals;
- **an operational mapping of mental health services,** conducted service by service and region by region, enabling observation of the actual structure of care provision across the country.

The data presented in this report are drawn from real-life experiences and are preliminary and descriptive in nature. They are not intended to replace academic research, nor to generate statistical generalisations about the Italian population as a whole.

Their value lies in the consistency and repetition of the findings: the same critical issues emerge across different tools and levels of analysis, from individual experience to clinical practice and, ultimately, to the organisation of services. This convergence of evidence points to structural problems that affect quality of care, trust in the healthcare system, and health outcomes for people with bipolar disorder. *The report therefore does not stem from an abstract theoretical exercise, but from a concrete and shared need, identified through close observation of the everyday experiences of those who live with, use, and work within mental health services.*

This approach is also aligned with international models, where the systematic collection of experience-based data has strengthened service accountability, improved quality of care, and supported the protection of rights. At the same time, this report represents a starting point for further development, including the expansion of data collection, collaboration with professionals and researchers, validation of the methods used, and the creation of shared tools to monitor mental health services over time.

The aim is to make this evidence accessible and usable, so that it can inform care practices that are more equitable, effective, and respectful of people's dignity, through ongoing dialogue with those who experience them directly.

02. Types of Data Presented

The evidence analysed in this document is drawn from a range of tools and data-collection approaches developed and used by the Associazione Italiana Bipolari (AIBP) within its associative, training, and institutional activities.

More specifically, data collection was based on:

- online surveys disseminated through targeted campaigns and the association's communication channels;
- voluntary participation by the individuals involved;
- descriptive quantitative analysis combined with thematic qualitative analysis;
- an operational census of mental health services, conducted region by region and service by service.

All data-collection activities took place outside controlled experimental or clinical settings and did not involve any intervention, modification, or influence on the care pathways of the individuals involved.
The data reflect a multi-year process of collection, organisation, and analysis carried out directly by AIBP, grounded in the observation of needs emerging from real-world contexts. Although not collected within academic or experimental settings, the data were developed and analysed within an explicit, coherent, and clearly articulated methodological framework.

> Taken together, these data make it possible to observe how psychiatric care operates from multiple perspectives, including people's lived experience, the clinical relationship, and the concrete organisation of services across the territory. Their value lies not in the size of the sample, but in the repeated emergence of the same critical issues across different tools, contexts, and complementary levels of analysis. This convergence makes it possible to interpret individual experiences not as isolated episodes, but as recurring signals of how the care system functions—or fails to function.

The report brings together four main types of data, collected for different purposes and through different methods, and analysed within a single, shared interpretative framework.

02. Tipologia dei dati presentati

2.1. Quantitative Data

2.1.1. National Online Survey

The report includes the preliminary findings of the **National Survey on Malpractice, Inequalities, and Violations in Psychiatric Patient Care**, promoted by the Associazione Italiana Bipolari (AIBP). The survey was disseminated online through targeted campaigns and the association's communication channels, and was designed to collect information on care experiences within both public and private services, across different stages of the psychiatric care pathway.

Unlike other tools developed and used by AIBP, this survey was intentionally opened to a broader population, including:
– people living with bipolar disorder;
– people living with other severe psychiatric conditions;
– family members and caregivers, understood as those who support people in care on a daily basis and directly observe their interactions with mental health services.

This methodological choice, described in detail in the survey's study protocol, reflects the need to examine malpractice and systemic criticalities not as issues tied to a single diagnosis, but as cross-cutting dynamics within psychiatric care. The inclusion of multiple perspectives also allows for the consideration of intersectional factors—such as family role, caregiving responsibilities, social conditions, and pathways of access to services—which can significantly shape care experiences and intensify their impact.

The data presented in this report represent a preliminary phase of data collection and analysis. They do not constitute definitive academic validation, but instead provide a structured and coherent empirical basis for identifying recurring patterns, guiding further analysis, and informing future methodological developments, as outlined in the study protocol.

[7] Associazione Italiana Bipolari, Protocollo di Studio Sondaggio Nazionale sulle Pratiche Scorrette, gli Abusi e le Discriminazioni nella Cura dei Pazienti Psichiatrici (maggio 2025) https://associazioneitalianabipolari.it/wp-content/uploads/2025/05/Protocollo-di-Studio-Sondaggio-Nazionale-sulle-Pratiche-Scorrette-gli-Abusi-e-le-Discriminazioni-nella-Cura-dei-Pazienti-Psichiatrici-1.pdf

2.1.2. Clinical-Relational Data - Training and Conference Use

Part of the data presented is drawn from collections and re-elaboratiions used in clinical and training settings, in particular within the conference “Body, Mind, and Bipolar Disorder: From Crisis to Integrated Care.” In this context as well, the data derive primarily from people living with bipolar disorder and were used to explore the role of the body, early warning signs, treatment side effects, and material conditions in mood stability and treatment adherence.

These data represent a clinical and relational translation of the evidence emerging from AIBP’s associative work and make it possible to engage directly with professionals, linking lived experience to concrete implications for care.

2.1.3. Structural and Systemic Data - Mental Health Services Census

Finally, the report includes data generated through a systematic effort to contact mental health services, carried out by AIBP service by service and region by region over a two-year period. In this case, the data are not self-reported by service users, but consist of information collected directly by the association on existing services, their responses to contact, their willingness to engage in dialogue, and the initiation of collaborative activities.

For the regions included in the dataset, this work achieved full coverage of existing services, effectively constituting a near-census rather than a sample. This material makes it possible to examine the actual structure of care provision and to relate users’ reported experiences to the concrete opportunities available at the territorial level. In this way, individual experiences can be connected to the organisation of services, making territorial and organisational inequalities visible.

[8] Associazione Italiana Bipolari, Corpo, mente e disturbo bipolare: dalla crisi alla cura integrata (settembre 2025) https://associazioneitalianabipolari.it/wp-content/uploads/2025/12/Corpo-mente-e-disturbo-bipolare-dalla-crisi-alla-cura-integrata.pdf

2.2. Qualitative Data

Thematic Analysis of Lived Experience

The report also incorporates a qualitative thematic analysis based on narratives collected through the campaign **“Bipolar Disorder: Beneath the Tip of the Iceberg.”** This dataset consists exclusively of contributions from people living with bipolar disorder and focuses on subjective experiences, the meanings attributed to care, and recurring patterns of relational, communicative, and institutional criticalities.

Although the number of contributions is limited, the analysis was conducted in a systematic manner and made it possible to identify recurring themes that are also reflected in the quantitative data and in the clinical–relational evidence presented in the report. This material is not intended to represent the population as a whole, but rather to add interpretative depth to the numerical findings and to clarify how and why certain practices, communication styles, or organisational choices may produce negative—or, conversely, protective—effects on the care experience.

From this perspective, the findings provide a concrete foundation for future developments in training and education. The aim is to use this evidence to design training pathways promoted by the Associazione Italiana Bipolari and, in the longer term, potentially replicable at the international level through the European network, should data collection be expanded on a broader scale. These pathways could be directed at university programmes and professional training contexts in psychiatry, psychology, and the health and social care professions, complementing diagnostic frameworks with practical guidance on how people actually need to be supported: which words help build a therapeutic alliance, which phrases risk worsening the situation, and how language shapes both the effectiveness and acceptability of care.

The same data can also support anti-stigma initiatives, as well as education and awareness-raising activities related to bipolar disorder. Data collection was deliberately structured to distinguish between different episodes and phases of the condition, recognising that what may be helpful in one context—for example during a depressive episode—may be ineffective or harmful in another, such as during a manic episode. This distinction makes it possible to develop more targeted, realistic, and experience-based communication and training tools that are closely aligned with people’s lived experience.

Methodological Framework and Transparency

This report brings together several data-collection activities promoted by the Associazione Italiana Bipolari (AIBP) over the course of 2025, developed within its associative, training, and institutional work. The aim is to provide a complementary account of people's reported experiences along psychiatric care pathways, together with selected observable aspects of how the mental health system and the territorial service network operate in practice. Taken together, these activities fall within an observational and descriptive design. Data collection took place outside controlled experimental or clinical settings and did not involve interventions, manipulation of variables, or any influence on the care pathways of the individuals involved. The report was not designed to test causal hypotheses, but to make visible recurring patterns, converging critical issues, and experiential trajectories emerging from systematic field observation.

Data sources

The report is based on three main types of data, analysed within a shared interpretative framework:

- **Experiential data**, collected directly from individuals through a structured national survey and exploratory data collections developed via thematic campaigns on the association's social media channels. Participation was voluntary and unpaid, with recruitment carried out primarily through AIBP's digital and community channels, following a convenience sampling approach consistent with the associative and bottom-up nature of the project. The national survey was the only instrument guided by a formal study protocol and explicitly included the participation of caregivers. The social media–based collections served an exploratory and generative function, aimed at identifying recurring themes, shared language, and unmet needs.
- **Thematic qualitative data**, derived from textual contributions and spontaneous materials, used to deepen understanding of meanings, relational dynamics, and subjective experiences, particularly across different episodes and phases of bipolar disorder. These materials were not intended to provide systematic measurement, but to complement and contextualise the quantitative findings.
- **Structural and systemic data**, derived from the census of mental health services conducted by AIBP through standardised contacts with service providers. This component examines service organisation, availability, and responsiveness, and is used to situate reported experiences within a broader organisational and territorial framework.

Methodological Framework and Transparency

Analysis and Integration of Evidence

Analytical approaches were defined in relation to the nature of the data collected. Survey data were summarised using descriptive statistics (counts and percentages) to observe how frequently specific experiences and critical issues were reported within the sample. Qualitative materials were analysed using a thematic approach, aimed at identifying recurring and convergent patterns. The integration of quantitative, qualitative, and structural components is a central feature of the report. The quantitative data make internal distributions and frequencies within the sample visible; the qualitative data help clarify meanings, dynamics, and contexts; and the service census adds a systemic perspective, allowing individual experiences to be interpreted in relation to the concrete organisation of care.

Sampling limitations and scope of the data

The data presented in this report are based on voluntary participation and convenience sampling. ***This means that respondents were likely primarily individuals who had a reason to take part, for example because they had experienced difficulties,*** inappropriate practices, or negative interactions within mental health care pathways. As a result, people who did not encounter significant problems with services are likely to be underrepresented. For this reason, ***the report does not aim to estimate the prevalence of abuse or malpractice in Italy, nor to provide nationally, regionally, or temporally representative figures.*** T

he findings should not be read as a comprehensive picture of the mental health system, but as a focused analysis of specific experiences. ***The purpose of this work is different: to understand, among those who reported critical experiences, which types of inappropriate practices occur most frequently, in which care settings they arise, and what consequences they have for trust, the therapeutic alliance, and continuity of care.*** In this sense, the report does not measure how widespread the phenomenon is, but how it takes shape and where it tends to concentrate. The value of the data therefore lies in their ability to identify recurring patterns and structural problems, making visible dynamics that would otherwise remain isolated or difficult to recognise. The report should be understood as an exploratory analytical tool, intended to clarify these phenomena and to support dialogue with services, as well as the development of more targeted and effective future interventions.

03. The National Survey on Malpractice in Psychiatric Care

This chapter presents the evidence emerging from the National Survey on Malpractice, Inequalities, and Violations in Psychiatric Patient Care, promoted by the Associazione Italiana Bipolari (AIBP). The survey represents the first nationwide effort to systematically collect data on psychiatric care experiences from the direct perspective of those involved. The initiative arises from the recognition of a structural gap in the Italian context: the lack of independent and comparable data able to capture not only clinical outcomes, but also the relational, communicative, and ethical quality of care pathways, including malpractice, inequalities in access, and critical issues related to informed consent.

The survey was designed as a descriptive and observational tool, with the aim of identifying recurring patterns in care experiences rather than estimating prevalence or establishing causal relationships. The structure of the questionnaire, defined and documented in the study protocol, was developed to cover key areas of the psychiatric care pathway, including access to services, the diagnostic process, continuity of care, the clinical relationship, informed consent, and the subjective outcomes of the care experience.

Unlike other data-collection tools used by AIBP, the survey was intentionally opened to a broad range of respondents, including people living with bipolar disorder, people living with other severe psychiatric conditions, and caregivers. This methodological choice reflects the need to examine malpractice and systemic criticalities as cross-cutting dynamics within the psychiatric care system, rather than as issues linked to a single diagnosis.

03. The National Survey on Malpractice in Psychiatric Care

Data were collected on a voluntary basis through an online questionnaire, disseminated via targeted campaigns and the association's communication channels. Chapter 3 provides a structured overview of the findings from the National Survey on Malpractice in Psychiatric Patient Care and is organised into the following sections:

3.1 Demographic characteristics of the sample, which outlines the main socio-demographic, clinical, identity-related, and intersectional variables of respondents. This section allows readers to understand the experiential positions from which responses were provided and to appropriately contextualise the evidence presented in subsequent sections;

3.2 Access, diagnosis, and continuity of care – context and reference framework, which examines difficulties in accessing services, challenges within the diagnostic process, and disruptions in long-term care, analysed as interconnected phases of the care pathway;

3.3 Clinical relationship, communication, and consent, which explores proposed treatment approaches, levels of involvement in decision-making, clarity and adequacy of information, the presence of pressure or purely formal consent, the quality of the practitioner–patient relationship, the emotional support provided, and the role of multidisciplinary care;

3.4 Malpractice and rights violations, focusing on breaches of self-determination and the institutional and systemic shortcomings emerging from reported experiences;

3.5 Subjective outcomes and health-related consequences, analysing reported impacts in terms of permanent or temporary harm to health, as well as emotional, relational, and sexual consequences associated with care experiences;

3.6 Context and stage of the care pathway in which malpractice occurred, examining the settings and services in which inappropriate or harmful practices were experienced (first-contact services, outpatient care, hospital settings, residential facilities, and emergency interventions), as well as the phase of the care pathway in which these episodes took place.

03. The National Survey on Malpractice in Psychiatric Care

3.7 Timing, setting, and consequences of the reported episode, focusing on the temporal and geographical context of the reported experiences, any reporting or complaint actions undertaken, and the consequences described in terms of health, wellbeing, and personal life;

3.8 Attitudes and experiences with healthcare professionals, analysing respondents' perceptions and evaluations of healthcare staff behaviour, including aspects such as respect, listening, availability, communication, and the emotional experience of the care interaction.

Taken together, these findings provide an initial, structured snapshot of the experiences reported by survey participants and constitute a concrete basis for dialogue with services, professionals, and institutions. The aim is not to assign individual responsibility, but to identify recurring dynamics that can be interpreted as indicators of systemic fragility.

The number of responses included in the different analyses may vary depending on the relevance of the questions, the inclusion criteria, and the completeness of responses. For each item or group of items, the corresponding denominators are reported in the relevant tables and graphical representations.

Methodological Notes for the Reader: How to Read These Data

Why Causal Conclusions Cannot Be Drawn from This Study

This is a cross-sectional study. This means that data were collected at a single point in time through a questionnaire, asking participants to report on past experiences. In other words, individuals are not followed over time, there is no observation of what happens "before" and "after," and no temporal sequence can be established. Instead, the study captures an overall snapshot of the situation as it appears at the time of data collection.

This type of data is useful to:

- make visible experiences that often remain isolated or unheard;
- show that certain critical issues are not isolated cases;
- identify recurring patterns across the care pathway;
- highlight areas where deeper investigation, better listening, and targeted intervention are needed.

If a person reports today,

"I experienced malpractice and then my health worsened,"

we cannot directly observe what happened step by step over time. ***What we are hearing is a retrospective account, reconstructed after the fact and based on memory and subjective experience.***

This means that individuals are not followed over time, as they would be in a study that continuously observes what happens "before" and "after."

It is similar to looking at a photograph:

we can see what is in the image, but we cannot reliably reconstruct the entire sequence of events that came before it.

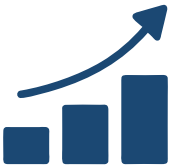
So why are these data important?

Because this study does not answer the question, "What exactly caused what?"
But it does address an equally fundamental question: "What are people experiencing, and how often?"

Methodological Notes for the Reader: How to Read These Data

Examples

For example, the regional distribution of reported cases reflects the geographic origin of respondents and the location of the episodes they described, and does not allow for estimates of the actual frequency of malpractice across different territories. The percentages observed therefore do not represent indicators of regional prevalence, but rather describe the concentration of reported experiences within the sample.



The distribution of reports by year indicates when respondents place the experiences they describe, not how many malpractice episodes actually occurred in each year. These data show how widespread certain experiences are among survey participants, but they do not allow conclusions to be drawn about whether the phenomenon is increasing or decreasing over time. The fact that many reports refer to recent years is largely due to recall effects: people tend to remember more recent experiences more clearly and, today, are better able to recognise and articulate them.

Prevalence refers to how many people, at a given point in time, report having experienced a certain situation.
It is similar to asking: "How many of the respondents say they have experienced this at least once?"

This report measures the prevalence of reported experiences: it describes how widespread they are among respondents, not when they began nor how many new cases occur each year.

Incidence, by contrast, refers to how many new cases occur within a given period of time, for example over the course of a year.
To measure incidence, individuals would need to be followed over time in order to observe when an experience occurs for the first time. This type of information cannot be derived from a survey completed at a single point in time

Methodological Notes for the Reader: How to Read These Data

When reading a data point, it is natural to think:
"If many people experienced this situation and then another, the first must have caused the second."

A Simple Example

Let us imagine asking 200 people:	"Did you experience significant side effects?" "Did you stop or reduce your medication?"
If we find that many people who experienced side effects later reduced their treatment, we cannot automatically conclude that:	"Side effects caused people to reduce their medication."
Reasons there may be many other possible explanations:	• the person was already considering discontinuation; • there were work-related or family-related difficulties; • the relationship with the clinician was fragile; • the medication was changed for other clinical reasons.

The survey shows that these experiences co-occur, not that one caused the other.

3.1 Sample Characteristics

This chapter is based on responses collected through the National Survey on Malpractice in Psychiatric Patient Care. The analysed sample consists of 211 adult respondents (N = 211). For clarity and formal consistency throughout the text, N refers to the total number of survey participants, while n indicates the size of specific subgroups analysed. This section provides a systematic description of the main socio-demographic, clinical, and identity-related characteristics of respondents, with the aim of making the sample profile to which the evidence presented in subsequent sections refers fully transparent.

Respondent Position in Relation to Diagnosis

In response to the question regarding personal experience of one or more psychiatric diagnoses included in the survey, 60% of respondents (n = 127) reported having one or more of the listed diagnoses. A further 34% (n = 72) indicated that they completed the questionnaire as a close person, family member, or representative of an individual with one or more psychiatric diagnoses. A smaller proportion of the sample, equal to 5% (n = 11), reported having none of the diagnoses included in the survey and not belonging to any of the above categories.

Relationship to the Person Concerned

Among respondents who completed the survey in reference to another person, the most frequently reported relationship was that of a family member or legal guardian (88%; n = 61), followed by partners or spouses (13%; n = 9). Responses corresponding to professional caregivers and to friends or acquaintances were residual (n = 1 for each category).

Basic Socio-Demographic Characteristics

Nine per cent of respondents (n = 18) reported being aged between 18 and 24 years; 22% (n = 45) fell within the 25–34 age group; 23% (n = 48) within the 35–44 group; 21% (n = 43) between 45 and 54 years; 17% (n = 35) between 55 and 64 years; and 5% (n = 10) between 65 and 74 years. No responses were recorded from individuals under the age of 18 or aged 75 years and over. With regard to gender identity, 80% of respondents (n = 160) identified as female and 16% (n = 32) as male. A further 2% of the sample (n = 3) identified as non-binary or third gender, while an additional 2% (n = 4) preferred not to disclose their gender identity.

The vast majority of respondents reported Italian as their first language (97%; n = 193). The remaining 3% of the sample (n = 6) indicated a different native language; however, all respondents in this subgroup reported feeling sufficiently confident in their understanding of the questionnaire.

What Are Intersectional Data and Why Do They Matter

Analysing data through an intersectional lens means recognising that experiences of care are not the same for everyone. Age, gender, level of education, language, health conditions, social status, and other characteristics can significantly shape how a person accesses services, whether they feel heard, and how they experience their care pathway.

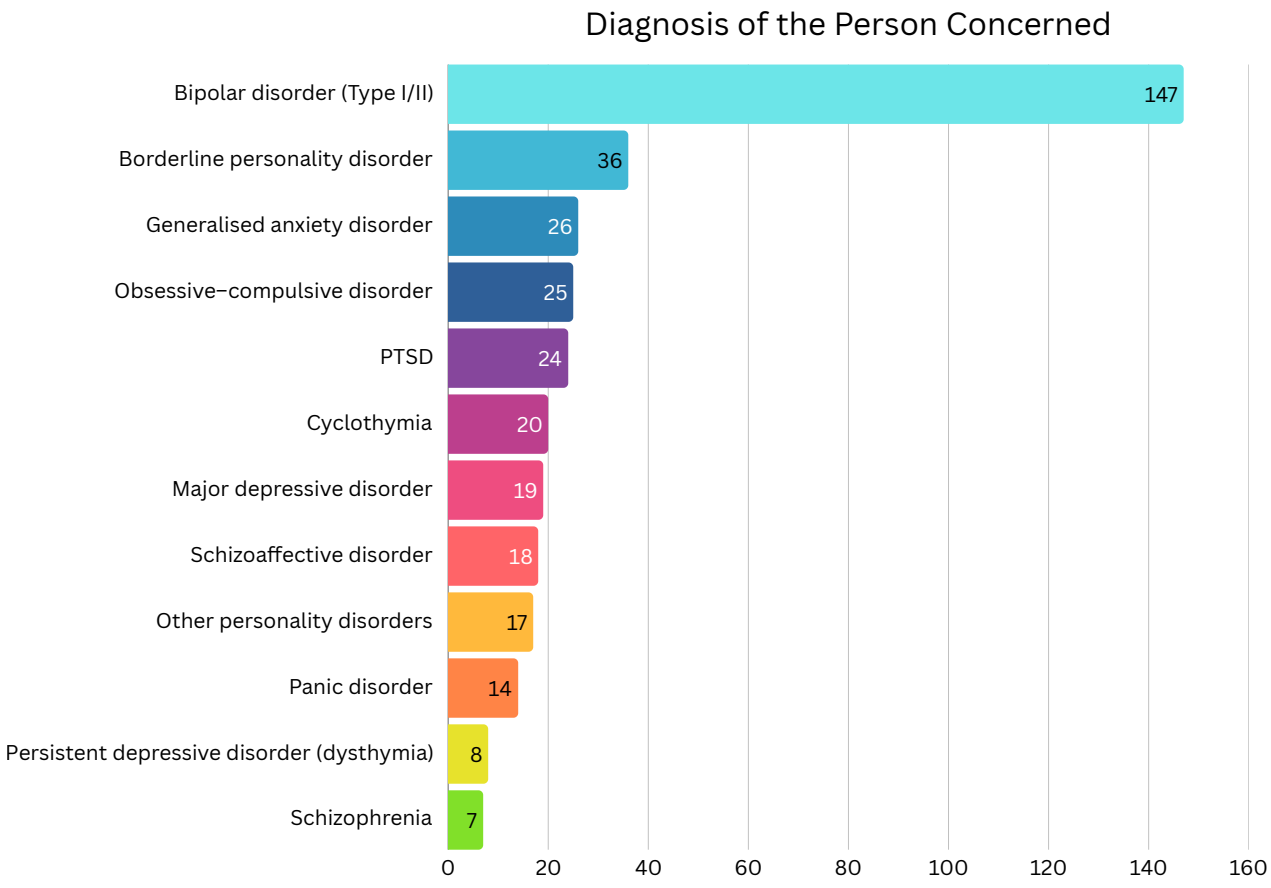
Considering these factors together helps avoid oversimplified interpretations and allows for a clearer understanding of who is more exposed to difficulties or inequalities. Intersectional data therefore make visible differences that might otherwise remain hidden and help guide more equitable and targeted interventions.

3.1 Sample Characteristics

Clinical Characteristics of the Sample

Among the 211 respondents included in the sample, 69.7% (n = 147) reported a diagnosis of bipolar disorder type I or II. Other psychiatric diagnoses frequently reported included borderline personality disorder (17.1%; n = 36), generalised anxiety disorder (12.3%; n = 26), obsessive–compulsive disorder (11.8%; n = 25), and post-traumatic stress disorder (11.4%; n = 24). Additional diagnoses reported included cyclothymia (9.5%; n = 20), major depressive disorder (9.0%; n = 19), schizoaffective disorder (8.5%; n = 18), other personality disorders (8.1%; n = 17), panic disorder (6.6%; n = 14), persistent depressive disorder (dysthymia) (3.8%; n = 8), and schizophrenia (3.3%; n = 7).

In response to the question regarding the presence of additional psychiatric diagnoses not included in the main list, 23.1% of respondents (n = 49) reported one or more additional psychiatric conditions, while 76.9% (n = 162) did not report further diagnoses. This finding indicates the presence of multiple psychiatric diagnoses in a substantial proportion of the sample. With regard to co-occurring health conditions, 35.2% of respondents (n = 70) reported additional physical, neurological, or neuropsychiatric conditions, while 64.8% (n = 129) did not report conditions of this type.

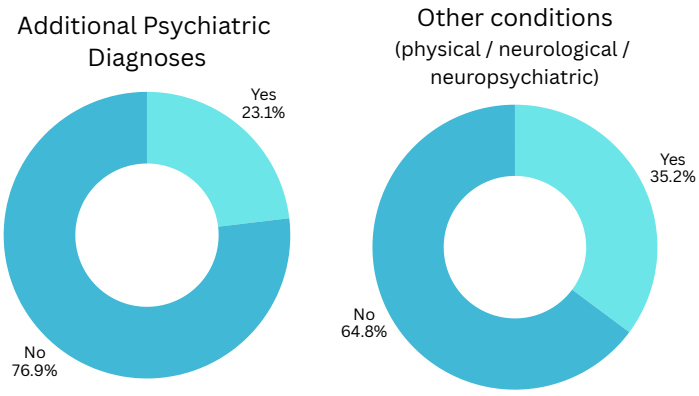


3.1 Sample Characteristics

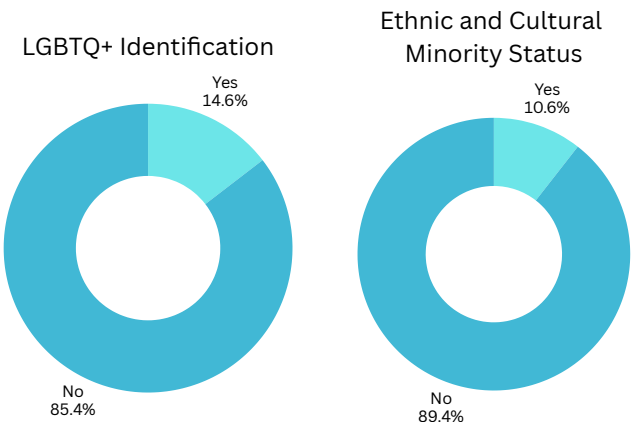
Legal Status and Decision-Making Capacity
Only a very small proportion of respondents (4 individuals, corresponding to 2%) reported having experienced compulsory treatment (TSO). The vast majority (195 individuals, 98%) reported never having had such an experience.

With regard to legal decision-making capacity, 93% of respondents (n = 185) reported having full decision-making capacity at the time of completing the survey. A further 7% of the sample (n = 14) indicated the presence of limitations in this area.

Identity-Related and Intersectional Variables
With regard to identity-related variables, 11% of respondents (n = 21) identified as belonging to an ethnic or cultural minority group, while 89% of the sample (n = 178) did not identify with this category. In relation to sexual orientation and gender identity, 15% of respondents (n = 29) reported belonging to the LGBTQ+ community, compared to 85% (n = 170) who did not report such identification. Regarding migratory status, 5% of the sample (n = 9) identified as belonging to a minority group based on migratory status, while 95% (n = 190) did not report this condition.



CLINICAL CHARACTERISTICS OF THE SAMPLE (COMORBIDITIES)

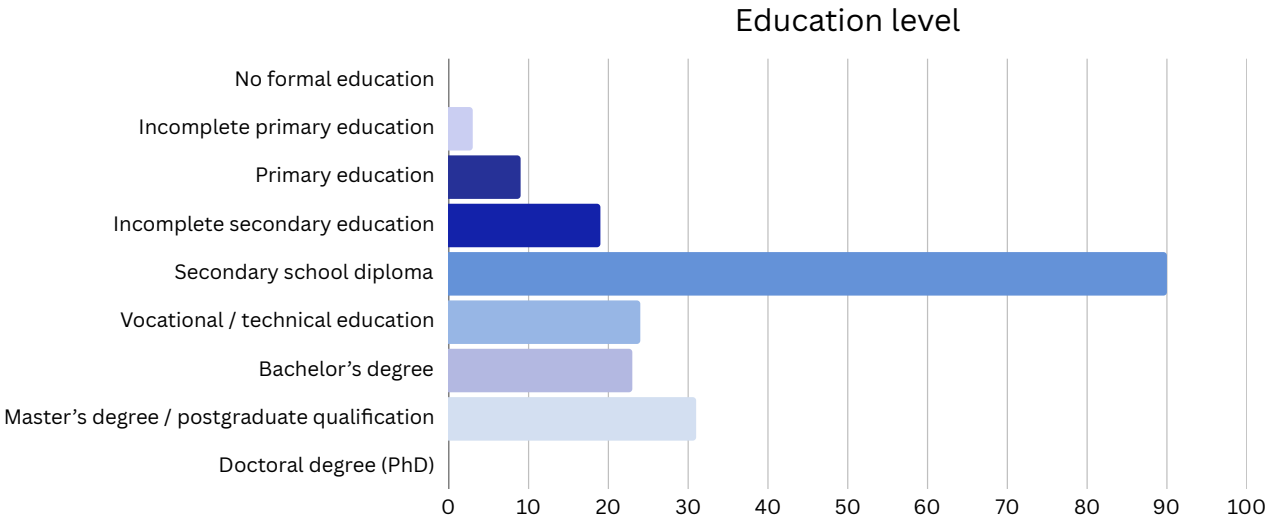


IDENTITY-RELATED AND INTERSECTIONAL VARIABLES

3.1 Sample Characteristics

Education Level

The educational level of the sample was heterogeneous. No respondents reported having no formal education. Primary education levels were overall underrepresented: 1.5% of the sample (n = 3) reported incomplete primary education, and 4.5% (n = 9) indicated completion of primary school as their highest level of education. Incomplete secondary education was reported by 9.5% of respondents (n = 19). The most frequently reported qualification was completion of secondary education, held by 45.2% of the sample (n = 90). Vocational or technical training was reported by 12.1% of respondents (n = 24). With regard to higher education, 11.6% (n = 23) reported holding a bachelor's degree, while 15.6% (n = 31) indicated a master's degree or equivalent postgraduate qualification. No respondents reported holding a doctoral degree.



Religious or Spiritual Beliefs and Their Consideration in Care

A minority of respondents reported adherence to a religious or spiritual belief system (21%; n = 41), while the majority indicated that they did not identify with any form of such belief (71%; n = 141). A further 8% of the sample (n = 17) chose not to answer the question. Among the 42 respondents who specified a religious or spiritual belief or value system, the most frequently reported identification was Christian (64.3%; n = 27). Buddhism was reported by 14.3% (n = 6), while 19.0% (n = 8) indicated a spiritual reference other than those listed. One individual (2.4%; n = 1) identified as a Jehovah's Witness. No respondents reported Muslim, Jewish, Hindu, or Sikh affiliations. With regard to the integration of religious or spiritual dimensions into the care pathway, 71% of respondents reported that these aspects were not considered. Only 10% indicated that such dimensions were actively taken into account, while 19% reported that the question was not applicable to their situation.

3.2 Access, Diagnosis, and Continuity of Care

This section examines participants' reported experiences in relation to access to mental health services, the diagnostic process, and continuity of care over time.

These dimensions are considered together, as they represent closely interconnected phases of the same care pathway, in which difficulties arising at one stage can have a significant impact on the development and long-term stability of care.

Timely access to services, the quality of diagnostic assessment, and the system's ability to ensure continuity of care are key elements in the construction of coherent and sustainable care pathways, particularly for people with complex or long-term clinical conditions.

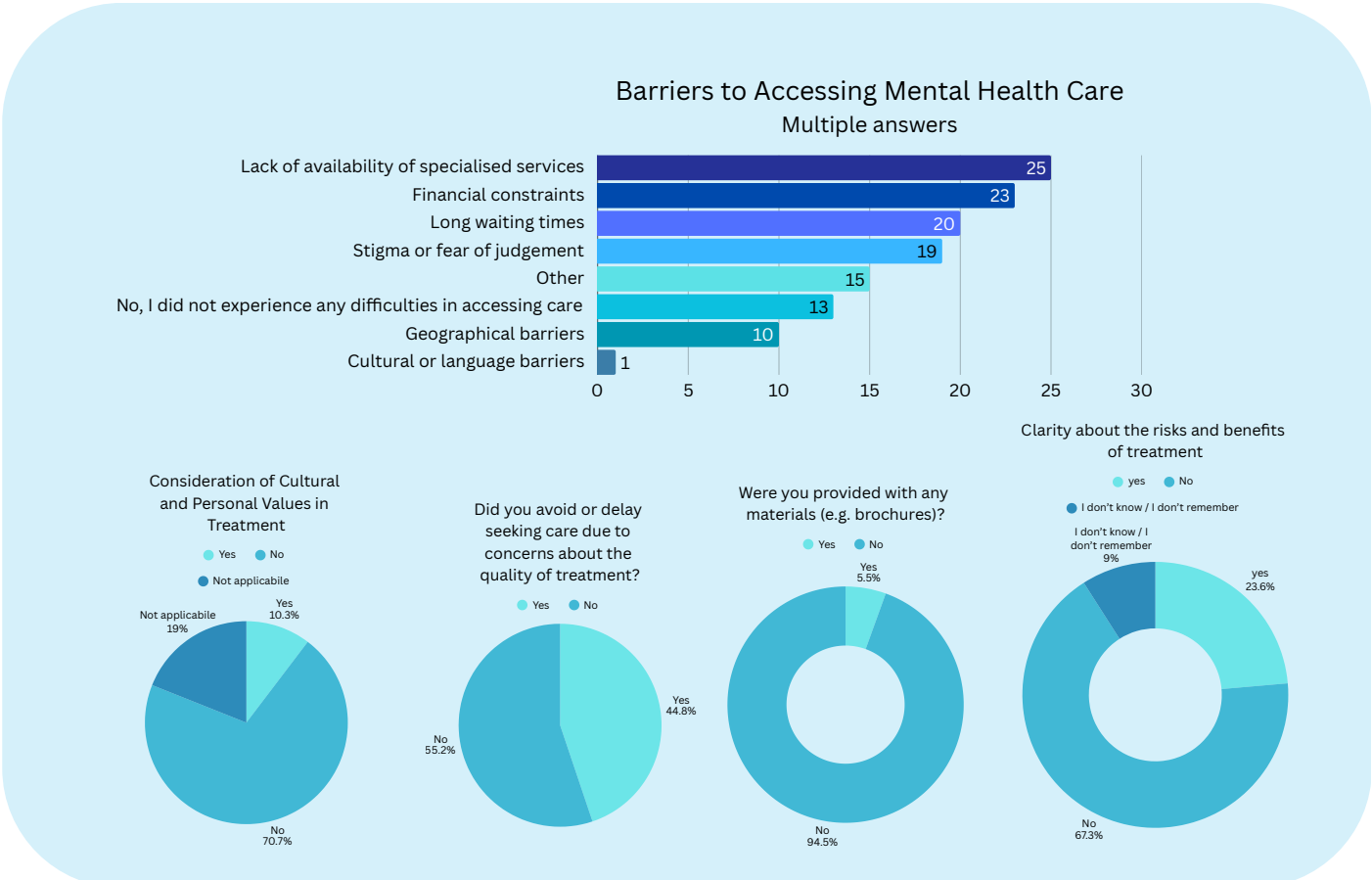
The analyses presented in this section are based on participants' responses to the relevant questionnaire items addressing these areas. The number of responses included may vary depending on the relevance of the questions, inclusion criteria, and completeness of responses.

3.2 Access, Diagnosis, and Continuity of Care

Avoidance or Delay in Seeking Care Due to Concerns About Treatment Quality
Forty-five per cent of respondents (n = 95) reported having avoided or delayed seeking care due to concerns about the quality of treatment. The remaining 55% (n = 116) indicated that they had neither postponed nor avoided access to care for this reason.

Difficulties in Accessing Mental Health Care (N = 58; multiple responses)
Among respondents who reported difficulties in accessing mental health care, the most frequently cited issue was the lack of availability of specialised services, reported by 44.8% (n = 25). Financial constraints were reported by 39.7% (n = 23), followed by long waiting times, indicated by 36.2% (n = 20).

A substantial proportion of respondents identified stigma or fear of judgement as a barrier to accessing care (32.8%; n = 19). Other, unspecified difficulties were reported by 25.9% (n = 15). Geographic barriers, such as distance from clinics or hospitals, were reported by 17.2% (n = 10), while cultural or language barriers were marginal (1.7%; n = 1).



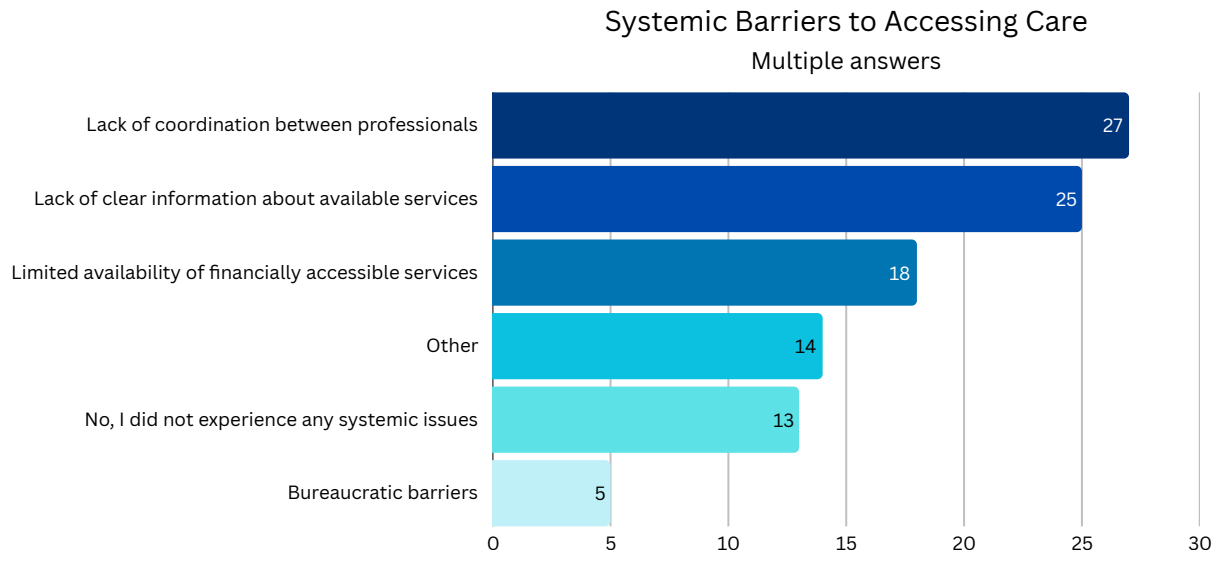
3.2 Access, Diagnosis, and Continuity of Care

Systemic Problems That Made Access to Care Difficult

Among respondents who reported difficulties in accessing care, the most frequently cited systemic issue was a lack of coordination between professionals, reported by 46.6% (n = 27). A similar proportion, 44.8% (n = 25), reported a lack of clear information about available services, resulting in difficulties navigating the care system.

Limited availability of economically affordable services was reported by 32.8% of respondents (n = 18), while 24.1% (n = 14) indicated the presence of additional, unspecified systemic problems. Bureaucratic barriers, such as difficulties related to referral systems or insurance coverage, were reported by 8.6% of the sample (n = 5).

Within the same subgroup, 22.4% of respondents (n = 13) reported not having encountered systemic problems in accessing care.



3.2 Access, Diagnosis, and Continuity of Care

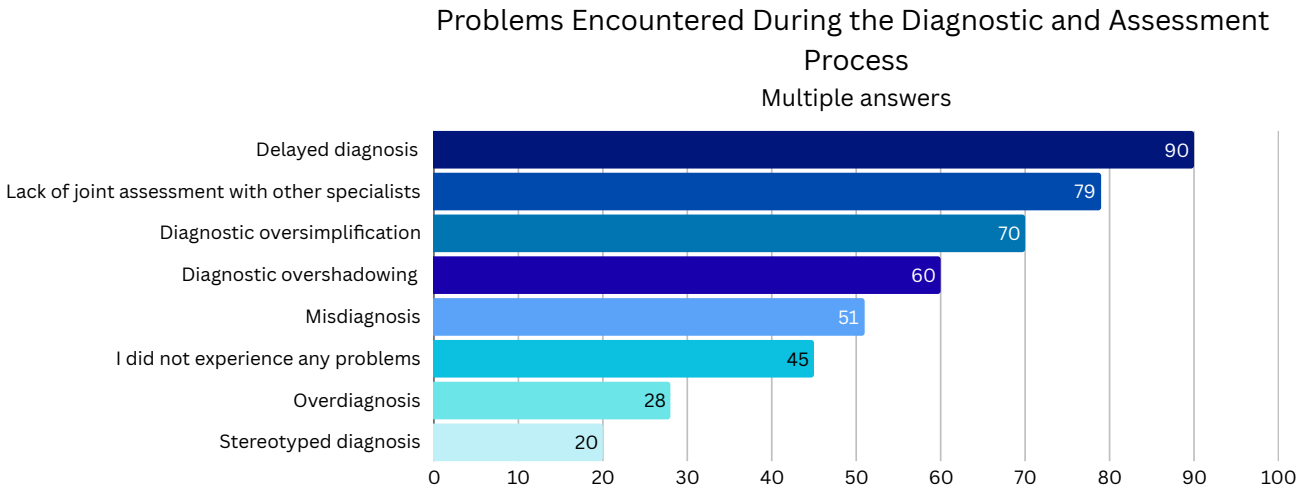
Problems Encountered During the Diagnostic and Assessment Process (N = 197; multiple responses)

Several difficulties emerged during the diagnostic and assessment process. The most frequently reported issue was delayed diagnosis, indicated by 45.7% of respondents (n = 90), pointing to delays in recognising or correctly interpreting symptoms.

A substantial proportion of participants also reported the absence of joint assessment with other specialists (40.1%; n = 79), highlighting limited multidisciplinary integration during the evaluation phase. Diagnostic oversimplification, defined as rapid diagnostic formulations based on rigid and poorly contextualised criteria, was reported by 36.0% of respondents (n = 71).

Diagnostic underestimation, involving the attribution of symptoms to pre-existing conditions or partial explanations, was reported by 31.0% (n = 61). Misdiagnosis emerged in 26.4% of responses (n = 52). Overdiagnosis, understood as assigning a diagnosis in the presence of normal behaviours or understandable reactions, was indicated by 14.7% of respondents (n = 29). Stereotyped diagnosis, influenced by gender-related or other identity-based biases, was reported by 10.7% (n = 21).

Within the sample, 22.8% of respondents (n = 45) reported not having experienced difficulties during the diagnostic and assessment process.



3.2 Access, Diagnosis, and Continuity of Care

Problems Encountered During the Diagnostic and Assessment Process	Explanation
Diagnostic overshadowing	Attributing a person's symptoms to a pre-existing condition or disability, while overlooking the possibility of new or co-occurring medical or psychiatric problems.
Diagnostic oversimplification	A diagnosis made too quickly by relying solely on written criteria, without adequately considering the person's life history or lived experience.
Overdiagnosis	Assigning a diagnosis even when behaviour falls within the normal range or represents an understandable reaction to difficult life events, such as bereavement or trauma.
Lack of joint assessment with other specialists	The clinician did not collaborate with other professionals (such as psychologists, neurologists, or general practitioners) to gain a more comprehensive understanding of the clinical situation.
Stereotyped diagnosis	A diagnosis influenced by biases related to gender, ethnicity, or a person's appearance, rather than by the individual's actual symptoms.
Delayed diagnosis	A diagnosis made late because symptoms were not recognised or were underestimated, particularly when the person appeared to be "functioning well".

3.2 Access, Diagnosis, and Continuity of Care

Problems Encountered During the Clinical and Therapeutic Treatment Process (N = 198; multiple responses)

A range of problems were reported during the clinical and therapeutic treatment process, often occurring concurrently. The most frequently reported issue concerned the management of side effects (57.1%; n = 113), with respondents indicating that monitoring and intervention regarding adverse effects of pharmacological treatments were not always adequate. A second highly recurrent issue was the lack of a multidisciplinary approach (53.5%; n = 106), reflecting limited integration between pharmacological, psychotherapeutic, and educational interventions. The use of standardised and impersonal treatments, not tailored to individual needs, was reported by 40.9% of respondents (n = 81).

Excessive or inappropriate use of sedation was reported by 35.9% (n = 71). Polypharmacy that was insufficiently assessed was indicated by 33.8% (n = 67), while overmedicalisation—defined as the use of psychotropic medication in the absence of solid or proportionate clinical indications—was reported in 33.3% of responses (n = 66). Incomplete or inadequate treatment was reported by 28.3% of respondents (n = 56). Interventions perceived as coercive, including compulsory hospitalisation or forced administration of medication, were reported by 23.2% (n = 46). Outdated treatments, based on obsolete protocols or not aligned with the most recent evidence, were indicated by 21.7% (n = 43). Physical restraint was reported by 19.2% of respondents (n = 38).

Psychotherapy perceived as inappropriate or harmful was reported by 18.7% (n = 37). Acute events posing a threat to life, such as overdoses or severe clinical crises, were reported by 14.1% (n = 28). Cases of death of the person concerned were reported by 1.0% of respondents (n = 2). Within this subgroup, 12.6% of respondents (n = 25) reported not having experienced problems during the clinical and therapeutic treatment process.

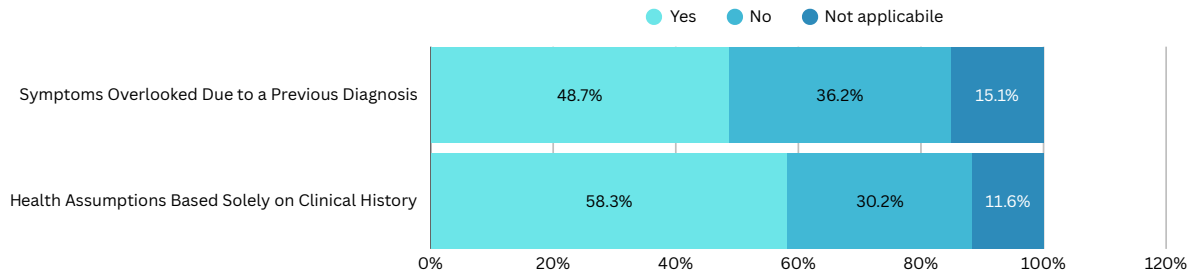
3.2 Access, Diagnosis, and Continuity of Care

Symptoms Overlooked Due to a Previous Diagnosis (N = 199)

Forty-nine per cent of respondents reported that some symptoms were overlooked because of a previous diagnosis. Thirty-six per cent indicated that they had not experienced this situation, while for 15% the question was not applicable.

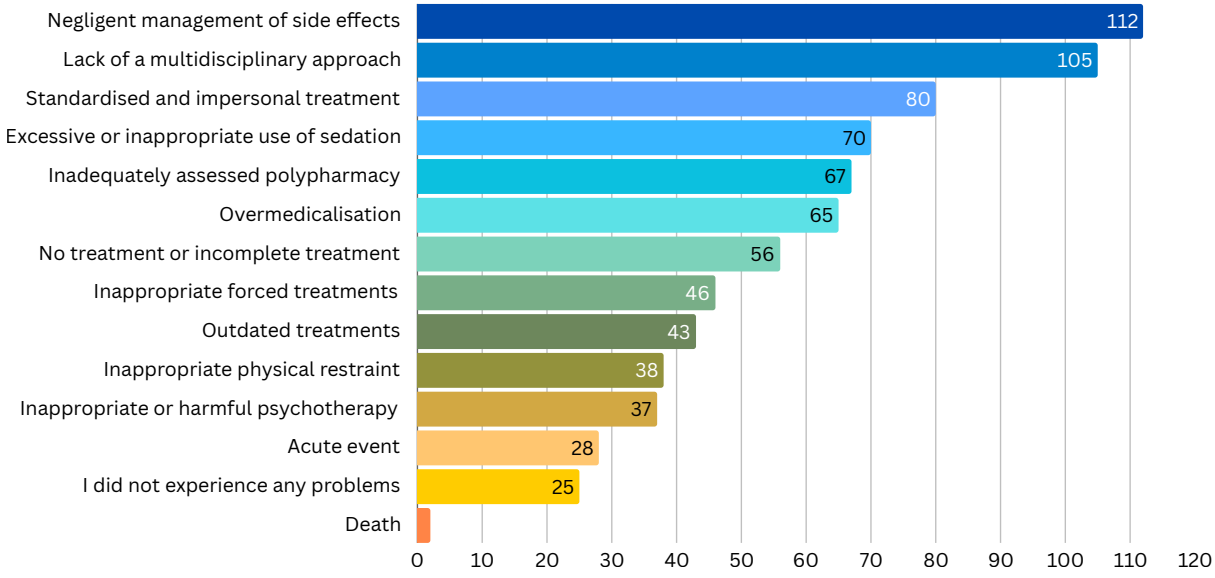
Health Assumptions Based Solely on Clinical History (N = 199)

Fifty-eight per cent of respondents reported the perception that assumptions about their health were made solely on the basis of their clinical history, without further assessment or investigation. Thirty per cent did not recognise this experience, while 12% indicated that the question was not applicable.



Problems Encountered During the Clinical and Therapeutic Treatment Process

Multiple answers



3.2 Access, Diagnosis, and Continuity of Care

Problems Encountered During the Clinical and Therapeutic Treatment Process	Explanation
Overmedicalisation	Excessive use of psychotropic medication, including in the absence of clear clinical evidence supporting the treatment.
Inadequately assessed polypharmacy	Prescription of multiple medications simultaneously without adequate assessment of combined effects and drug interactions.
Forced treatments	Compulsory hospitalisation, involuntary treatment (TSO), or administration of medication without genuinely informed consent.
Outdated treatments	Use of obsolete protocols or practices that fail to respect the person's dignity, such as prolonged physical restraint or interventions not aligned with current evidence.
Physical restraint	Immobilisation of the person without a genuine clinical necessity, or used as a form of punishment.
Excessive or inappropriate use of sedation	Use of sedative medication to "silence" or "manage" individuals considered difficult, rather than adopting appropriate therapeutic strategies.
Standardised and impersonal treatment	Failure to adapt treatment to the individual needs of the person.
Standardised and impersonal treatment	Absence of integrated care involving psychotherapy, education, rehabilitation, and/or social interventions.
Inappropriate or harmful psychotherapy	Blaming approaches, methods lacking scientific validation, or therapies imposed against the person's will.
No treatment or incomplete treatment	Lack of adequate care or premature discontinuation of treatment, particularly when the person is considered "resistant" or "difficult".
Negligent management of side effects	Side effects (such as extrapyramidal symptoms, sexual dysfunction, or weight gain) that are overlooked, minimised, or denied.
Acute event	An event that posed a threat to the person's life, such as overdose or medication intoxication, requiring urgent medical intervention.

3.2.1 Conclusion - Access, Diagnosis, and Continuity of Care

Access, Diagnosis, and Continuity of Care: Overall Picture

This section brought together participants' reported experiences related to access to mental health services, the diagnostic pathway, and continuity of care over time. Taken together, responses indicated that these phases were not experienced as separate steps, but as interconnected elements of a single care pathway. The data suggested that difficulties did not cluster at one specific point; rather, they tended to recur and reinforce one another, contributing to care experiences that were frequently fragmented or discontinuous.

Difficulties in Accessing Services

Critical issues emerged already at the point of access to services. Many participants reported organisational barriers, long waiting times, and difficulties in understanding where to seek help or how to navigate the system. A substantial proportion also reported having delayed or avoided seeking care due to concerns about the quality of the services available. Among those who encountered concrete obstacles, the most frequently reported difficulties included a lack of specialised services, financial barriers, and prolonged waiting times, often compounded by unclear information and a pervasive sense of disorientation. Within this context, poor coordination between professionals emerged as a key systemic factor limiting effective access to care.

Challenges in the Diagnostic Process

The diagnostic and assessment phase was similarly characterised by significant challenges. The most frequently reported issue concerned delayed diagnosis, which in some cases extended over several years. This was often accompanied by limited integration between professionals and approaches, with assessments perceived as overly simplified or insufficiently attentive to the person's overall clinical and personal history. Some participants reported experiences of symptom minimisation, misdiagnosis, or diagnoses shaped by stereotypes rather than by thorough and comprehensive evaluation. A smaller proportion of respondents, however, reported not having encountered major difficulties during this phase.

Clinical Treatment and Therapeutic Management

During treatment, the most critical area concerned the management of side effects, which was often described as inadequate or insufficiently monitored over time. This issue was frequently linked to the absence of a multidisciplinary approach and to the use of standardised treatment strategies perceived as poorly tailored to individual needs. With varying frequency, participants also reported experiences of excessive sedation, insufficiently assessed polypharmacy, overmedicalisation, and treatment approaches considered incomplete or outdated.

3.2.1 Conclusion - Access, Diagnosis, and Continuity of Care

Interventions Experienced as Coercive or Not Shared

Some participants reported interventions that were experienced as imposed, including compulsory hospitalisations or the forced administration of medication, which had a negative impact on their overall care experience. In a smaller proportion of cases, accounts also included acute clinical events or particularly severe outcomes.

Continuity of Care and Transitions Between Services

A further critical issue concerned continuity of care over time. The experiences collected highlighted difficulties in maintaining stable clinical reference points and in effectively managing transitions between different phases or services within the care pathway. These discontinuities affected perceptions of coherence and reliability of care, making it more difficult to build trust and to develop a shared therapeutic plan.

Symptom Underestimation and Diagnostic Rigidity

Across all phases of the care pathway, there was a strong and recurrent reporting of new or clinically relevant symptoms being overlooked because of a pre-existing diagnosis. Many participants described the feeling that assessments were shaped primarily by past clinical history, without further investigation or updating. This approach contributed to a perceived lack of personalisation of care and to a sense of not being adequately heard.

Taken together, the data showed that difficulties within mental health care pathways were not isolated episodes, but recurred across access, diagnosis, and treatment. The overall picture pointed to continuity, coordination, and personalisation of care as central areas of fragility, despite the diversity of individual experiences within the sample.

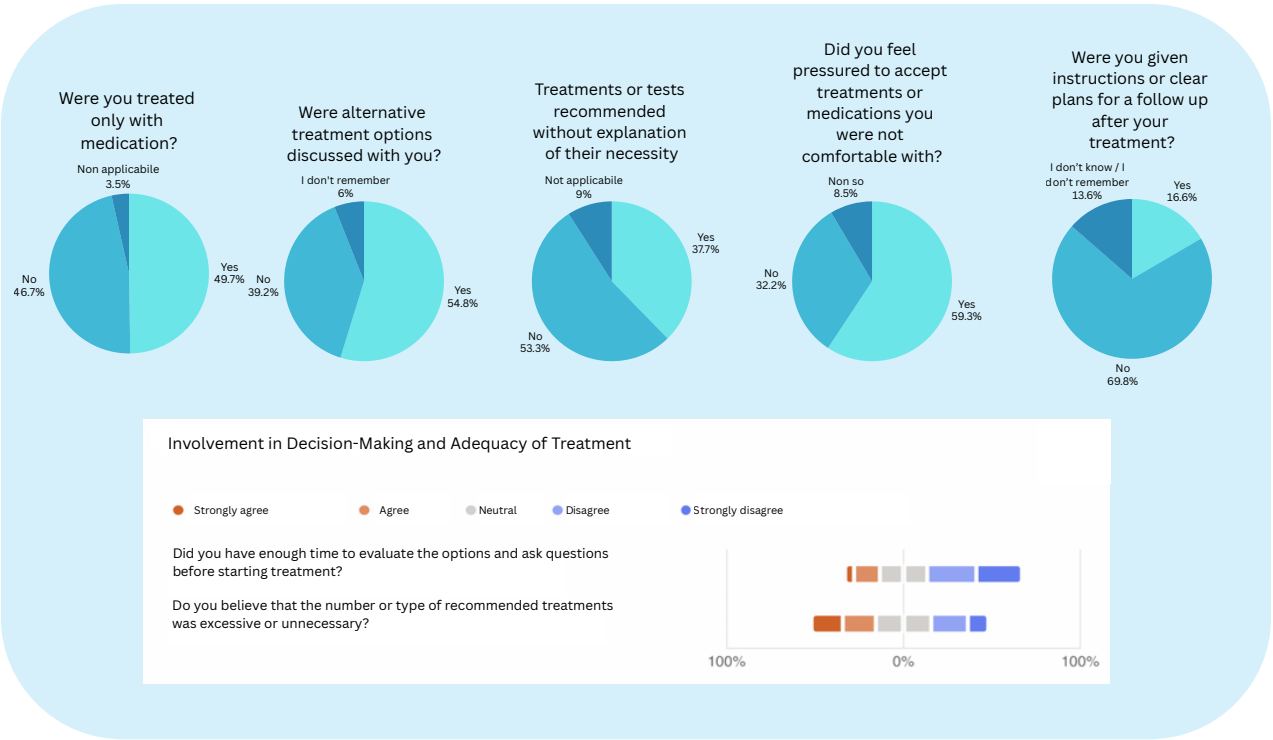
The evidence presented was based on responses to the specific questionnaire items addressing these areas; the number of responses included may have varied depending on the relevance of the questions and the completeness of the responses provided.

3.3 Clinical Relationship, Communication, and Consent

This section examines participants' reported experiences in relation to the clinical relationship, communication practices, and the informed consent process within psychiatric care. The quality of the relationship between individuals and healthcare professionals—together with the clarity of the information provided and the degree of involvement in decision-making—represents a central element in the effectiveness, adherence, and sustainability of care pathways. The evidence presented in this section is based on responses to the questionnaire items specifically addressing these aspects and allows observation of how the clinical relationship and communication are experienced across different care settings. The number of responses included may vary depending on question characteristics and the completeness of responses.

Pharmacological Treatment Only (N = 199)

Fifty per cent of respondents reported having been treated exclusively with medication. A further 47% indicated that they had also received other forms of intervention, while for 4% the question was not applicable. With regard to the discussion of alternative treatment options, 55% of respondents reported that possibilities beyond pharmacological treatment—such as psychotherapy or lifestyle modifications—were considered. By contrast, 39% indicated that such options were not discussed, while 6% reported that they did not recall whether this aspect had been addressed.



3.3 Clinical Relationship, Communication, and Consent

Involvement in Decision-Making and Adequacy of Treatment (N = 198)
With regard to the perceived time available to evaluate treatment options and ask questions before starting treatment, 19.7% of respondents expressed agreement or strong agreement, while 26.8% reported a neutral position. The majority, accounting for 53.6%, expressed disagreement or strong disagreement, indicating that they did not feel sufficiently involved in the decision-making process.

Concerning the adequacy of the number or type of recommended treatments, 36.4% of respondents expressed agreement or strong agreement, 31.3% reported a neutral position, and 32.3% expressed disagreement or strong disagreement. Overall, while a portion of respondents evaluated the proposed treatments as adequate, a substantial share reported limited involvement in decision-making during the phases preceding the initiation of treatment.

Pressure to Accept Treatments or Medications
Fifty-nine per cent of respondents reported having felt pressured to accept treatments or medications they were not comfortable with. Thirty-two per cent indicated that they had not experienced this situation, while 9% reported that they did not know or did not remember.

Problems in the Clinician–Patient Relationship (N = 196; multiple responses)
Several problematic elements were reported in the clinician–patient relationship, often occurring concurrently.

The most frequently reported issue concerned lack of empathy or insufficient listening, indicated by 61.2% of respondents (n = 120), with relationships described as cold, judgmental, or distant.

Lack of continuity of care, associated with frequent changes of therapists or the absence of a structured follow-up, was reported by 43.4% of respondents (n = 85). An approach perceived as dehumanising, focused primarily on symptoms rather than on the person, was reported by 41.3% (n = 81).

Issues related to communication and consent also emerged with notable frequency. The perception that informed consent was not fully ensured, due to the use of medical language that was difficult to understand or to imposed decisions, was reported by 37.2% of respondents (n = 73). Patient-blaming attitudes were reported by 36.7% (n = 72).

Clinical gaslighting, understood as the minimisation or questioning of reported experiences, was reported by 31.1% of respondents (n = 61). Difficulty openly addressing topics such as suicide and self-harm, described as silence or the presence of taboos, was reported by 30.1% (n = 59). Differences in treatment related to social or cultural status were less frequent but still present, and were reported by 7.7% of respondents (n = 15).

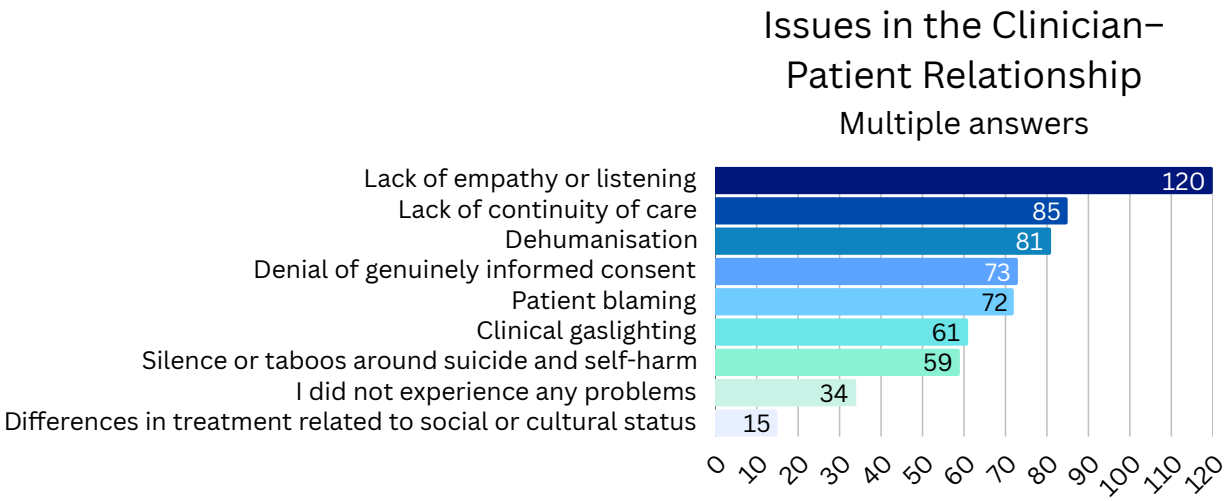
Within the sample, 17.3% of respondents (n = 34) reported not having experienced problems in their relationship with healthcare professionals.

3.3 Clinical Relationship, Communication, and Consent

Emotional or Psychological Support During Treatment (N = 200)
With regard to the availability of emotional or psychological support during treatment, 58.5% of respondents (n = 117) reported not having received any form of support. A further 19.5% (n = 39) indicated that support was provided spontaneously, without the need to request it, while 17.5% (n = 35) reported that support was offered only after an explicit request. For 4.5% of respondents (n = 9), the question was not applicable. Overall, the data indicate that for a substantial proportion of the sample, emotional or psychological support did not constitute a meaningful component of the treatment pathway.

Listening, Respect, and Person-Centred Care (N = 198)
With regard to the consideration of personal values, preferences, and individual needs within treatment, responses show a predominance of neutral or negative positions. Eighteen point three per cent of respondents expressed agreement or strong agreement that these aspects were adequately taken into account, while 33.0% reported a neutral position. By contrast, 48.7% expressed disagreement or strong disagreement, indicating a limited perception of person-centred care within the treatment pathway.

A similar pattern emerges with respect to the time dedicated by healthcare professionals to listening to and addressing individuals' concerns. In this case, 24.8% of respondents expressed agreement or strong agreement that sufficient time was devoted to listening, 23.2% reported a neutral position, and 52.1% expressed disagreement or strong disagreement. Overall, more than half of respondents reported negative evaluations regarding the quality and adequacy of listening received during their treatment experience.



3.3 Clinical Relationship, Communication, and Consent

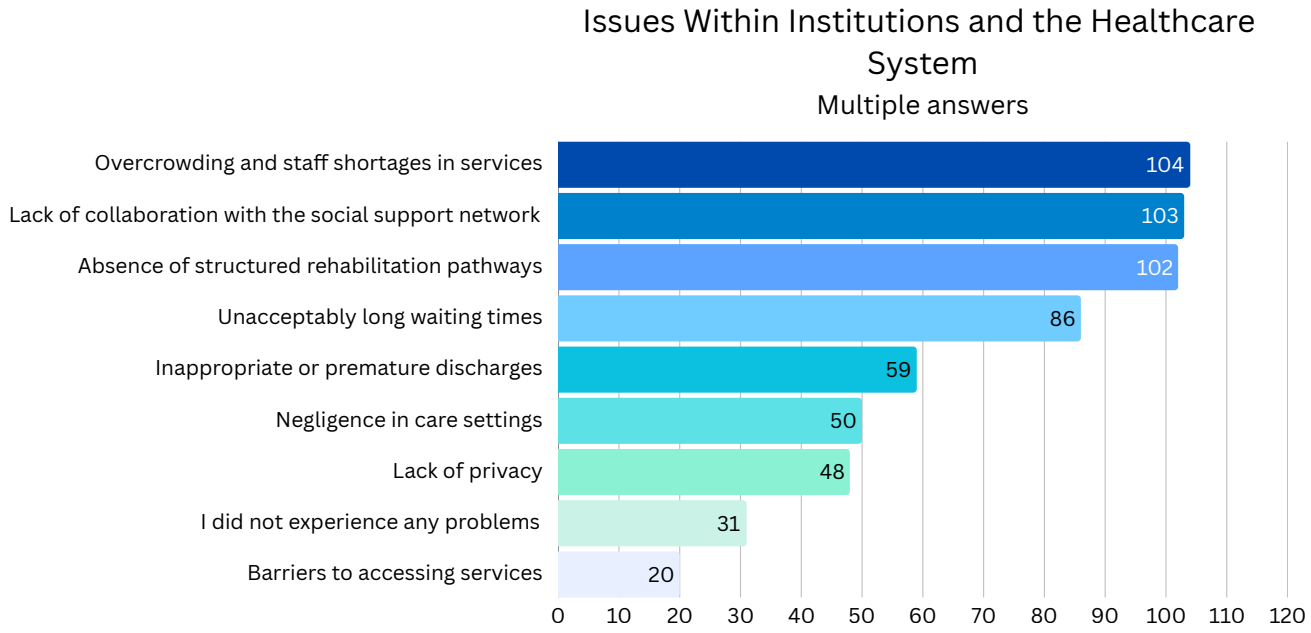
Problems Identified within Institutions and the Healthcare System (N = 196; multiple responses)

At the institutional and healthcare system level, respondents reported several critical issues. The most frequently mentioned concerned overcrowded services and staff shortages, reported by 53.1% of respondents (n = 104), with direct consequences for the time available to patients and the overall quality of care.

A similarly high proportion of respondents reported a lack of collaboration with the broader social support network, including family members, friends, and community-based services (52.6%; n = 103), as well as the absence of structured rehabilitation pathways (52.0%; n = 102). These findings point to care models that are often limited to acute phases, with significant challenges in ensuring continuity of care over time.

Unacceptably long waiting times, particularly for first appointments or access to specialist services, were reported by 43.9% of respondents (n = 86). Inappropriate or premature discharges, involving a return home without adequate support, were reported by 30.1% (n = 59).

Additional concerns included negligent conditions within care settings, such as unsafe environments or inadequate hygiene standards (25.5%; n = 50), and lack of privacy, related to insufficient confidentiality in the handling of clinical information or consultations conducted in non-protected settings (24.5%; n = 48). Barriers to access, including linguistic, economic, cultural, or bureaucratic obstacles, were reported by 10.2% of respondents (n = 20). Within the sample, 15.8% of respondents (n = 31) reported no institutional or system-level problems.



3.3 Clinical Relationship, Communication, and Consent

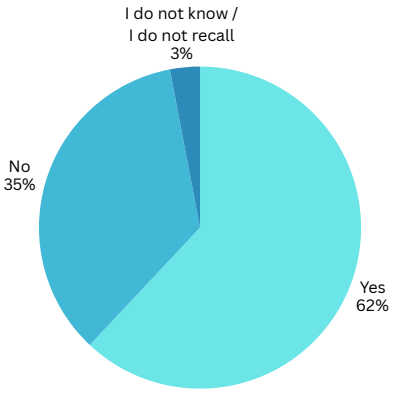
Involvement and perceived usefulness of multiple professionals in care (n = 200; usefulness assessment n = 149)

With regard to the involvement of multiple healthcare professionals in the care pathway, 62.0% of respondents (n = 124) reported that their care included more than one professional figure. By contrast, 35.0% (n = 70) indicated that their care did not involve multiple professionals, while 3.0% (n = 6) reported that they did not know or did not recall.

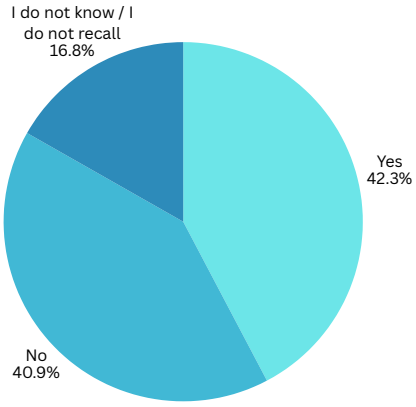
Among respondents who evaluated the usefulness of involving multiple professionals, 42.3% (n = 63) expressed a positive assessment, indicating that multidisciplinary work was beneficial to their treatment. Conversely, 41.0% (n = 61) reported that such involvement was not perceived as useful, while 16.8% (n = 25) indicated that they did not know or did not recall.

Overall, these findings show that, although the involvement of multiple healthcare professionals is relatively common, perceptions of its usefulness are mixed. This suggests that the mere presence of a multidisciplinary team does not necessarily translate into an experience perceived as effective or well coordinated.

Were multiple healthcare professionals involved in your care?



If yes, was the involvement of a multidisciplinary team helpful for your treatment?



3.3.1 Conclusion - Clinical Relationship, Communication, and Consent

Clinical relationship, communication, and informed consent: overview
The data collected in this section provided a detailed account of how participants experienced the clinical relationship, communication with healthcare professionals, and the informed consent process. Responses revealed the presence of recurring patterns alongside a non-uniform distribution of reported issues, with markedly different experiences across the sample.

Treatment framework and therapeutic options
With regard to treatment planning, a clear polarisation emerged between exclusively pharmacological pathways and approaches that also included other forms of intervention. The opportunity to discuss therapeutic options beyond medication alone was reported in a substantial proportion of cases, but it did not appear to be a systematic practice. A comparable share of participants reported that such alternatives were not discussed. This finding highlighted significant variability in how information was provided and in the degree of dialogue around therapeutic choices.

Involvement in decision-making processes
Analysis of involvement in therapeutic decision-making indicated that the most frequently reported experience was the perception of insufficient time to consider proposed options and to ask questions prior to treatment initiation. Assessments of the appropriateness of recommended treatments were distributed across positive, neutral, and negative evaluations, with no clear predominance of favourable judgments. Overall, a central theme emerged: involvement in decision-making was often limited in the phases preceding treatment initiation, regardless of respondents' ultimate views on the adequacy of the therapies proposed.

Perceived pressure and informed consent
Consistent with the findings on decision-making involvement, the perception of pressure to accept treatments or medications that were not fully shared or agreed upon represented one of the most frequently reported experiences in this section. This element stood out among the data related to communication and informed consent, clearly outweighing responses indicating the absence of such pressure.

Relationship with healthcare professionals
Regarding the relationship between healthcare professionals and patients, analysis of multiple-response items revealed a clear hierarchy among reported issues. The most frequently cited concern was a lack of empathy and attentive listening. This was followed—at lower but still substantial frequencies—by a lack of continuity of care and the adoption of approaches perceived as dehumanising and primarily symptom-focused. Issues related to communication and informed consent occupied an intermediate position within this overall pattern.

3.3.1 Conclusion - Clinical Relationship, Communication, and Consent

Experiences of informed consent perceived as incomplete, instances of patient blame, and the minimisation of reported lived experiences were widespread. Difficulties in openly addressing topics such as suicide and self-harm emerged with slightly lower frequency. Differences in treatment related to social or cultural status were reported less often. A minority of respondents reported no issues in their relationship with healthcare professionals.

Listening, respect, and person-centred care

Responses concerning listening, respect, and person-centredness reinforced this overall pattern. Neutral and negative evaluations were more frequent than positive ones, both in relation to the consideration of personal values, preferences, and individual needs, and to the time dedicated to listening and addressing concerns. Across both dimensions, positive assessments represented the least frequent responses.

Institutional and system-level issues

At the institutional and health system level, the most frequently reported issues related to service overcrowding and staff shortages. Closely following, with similar frequencies, were the lack of collaboration with the person's social support network and the absence of structured rehabilitation pathways. Waiting times perceived as unacceptable occupied the next position, followed by discharges considered inappropriate or premature. Conditions of neglect within care settings and issues related to the protection of privacy were reported less frequently. Barriers to access of a linguistic, economic, cultural, or bureaucratic nature were the least frequently reported area. As in other sections, a minority of participants reported no institutional or system-level problems.

Multidisciplinary involvement

Finally, with regard to the involvement of multiple professionals in the care pathway, the data indicated that such involvement was reported more often than its absence. However, among those who assessed its usefulness, positive and negative evaluations were distributed almost evenly. This finding pointed to substantial heterogeneity in reported experiences and to a lack of consistency in how the effectiveness of multidisciplinary work was perceived.

3.4 Inappropriate Practices and Rights Violations

This section examines the experiences reported by participants in relation to practices perceived as inappropriate and to violations of rights occurring throughout psychiatric care pathways. Respect for self-determination, fundamental rights, and procedural safeguards represents an essential foundation of care, particularly in contexts marked by power asymmetries and heightened vulnerability.

The analyses presented are based on responses to the questionnaire items specifically addressing these issues and allow for an examination of how such practices are experienced and interpreted by individuals within mental health services. The number of responses considered may vary depending on the relevance of the questions and the completeness of the responses.

Violations of rights and self-determination (N = 192; multiple response)

A substantial number of respondents reported experiences consistent with violations of human rights and self-determination within the context of care. The most frequently reported issue concerns a lack of information about one's rights, indicated by 47.9% of respondents (n = 92).

Exclusion from decision-making processes, with no active involvement in care-related choices, was reported by 37.0% of respondents (n = 71). Decisions perceived as paternalistic, made without the direct involvement of the person concerned, were indicated by 35.9% (n = 69). Episodes of institutional stigma—where a psychiatric diagnosis influenced access to rights or the type of treatment received—were reported by 32.3% of respondents (n = 62).

Experiences of abuse of power or psychological coercion, including implicit pressure or veiled threats, were reported by 28.6% (n = 55). Treatments carried out without consent perceived as genuinely informed, even when formally legitimate, were indicated by 20.3% of respondents (n = 39). Excessive control over private life, including restrictions on personal relationships or individual choices, was reported by 14.6% (n = 28).

Overall, 31.3% of respondents (n = 60) reported not having experienced violations of human rights or self-determination. Taken together, the data indicate that many participants associate their care experiences with practices perceived as limiting autonomy, dignity, and the ability to actively participate in decisions affecting their lives.

3.4 Inappropriate Practices and Rights Violations

3.4.2 Conclusion - Inappropriate Practices and Violations of Rights

Perceived Inappropriate Practices and Violations of Rights

The data presented in this section described how participants experienced and understood practices perceived as inappropriate or as violations of rights and self-determination within psychiatric care pathways. Responses showed a varied pattern of experiences, with different issues reported more or less frequently across the sample.

Information about rights and participation in decision-making

The most frequently reported issue concerned the lack of information about one's rights. This emerged clearly across responses, suggesting that unclear, insufficient, or inaccessible information represented one of the main problems identified by participants. With slightly lower but still substantial frequency, respondents reported being excluded from decision-making processes and experiencing decisions perceived as paternalistic. Together, these experiences reflected limited involvement of individuals in decisions concerning their own care.

Institutional stigma and power imbalances

Another set of experiences, reported with intermediate frequency, related to episodes of institutional stigma. In these cases, a psychiatric diagnosis was perceived as influencing access to rights or shaping the type of treatment received. At similar levels of frequency, participants described situations experienced as abuse of power or psychological pressure. These accounts referred to implicit pressure, veiled threats, or relationships perceived as unbalanced, even in the absence of formally coercive measures.

Consent perceived as not genuinely informed and control over private life

Reported less frequently, but still present within the sample, were experiences of treatments carried out without consent perceived as genuinely free and informed, even when such treatments were formally legitimate. Participants also described forms of control experienced as excessive over their private lives, including restrictions on personal relationships or individual choices. Although less common than other issues, these experiences contributed to outlining how violations of self-determination were lived and interpreted.

Absence of violations and variability of experiences

Alongside reports of practices perceived as inappropriate, a non-negligible proportion of participants stated that they did not experience violations of rights or self-determination within their care pathways. This finding highlighted the wide variability of experiences within the sample.

3.4.2 Conclusion - Inappropriate Practices and Violations of Rights

Overall, among participants who reported negative experiences, practices perceived as inappropriate are mainly concentrated in how information is provided, how people are involved in decision-making, and how power is managed within the care relationship. More direct forms of control or restriction of personal life are reported less often.

3.5 Subjective Outcomes and Consequences for Health

This section examines the subjective outcomes and health-related consequences reported by participants in relation to their care experiences. Beyond traditional clinical outcomes, care pathways can have significant effects on psychological, physical, and relational wellbeing, as well as on overall quality of life, both in the short and long term. The evidence presented in this section is based on responses to questionnaire items specifically addressing these dimensions and allows these impacts to be observed from the direct perspective of those involved. The number of responses considered may vary depending on the nature of the questions and the completeness of the responses.

Impacts on health and personal well-being

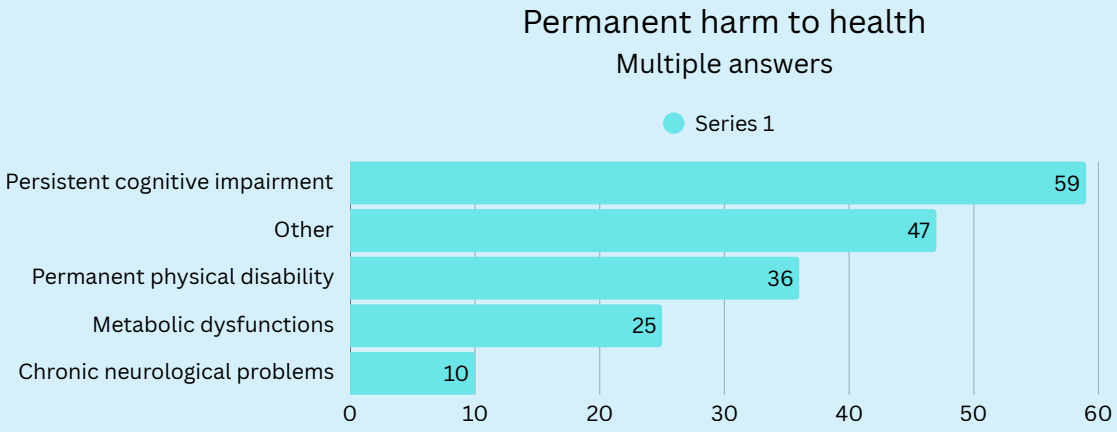
The responses highlight significant and heterogeneous consequences for participants' health and well-being, affecting physical, cognitive, emotional, relational, and sexual domains. With regard to permanent health damage (N = 109), the most frequently reported outcome is persistent cognitive impairment, accounting for 33% of responses.

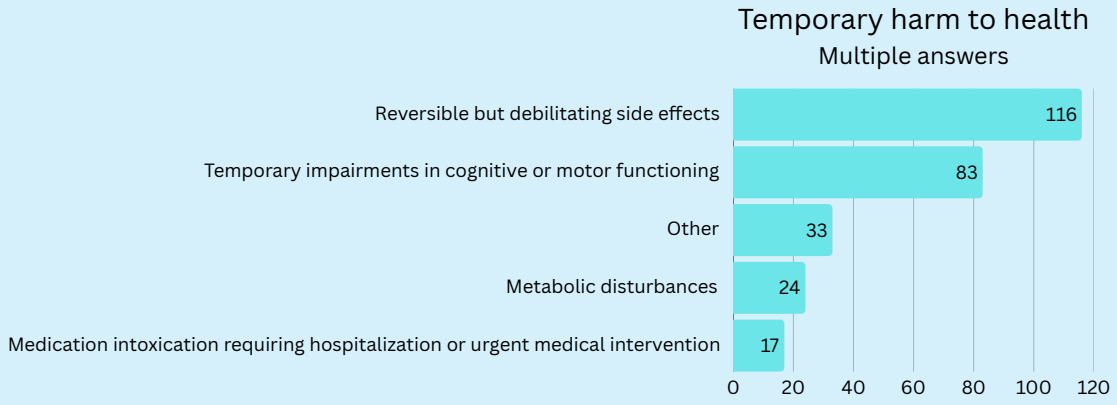
This is followed by other permanent effects not attributable to a specific category (27%) and permanent physical disability (20%). Medication-induced metabolic disorders, such as diabetes or hypertension, account for 14% of reports, while chronic neurological problems, including movement disorders or extrapyramidal syndromes, are reported in 6% of cases.

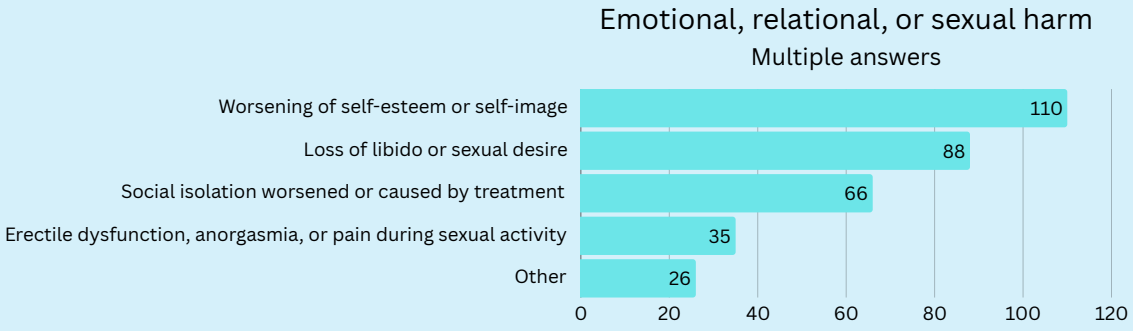
Temporary health damage also emerges as widespread. Among the reported outcomes (N = 151), reversible but highly debilitating side effects—such as nausea, dizziness, or rapid weight gain—represent the largest share (42%). Temporary cognitive or motor impairments account for 30% of responses, while unspecified temporary effects fall into the "other" category (12%). Transient metabolic alterations associated with pharmacological treatments are reported in 9% of cases, and medication intoxications requiring urgent medical intervention in 6%.

In the emotional, relational, and sexual domains (N = 156), the most frequently reported impact is a worsening of self-esteem or self-image, indicated in 34% of responses. This is followed by reduced or lost libido and sexual desire(27%) and social isolation, either aggravated by or directly resulting from the care experience, reported in 20% of cases.

3.5 Subjective Outcomes and Consequences for Health







3.5.1 Conclusion - Subjective Outcomes and Consequences for Health

Subjective outcomes and consequences for health

The data presented in this section provided a detailed overview of the subjective outcomes and health-related consequences reported by participants in relation to their care experiences. Responses showed a varied distribution of impacts across multiple dimensions of wellbeing, with different levels of severity and duration.

Permanent harm to health

With regard to permanent harm to health, the most frequently reported outcome was persistent cognitive impairment. This category represented the most commonly reported form of long-term harm. It was followed, at a moderate level of frequency, by permanent effects not clearly attributable to specific categories and by permanent physical disability. Metabolic disorders associated with pharmacological treatments and chronic neurological problems were reported less often, remaining present but comparatively less common outcomes within this area.

Temporary harm to health

Temporary harm to health appeared to be widespread and was characterised by a broad range of manifestations. The most frequently reported outcome in this category consisted of reversible but highly burdensome side effects, such as severe physical symptoms or significant weight changes. Less frequently reported were temporary impairments in cognitive or motor functioning. Unspecified temporary effects and transient metabolic disturbances followed in the distribution of responses. Medication intoxication requiring urgent medical intervention represented the least frequently reported category among temporary harms.

Emotional, relational, and sexual impacts

At the emotional, relational, and sexual level, the data revealed a clear pattern of reported impacts. The most frequently described experience was a worsening of self-esteem or self-image. This was followed by a reduction or loss of libido and sexual desire. Social isolation, described as being worsened or directly linked to the care experience, was reported less often. Taken together, these dimensions outlined a set of consequences primarily affecting subjective wellbeing and interpersonal relationships.

Overall, the descriptive analysis indicated that the consequences reported by participants spanned multiple levels of severity and duration. Both permanent outcomes and temporary effects emerged, with a substantial impact on cognitive, physical, and emotional–relational domains.

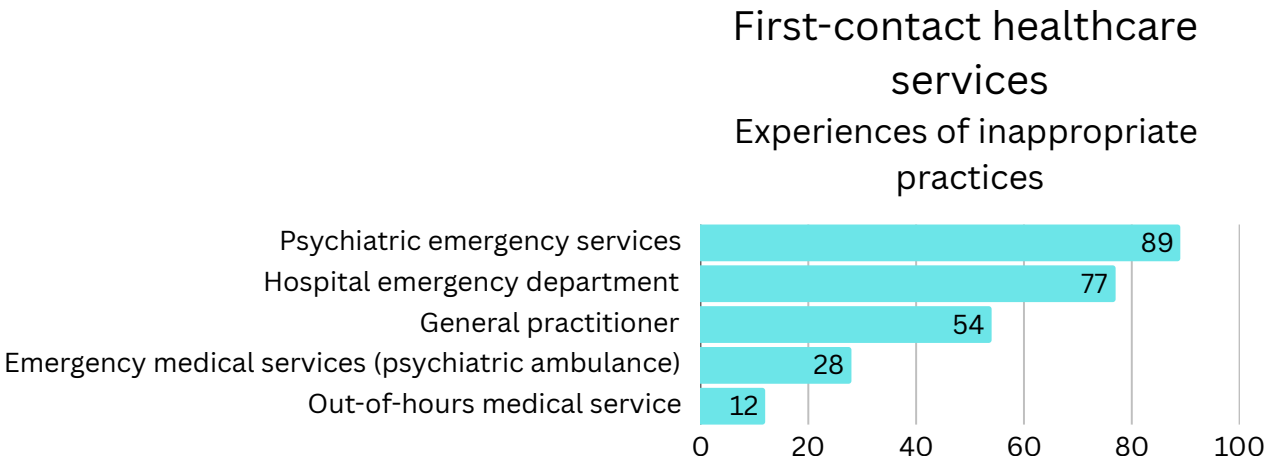
3.6 Contexts in Which Inappropriate Practices Occurred

This section analyses the care settings and phases of the care pathway in which participants place their experiences of malpractice or inappropriate practices.

Identifying the settings and moments in which such episodes occur is a relevant element for understanding the organisational and institutional dynamics that may facilitate their emergence or limit their recognition.

The analyses presented are based on responses to the questionnaire items dedicated to these aspects and allow observation of how experiences are distributed across different services and stages of the care pathway. The number of responses considered may vary depending on the relevance of the questions and the completeness of responses.

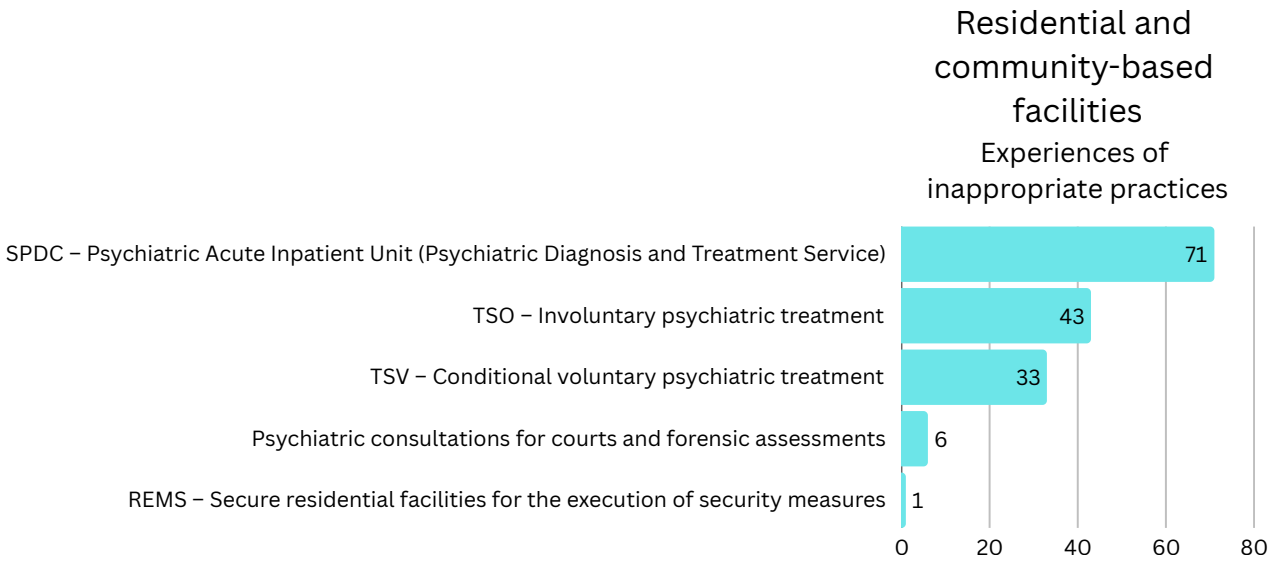
First-Contact Healthcare Services (N = 159; multiple responses)
Reports of malpractice are particularly prevalent in first-contact healthcare services, indicating that critical issues may arise already in the initial phases of access to care. The most frequently reported setting is psychiatric emergency services, which account for 34% of reports (n = 89). This is followed by hospital emergency departments, indicated in 30% of cases (n = 77), and general practitioners, reported in 21% of responses (n = 54). Psychiatric emergency ambulances (118 services) account for 11% of reports (n = 28), while out-of-hours medical services are indicated in 5% of cases (n = 12). Taken together, these data show that malpractice is not confined to specialist or advanced care settings, but may already emerge at the point of first access, with potential consequences for the subsequent course of the care pathway.



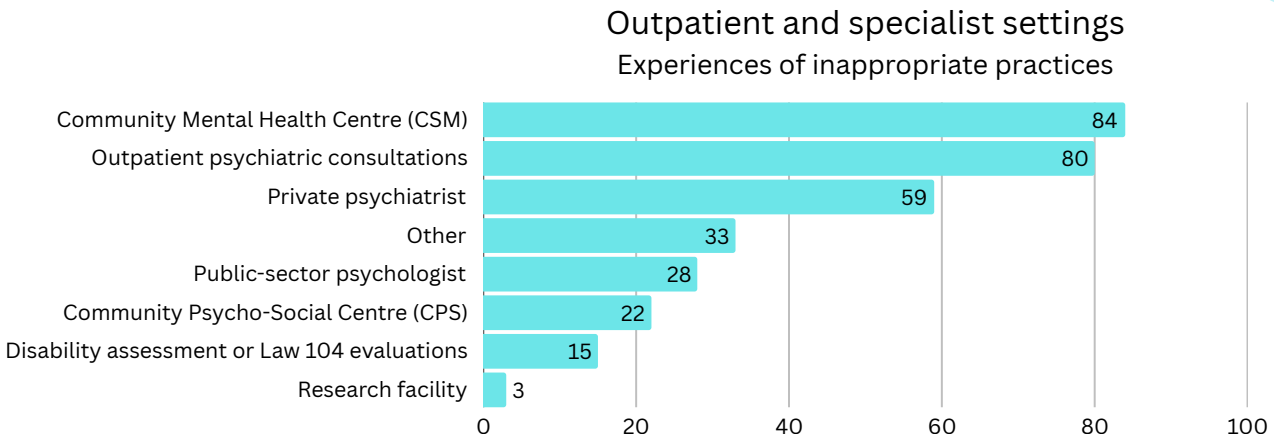
3.6 Contexts in Which Inappropriate Practices Occurred

Outpatient and specialist settings (N = 172; multiple responses)
Within outpatient and specialist care settings, reports are widely distributed and concern both public and private services. The most frequently reported setting is the Community Mental Health Centre (CMHC), accounting for 49% of reports (n = 84). This is followed by outpatient psychiatric consultations, in either public or private settings, reported in 47% of cases (n = 80), and experiences with private psychiatrists, indicated in 34% of responses (n = 59). Smaller proportions concern public-sector psychologists (16%, n = 28) and Community Psycho-Social Centres (CPS), reported in 13% of cases (n = 22). Assessments related to disability benefits or Law 104 account for 9% of reports (n = 15), while research facilities are marginal (2%, n = 3). The category "other" represents 19% (n = 33) of responses and includes outpatient contexts not fully captured by the predefined options. Overall, these data indicate that inappropriate practices are also present in ongoing and specialist care settings, and not exclusively in emergency situations.

Residential and community-based facilities (N = 107; multiple responses)
In residential and community-based facilities, reports of inappropriate practices are more strongly concentrated in services responsible for managing acute phases and coercive measures. Psychiatric Acute Inpatient Units (SPDC) represent the most frequently reported setting, accounting for 46% of reports (n = 71). Involuntary treatment orders are reported in 28% of cases (n = 43), while conditional voluntary treatment is indicated in 21% of responses (n = 33). Psychiatric evaluations for courts and forensic assessments account for 4% of reports (n = 6), while REMS (secure residential facilities for the execution of security measures) are marginal (1%, n = 1). Overall, these findings show that inappropriate practices tend to cluster in residential settings linked to crisis management, inpatient care, and restrictive measures, with significant implications for self-determination and the subjective experience of care.



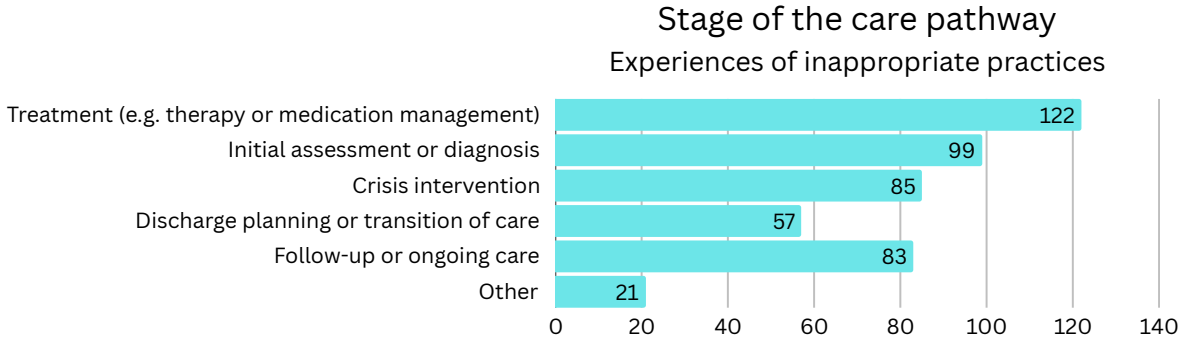
3.6 Contexts in Which Inappropriate Practices Occurred



Stage of the care pathway in which inappropriate practices occurred (N = 177; multiple responses)

Responses show that reported inappropriate practices are distributed across different stages of the care pathway, rather than being confined to a single moment. The most frequently reported stage is the treatment phase, including therapy or medication management, indicated by 68.9% of respondents (n = 122). Initial assessment or the diagnostic process represents another critical phase, reported by 55.9% of respondents (n = 99), suggesting that difficulties may emerge already at the earliest points of contact with services. Crisis intervention settings are reported by 48.0% of respondents (n = 85), while issues occurring during follow-up or subsequent care are indicated by 46.9% (n = 83), showing that critical issues may persist beyond the acute phase of treatment.

Discharge planning and transitions between services are reported by 32.2% of respondents (n = 57), highlighting a specific vulnerability during handovers and care reorganisation. Finally, 11.9% of respondents (n = 21) refer to other stages not captured by the predefined options. Overall, these data indicate that inappropriate practices are not limited to a single phase of the care pathway, but may occur at multiple and sometimes overlapping points, revealing a pattern of vulnerabilities across the entire continuum of care.



3.6.1 Conclusion - Contexts in Which Inappropriate Practices Occurred

Care settings and stages of the care pathway

The analysis of data related to care settings made it possible to situate the inappropriate practices reported by participants across a range of services and at different moments along the care pathway. Reports were not concentrated in a single, clearly defined context, but were distributed across multiple areas of the healthcare system.

First-contact healthcare services

Within first-contact services, reports were primarily concentrated in settings dedicated to emergency management. Psychiatric emergency services emerged as the most frequently reported context, followed by hospital emergency departments. General practitioners were mentioned less often, while psychiatric emergency ambulances and out-of-hours medical services were reported more rarely. This distribution indicated that experiences of inappropriate practices were already present at the earliest stages of access to care, in environments characterised by high operational pressure and limited time availability.

Outpatient and specialist settings

In outpatient and specialist settings, reports were widespread and not limited to a single type of service. Community Mental Health Centres represented the most frequently reported context. These were followed by outpatient psychiatric consultations in both public and private settings, as well as experiences with private psychiatrists. Public-sector psychologists and Community Psycho-Social Centres were reported less often. Assessments related to disability benefits or Law 104, as well as research facilities, occupied a marginal position in the distribution of responses. The proportion of responses classified as “other” further indicated the presence of a wide range of outpatient contexts not fully captured by the predefined questionnaire options. Overall, these findings showed that inappropriate practices were also reported within services intended for ongoing and continuous care.

Residential and community-based facilities

With regard to residential and community-based facilities, reports were predominantly concentrated in contexts responsible for crisis management and inpatient care. Psychiatric Acute Inpatient Units (SPDC) represented the most frequently reported setting. These were followed by involuntary psychiatric treatment and, at lower frequencies, conditional voluntary treatment. Psychiatric consultations in judicial contexts and secure residential facilities for the execution of security measures were mentioned only rarely. This distribution placed reported experiences primarily within settings characterised by higher levels of care intensity and greater restrictions, highlighting their relevance for issues of self-determination and the subjective experience of care.

3.6.1 Conclusion - Contexts in Which Inappropriate Practices Occurred

Stages of the care pathway

The analysis of care pathway stages showed that reported inappropriate practices were distributed across different moments of care. The treatment phase, understood as the management of therapy and medication, was the most frequently indicated stage. This was followed by the initial assessment or diagnostic process and by crisis intervention. Issues reported during follow-up and subsequent care were also widely represented. Transitions between services and discharge planning were indicated less often, while other stages not captured by the predefined options accounted for a residual proportion.

Taken together, these data described a distribution of reported inappropriate practices spanning first-contact services, outpatient settings, residential facilities, and multiple stages of the care pathway. Rather than being confined to a single area, inappropriate practices appeared across the continuum of care.

3.7 Time, Location, and Consequences of the Reported Episode

This section examines the temporal and geographical placement of the episodes reported by participants, as well as the consequences described in terms of health, well-being, and personal life. The temporal and contextual dimensions of these experiences are important for understanding how such episodes fit into individuals' care histories and into the functioning of services over time. The evidence presented is based on responses to the questionnaire items addressing these aspects and allows for a systematic examination of these dimensions. The number of responses considered may vary depending on the characteristics of each question and the completeness of responses.

Year in which the reported episode occurred (N = 178)

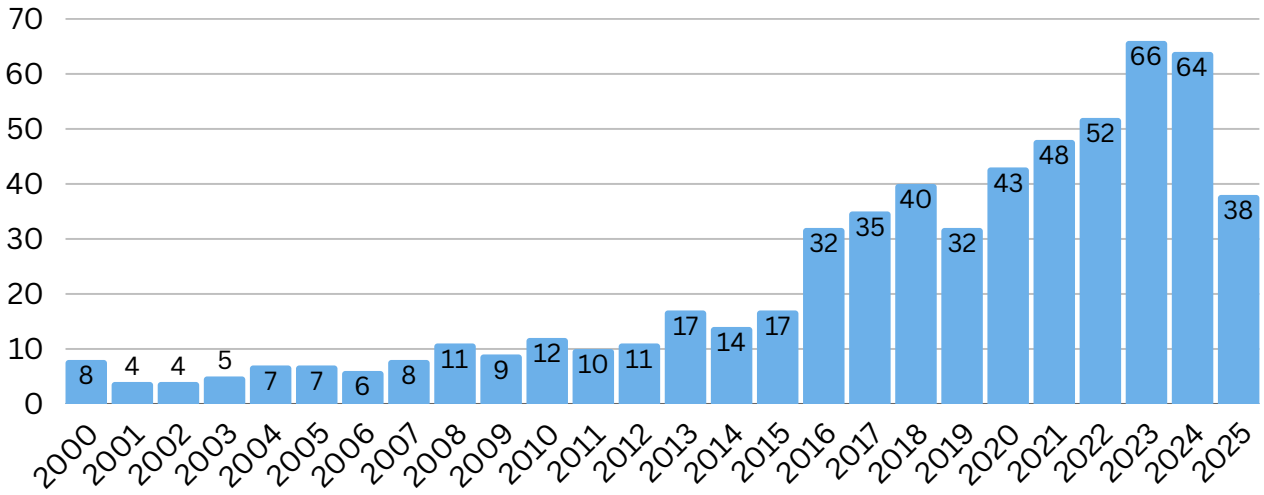
Reported episodes are distributed across a broad time span, from 2000 to 2025, with a progressively increasing concentration in more recent years. The early 2000s account for relatively small proportions: the year 2000 is reported in 4.5% of cases (n = 8), while 2001 and 2002 each account for 2.2% (n = 4). The year 2003 represents 2.8% (n = 5), 2004 and 2005 each account for 3.9% (n = 7), 2006 for 3.4% (n = 6), and 2007 for 4.5% (n = 8). From 2008 onwards, a gradual increase is observed: both 2008 and 2012 are reported in 6.2% of responses (n = 11), 2009 in 5.1% (n = 9), 2010 in 6.7% (n = 12), and 2011 in 5.6% (n = 10). During the period 2013–2015, reports increase further, with 2013 and 2015 each indicated in 9.6% of cases (n = 17) and 2014 in 7.9% (n = 14). From 2016 onwards, a marked concentration of reported experiences emerges. The years 2016 and 2019 each account for 18.0% of reports (n = 32), 2017 for 19.7% (n = 35), and 2018 for 22.5% (n = 40). The most recent years show the highest proportions: 2020 is reported in 24.2% of cases (n = 43), 2021 in 27.0% (n = 48), 2022 in 29.2% (n = 52), 2023 in 37.1% (n = 66), and 2024 in 36.0% (n = 64). The year 2025, ongoing at the time of data collection, is reported in 21.3% of responses (n = 38). Overall, the temporal distribution highlights a clear concentration of reported experiences in more recent years.

Region in which the reported episode occurred (N = 178)

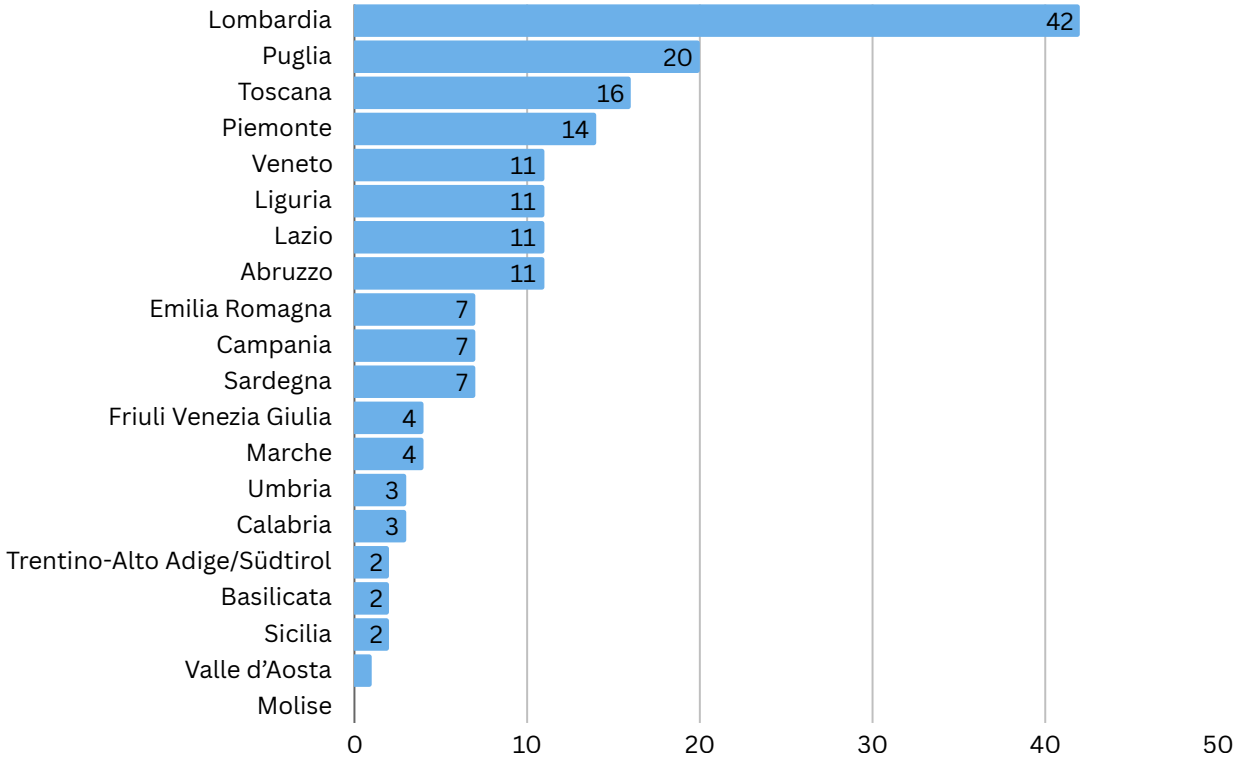
Reports of inappropriate practices or healthcare-related shortcomings are distributed across most of the national territory, with higher concentrations in certain regions. Lombardy is the most frequently reported region, accounting for 23.6% of reports (n = 42). This is followed by Apulia, reported by 11.2% of respondents (n = 20), and Tuscany, with 9.0% (n = 16). Piedmont accounts for 7.9% of reports (n = 14). A group of regions shows similar proportions: Veneto, Liguria, Lazio, and Abruzzo are each reported by 6.2% of respondents (n = 11). Emilia-Romagna, Campania, and Sardinia each account for 3.9% of reports (n = 7). Lower proportions are observed for Friuli Venezia Giulia and Marche (2.2% each; n = 4), Umbria and Calabria (1.7%; n = 3), and Trentino–Alto Adige/Südtirol, Basilicata, and Sicily (1.1%; n = 2). Valle d'Aosta is reported in a single case (0.6%), while no reports are recorded for Molise. Overall, the geographical distribution indicates that reported experiences are not confined to a single area of the country, but involve many regions, with higher concentrations in more densely populated areas and those with a greater volume of healthcare services.

3.7 Time, Location, and Consequences of the Reported Episode

In which year(s) did the person concerned experience inappropriate practices?



In which region did the episode of malpractice or healthcare service failure occur?



3.7.1 Conclusion - Time, Location, and Consequences of the Reported Episode

Temporal and geographical distribution of reported episodes

From a temporal perspective, reported episodes were distributed across a wide time span, ranging from the early 2000s to the period in which data collection took place. The earliest years included a relatively small number of reports, while from the late 2000s onwards there was a gradual increase in the number of experiences attributed to subsequent years. This pattern became particularly clear from 2016–2017 onwards, with a growing concentration of reports in more recent years and a substantial proportion of experiences located between 2020 and 2024. The current year was also represented, although with fewer reports than in the immediately preceding years, taking into account that data collection did not cover the full year. Overall, the data described a distribution weighted towards more recent years, while still including experiences reported over a period of more than twenty years.

Geographical distribution of reported episodes

With regard to geographical location, reports were distributed across a wide portion of the national territory. Some regions accounted for a higher number of reported episodes. Lombardy emerged as the most frequently indicated region, followed by a group of regions with intermediate levels of reporting, including Apulia, Tuscany, and Piedmont. Several other regions showed similar but lower proportions of reports, while some were represented by very small numbers or single cases. Taken together, the data described a broad territorial distribution, involving regions in Northern, Central, and Southern Italy, without indicating a concentration limited to specific geographical areas.

Interpretative limits of temporal and geographical data

It is important to note that the temporal and geographical information collected referred solely to the year and the region in which respondents located the reported episode. These data did not allow reconstruction of changes over time, nor did they permit estimation of incidence, prevalence, or year-to-year variation. Similarly, the geographical distribution did not allow conclusions about the actual spread of inappropriate practices at the regional level, nor comparisons between territories, as it reflected only the location of episodes reported by the survey sample.

Overall, the descriptive analysis outlined a picture in which reported experiences were predominantly located in more recent years and distributed across many Italian regions. What emerged was a broad temporal and territorial spread of reports, which situated participants' experiences in context without allowing conclusions about trends over time or about the true distribution of the phenomenon across regional settings.

3.8 Attitudes and Experiences with Healthcare Staff

This section examines participants' perceptions and evaluations of the attitudes and behaviours of healthcare staffencountered throughout their care pathways. Elements such as respect, listening, availability, and communication style play a central role in shaping the care experience, trust in services, and the possibility of building an effective therapeutic alliance. The analyses presented here are based on responses to questionnaire items specifically addressing these aspects and allow insight into how these dimensions are experienced across different care settings. The number of responses considered may vary depending on the relevance of the questions and the completeness of responses.

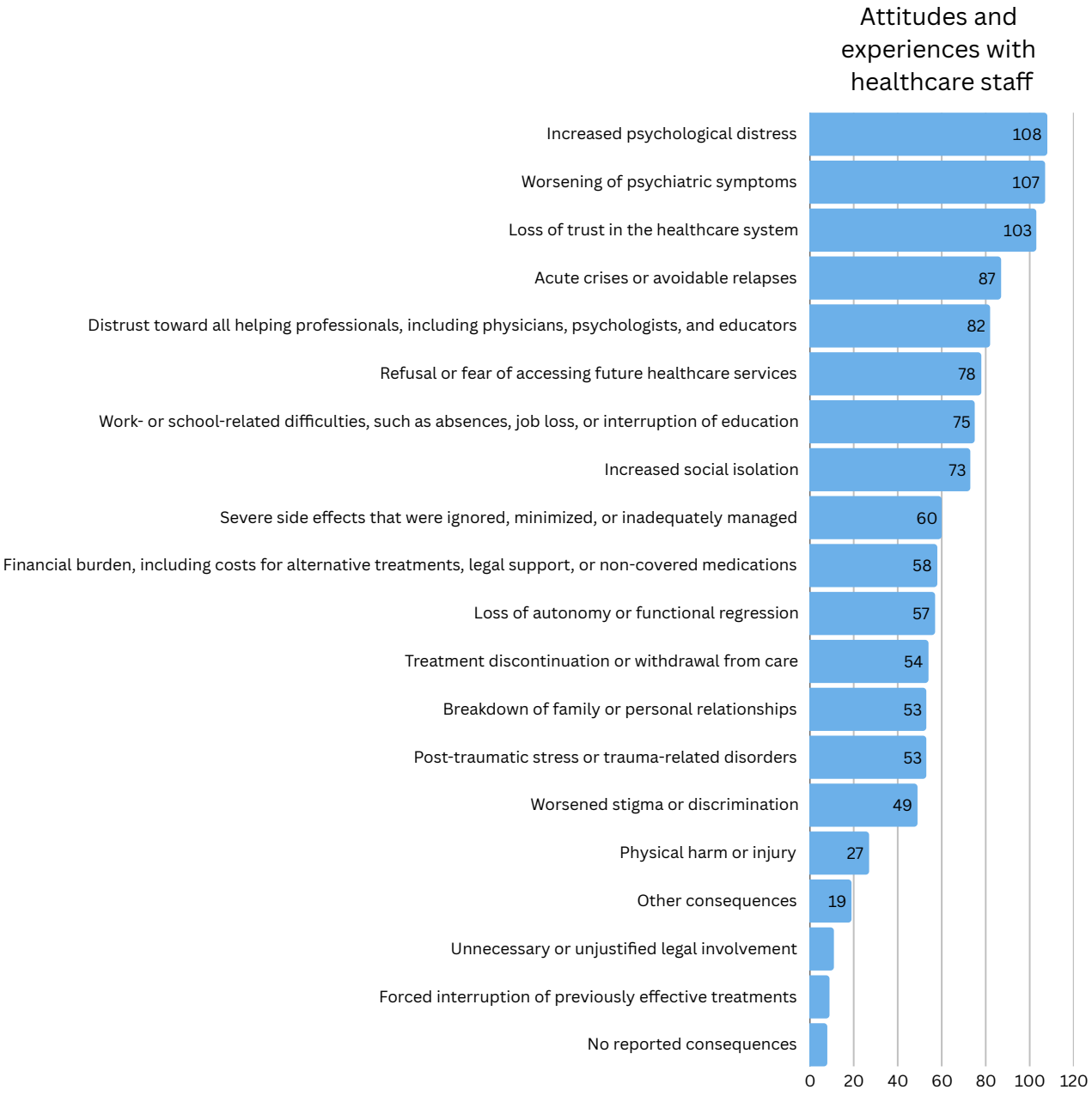
Direct consequences of inappropriate practices on health and well-being (N = 179; multiple responses)

Responses indicate that the reported inappropriate practices are, in most cases, associated with substantial consequences at the clinical, psychological, social, and relational levels. The most frequently reported outcomes concern mental well-being: 60.9% of respondents report an increase in psychological distress, while 60.3% associate the experience with a worsening of psychiatric symptoms. A significant impact also emerges in relation to the care system itself. Loss of trust in the healthcare system is reported by 58.1% of respondents, while a more generalised loss of trust in all helping professionals (including doctors, psychologists, and educators) is reported by 45.8% of the sample. Consistently, 44.1% report avoidance of, or fear related to, accessing future healthcare services, suggesting a potential disruption in continuity of care.

Responses further show a frequent association with avoidable clinical deterioration. Nearly half of respondents (49.2%) report the onset of acute crises or relapses, while 34.1% report severe side effects that were ignored, minimised, or inadequately managed. Additionally, 30.2% report outcomes consistent with trauma-related or post-traumatic stress symptoms. The consequences for daily functioning and social life are also widely represented. Increased social isolation is reported by 41.3% of respondents, while 41.9% report negative impacts on work or education, including prolonged absences, job loss, or interruption of studies. Loss of autonomy or functional regression is reported by 32.4% of the sample. At the relational level, 30.2% report a breakdown of family or personal relationships, while 27.9% report increased stigma or discrimination following the experience. Treatment discontinuation or withdrawal from care is reported by 30.7% of respondents, highlighting a further point of vulnerability in care trajectories. Economic consequences are also significant: 33.0% report financial burdens, including costs related to alternative treatments, uncovered medications, or legal assistance. Smaller proportions report forced interruption of previously effective treatments (5.6%) or involvement in judicial proceedings perceived as unnecessary or unjustified (6.1%). A minority of respondents (4.5%) report no consequences, while 10.6% indicate other outcomes not captured by the predefined categories.

3.8 Attitudes and Experiences with Healthcare Staff

Overall, the distribution of responses shows that the reported inappropriate practices are associated, for the majority of respondents, with multiple and co-occurring consequences, affecting both mental health and social functioning, as well as the relationship with healthcare services. As this was a multiple-response question, the percentages reflect the frequency with which specific consequences were reported within the sample and do not constitute estimates of incidence or prevalence in the general population.



3.8 Attitudes and Experiences with Healthcare Staff

Perceived empathy in the care relationship (N = 177)

In response to the statement "Healthcare staff demonstrated empathy toward me," the findings point to an overall critical assessment of the relational dimension of care. Negative evaluations predominate: 27.3% of respondents strongly disagree and 21.6% disagree, resulting in a total of 48.9% who did not perceive empathy in staff behavior. Positive evaluations are less frequent: 19.9% agree and 4.0% strongly agree (23.9% overall). A non-negligible proportion of respondents selected a neutral position (27.3%), suggesting experiences perceived as ambivalent, variable, or not clearly interpretable in terms of emotional support received.

Perceived suspicion and distrust in healthcare staff behavior (N = 177)

Regarding the statement "Healthcare staff showed suspicion or distrust toward me," responses indicate a substantial presence of attitudes perceived as distrustful within the care relationship. A majority of respondents (52.8%) reported agreement (agree: 33.3%; strongly agree: 19.5%), indicating that they perceived suspicion or lack of trust on the part of healthcare staff. Disagreement responses are considerably less frequent, with 13.8% disagreeing and 6.3% strongly disagreeing (20.1% overall), while 27.0% of respondents reported a neutral position.

Perceived judgmental attitudes in interactions with healthcare staff (N = 177)

In response to the statement "Healthcare staff appeared judgmental toward me," the findings show a marked imbalance toward negative evaluations of the relational experience. A total of 59.1% of respondents expressed agreement with the statement (agree: 30.1%; strongly agree: 29.0%), indicating a perceived presence of judgemental attitudes on the part of healthcare staff. Disagreement responses were comparatively limited: 11.9% reported disagreement and 5.7% strong disagreement (17.6% overall). A further 23.3% of respondents selected a neutral position. Overall, this distribution suggests that for a substantial proportion of the sample, interactions with healthcare staff were experienced as evaluative or stigmatising, with potential negative effects on the quality of the therapeutic relationship, open communication, and individuals' willingness to express needs, difficulties, or symptoms authentically.

Perceived disrespectful or degrading behaviours by healthcare staff (N = 177)

For the statement "Healthcare staff were disrespectful or degrading towards me," responses indicate a considerable prevalence of experiences perceived as harmful to personal dignity. Overall, 48.6% of respondents agreed with the statement (strongly agree: 26.3%; agree: 22.3%), reporting behaviours considered disrespectful or degrading during the course of treatment. Disagreement responses were less frequent: 18.3% reported disagreement and 8.6% strong disagreement (26.9% overall). A further 24.6% of respondents selected a neutral position. The distribution of responses suggests that a substantial proportion of the sample perceived communication styles or

3.8 Attitudes and Experiences with Healthcare Staff

behaviours incompatible with a respectful, person-centred approach, with potential implications for feelings of safety, trust in professionals, and the overall quality of the therapeutic relationship.

Minimisation or dismissal of reported symptoms (N = 177)

For the statement "Healthcare staff minimised or ignored my symptoms," the response distribution shows a clear predominance of agreement. A total of 56.9% of respondents reported agreement or strong agreement (agree: 31.3%; strongly agree: 25.6%), indicating that more than half of the sample perceived their symptoms as being downplayed, devalued, or insufficiently acknowledged during treatment. Disagreement responses account for 21.0% overall (disagree: 16.5%; strongly disagree: 4.5%), while 22.2% of respondents selected a neutral position. Overall, responses are markedly skewed towards agreement, with a non-negligible proportion of neutral positions and a minority who did not report this experience.

Perceived exaggeration of reported symptoms by healthcare staff (N = 177)

In response to the statement "Healthcare staff exaggerated my symptoms," the distribution of responses shows a predominance of disagreement. A total of 47.2% of respondents report disagreement or strong disagreement (disagree: 32.8%; strongly disagree: 14.4%), indicating that nearly half of the sample did not perceive an amplification of their symptoms by healthcare staff.

Agreement responses are less frequent: 24.7% of respondents report agreement or strong agreement (agree: 10.9%; strongly agree: 13.8%). A further 28.2% selected a neutral position.

Perceived pressure in treatment-related decision-making (N = 177)

For the statement "I felt under pressure from healthcare staff when making decisions about my treatment," the distribution of responses shows a predominance of agreement. A total of 50.3% of respondents fall within the agree or strongly agree categories (agree: 25.7%; strongly agree: 24.6%), indicating that approximately half of the sample perceived pressure during the decision-making process related to their treatment. Disagreement responses account for 21.1% overall (disagree: 16.0%; strongly disagree: 5.1%), while 28.6% of respondents selected a neutral position.

3.8 Attitudes and Experiences with Healthcare Staff

Adequacy of Privacy in Communication with Healthcare Staff (N = 177)

For the statement "I had sufficient privacy to speak freely with healthcare staff," responses are distributed heterogeneously across categories. A total of 39.8% of respondents express a positive evaluation (agree: 28.4%; strongly agree: 11.4%). Disagreement accounts for 32.9% of the sample overall (disagree: 17.6%; strongly disagree: 15.3%), while 27.3% of respondents report a neutral position.

Physical Maltreatment by Healthcare Staff (N = 177)

For the statement "I experienced physical maltreatment by healthcare staff (e.g. being physically restrained without my consent)," the distribution of responses shows a predominance of disagreement. A total of 65.9% of respondents fall into the disagree or strongly disagree categories (22.0% and 43.9%, respectively), indicating that the majority of the sample does not report having experienced this type of event. Agreement accounts for 21.9% overall (agree: 9.8%; strongly agree: 12.1%), while 12.1% express a neutral position.

Verbal Maltreatment by Healthcare Staff (N = 177)

For the statement "I experienced verbal maltreatment by healthcare staff (e.g. being called offensive names)," the distribution of responses shows a predominance of disagreement. A total of 58.1% of respondents fall into the disagree or strongly disagree categories (23.0% and 35.1%, respectively). Overall agreement accounts for 24.7% of the sample (agree: 13.2%; strongly agree: 11.5%), while 17.2% express a neutral position.

Emotional Maltreatment by Healthcare Staff (N = 177)

For the statement "I experienced emotional maltreatment by healthcare staff (e.g. being mocked or ignored when I asked for help)," the distribution of responses shows a predominance of agreement. A total of 50.6% of respondents fall into the agree or strongly agree categories (28.2% and 22.4%, respectively), indicating that approximately half of the sample reports having experienced events consistent with emotional maltreatment during treatment. Disagreement accounts for 35.1% overall (disagree: 18.4%; strongly disagree: 16.7%), while 14.4% express a neutral position.

Perceived Improvement in Mental Health Following Treatment (N = 177)

Responses to the item concerning improvement in mental health are predominantly concentrated in the disagreement categories. Nearly half of the sample (49.7%) report not having observed an improvement attributable to the treatment received (disagree: 15.4%; strongly disagree: 34.3%). Positive evaluations are less frequent (29.1% overall), while 21.1% of respondents report a neutral position.

Perception of Being Labelled as Extreme or Irrational Behaviour (N = 177)

In response to the statement "I felt I was treated as if my behaviour were extreme or irrational," responses show a clear concentration in the agreement categories. More than half of the sample (56.6%) report agreeing or strongly agreeing (34.3% and 22.3%, respectively), while disagreement is less frequent (21.7% overall; disagree: 12.6%;

3.8 Attitudes and Experiences with Healthcare Staff

strongly disagree: 9.1%). A further 21.7% of respondents express a neutral position.

Inappropriate Physical Contact by Healthcare Staff (N = 177)

For the statement "I was touched inappropriately by healthcare staff," the majority of responses fall within the disagreement categories. Overall, 71.3% of respondents report disagreeing or strongly disagreeing (22.4% and 48.9%, respectively), while agreement is less frequent (14.9% overall; agree: 4.6%; strongly agree: 10.3%). A total of 13.8% of respondents express a neutral position.

3.8 Attitudes and Experiences with Healthcare Staff

3.8.1 Conclusion - Attitudes and Experiences with Healthcare Staff

Attitudes and Experiences with Healthcare Staff

The data collected in this section provided a detailed account of how participants perceived the attitudes, behaviours, and relational approaches of healthcare staff encountered throughout their care pathways. Overall, responses showed a varied distribution of experiences, with a clear predominance of critical evaluations across several areas, alongside heterogeneous positions within the sample.

Direct consequences of inappropriate practices on health and well-being

With regard to the direct consequences of practices perceived as inappropriate on health and well-being, the majority of participants associated these experiences with multiple and overlapping outcomes. The most frequently reported consequences concerned a deterioration in mental wellbeing and psychiatric symptoms. These outcomes were accompanied by a marked impact on the relationship with the healthcare system. In particular, loss of trust in health services and the extension of mistrust to all helping professionals emerged as highly common, together with fear of, or refusal to, seeking care again in the future. Alongside these elements, a substantial proportion of participants reported acute crises or clinical relapses, severe side effects that were inadequately managed, and outcomes consistent with stress- or trauma-related conditions.

Impact on daily functioning and social life

The impact on daily functioning was reported with high frequency and affected multiple areas of life. Among the most commonly reported outcomes were increased social isolation and difficulties in work or educational settings. These were followed by loss of autonomy or forms of functional regression. At the relational level, participants reported breakdowns in family or personal relationships and a worsening of experiences of stigma or discrimination. Treatment discontinuation or abandonment also represented a recurrent outcome. Financial consequences, related to healthcare expenses, medications, or legal support, were widely reported. Forced interruption of previously effective treatments and judicial involvement perceived as unnecessary were indicated less often. A minority of participants reported no consequences or outcomes not captured by the predefined categories.

Empathy, trust, and the relational climate

At the relational level, evaluations of empathy pointed to an overall pattern weighted towards negative or mixed perceptions. A substantial proportion of participants did not recognise empathic behaviour on the part of healthcare staff, while positive evaluations were less frequent. The presence of a notable share of intermediate responses suggested experiences perceived as variable or inconsistent, depending on the setting and the professionals involved. Perceptions of suspicion, distrust, and judgemental attitudes emerged particularly strongly.
In these domains, agreement responses clearly outweigh disagreement, indicating that a significant portion of the sample experienced the care relationship as marked by mistrust,

3.8.1 Conclusion - Attitudes and Experiences with Healthcare Staff

evaluation, or stigmatisation. Here again, intermediate responses reflect non-uniform experiences; however, the overall weight of critical evaluations remains predominant.

Disrespectful behaviours, decision-making pressure, and privacy

With regard to disrespectful or degrading behaviours, reports indicated a substantial presence of experiences perceived as undermining personal dignity, although with a more varied distribution compared to other areas. By contrast, perceptions of symptom exaggeration by healthcare staff showed a more balanced pattern, with a predominance of disagreement and a sizeable proportion of neutral responses, making this one of the least polarised aspects.

Perceived pressure in treatment-related decision-making was instead widely reported and stood out among the most frequently cited critical issues. Assessments of privacy in communication presented a mixed picture, with a relatively even distribution of positive, negative, and neutral judgements, suggesting highly variable experiences across different care contexts.

Mistreatment and perceived treatment outcomes

Responses concerning physical mistreatment and inappropriate physical contact showed a predominance of disagreement, indicating that these experiences were not among the most frequently reported. Emotional mistreatment, however, was widely reported and ranked among the most prevalent relational experiences. Verbal mistreatment occupied an intermediate position, with a notable share of critical evaluations, though less pronounced than those related to emotional mistreatment.

Finally, perceptions of mental health improvement following treatment were predominantly negative, with a substantial proportion of participants not recognising any benefit attributable to the care received. Consistently, feeling labelled as exhibiting extreme or irrational behaviour emerged as a frequent experience and stood out among the most clearly reported critical aspects.

Overall, the data depicted perceptions of healthcare staff attitudes and behaviours characterised by a predominance of experiences perceived as disrespectful, judgemental, or coercive, and associated with multiple consequences for wellbeing, daily functioning, and the relationship with services. At the same time, the distribution of responses highlighted marked heterogeneity of experiences within the sample.

04. Bipolar Disorder: Beneath the Tip of the Iceberg - An Analysis of Real-World Experiences

Addressing communication in bipolar disorder is not simply useful: it is a clinical and human priority. Even today, many people with psychiatric disorders are treated as if they were patients with acute physical conditions, through standardised, impersonal, and often cold forms of communication. Brief, protocol-driven phrases that might appear neutral in a general medical context can instead have a significant negative impact on the psychological wellbeing of a person with bipolar disorder.

In the case of a physical condition, such as a fractured limb, the quality of communication certainly affects the patient's subjective experience, but it does not alter the direct clinical outcome: with appropriate treatment, the arm heals. In psychiatric care, by contrast, the way therapeutic dialogue is conducted profoundly influences the course of treatment. Communication perceived as cold, judgemental, or rushed can be emotionally destabilising, increase distrust toward professionals, and, in more delicate cases, trigger a worsening of the clinical picture.

In bipolar disorder, the relational and communicative dimension is an integral part of therapy. The goal is not merely to provide information, but to create a safe, welcoming, and non-stigmatising framework in which the patient can feel recognised as a person, rather than reduced to a diagnosis. Empathy, respect, and human warmth are not optional elements: they form the foundations of an effective and sustainable therapeutic relationship.

High-quality communication fosters trust, encourages collaboration, and supports adherence to treatment. It enables individuals to express what they are truly experiencing, to anticipate early warning signs of crisis, and to share their experiences more accurately, thereby improving the quality of available clinical information. Moreover, it helps preserve a sense of dignity, identity, and agency—dimensions that are often undermined in more institutionalised care settings.

04. Bipolar Disorder: Beneath the Tip of the Iceberg - An Analysis of Real-World Experiences

For mental health professionals, developing disorder-specific communication skills reduces the risk of conflict, improves clinical effectiveness, and helps prevent avoidable critical situations. For family members, understanding the importance of genuine, non-judgemental listening can be decisive in everyday relationships, particularly during the most unstable phases of the disorder.

Recognising the central role of communication in the treatment of bipolar disorder means moving beyond a narrow, reductionist view of care toward an integrated approach that acknowledges the emotional, relational, and social dimensions of mental health. It means clearly affirming that words, tone, listening, and presence are not secondary or supportive elements, but core components of care itself. Thoughtful and attentive communication is the foundation for building strong therapeutic alliances, supporting meaningful recovery pathways, and safeguarding the dignity and wellbeing of people living with a complex psychiatric condition.

The campaign "Bipolar Disorder: Beneath the Tip of the Iceberg" is the first national initiative promoted by the Associazione Italiana Bipolari, created with the explicit aim of improving understanding of bipolar disorder and fostering a concrete, ongoing dialogue between people with lived experience, mental health professionals, and civil society.

The campaign is grounded in a reflection that has guided our work from the outset: knowing the clinical definition of bipolar disorder does not equate to understanding what it is like to live with it. Professionals are often well equipped to identify symptoms, but less accustomed to listening to people in the full complexity of their lived experience. Depressive, manic, and mixed episodes are described in technical terms, while relational contexts, invisible suffering, and the identity-level consequences of these experiences are too often overlooked.

In 2025, in collaboration with Telefono Amico, we began designing a dedicated training programme for volunteers responding to crisis situations. The starting point was a public survey addressed to people diagnosed with bipolar disorder. Hundreds of responses were collected on what helps and what worsens experiences across different phases of the condition. This material generated a rich body of insights, which were subsequently reorganised into a structured thematic analysis. From this process, the campaign emerged.

04. Bipolar Disorder: Beneath the Tip of the Iceberg - An Analysis of Real-World Experiences

“Bipolar Disorder: Beneath the Tip of the Iceberg” is not a traditional information campaign, but a space for listening and reflection. We did not begin with what we wanted to say, but with what people needed to tell. We chose to place real experiences at the centre—words that hurt or help, and the ways in which communication can shape the course of the illness, trust in care, and the ability to ask for help.

The campaign ran for one month and was conducted entirely online through the Associazione Italiana Bipolari’s Instagram channel, which reaches over 1,800 followers. Participation was open and voluntary, with the aim of collecting first-hand accounts from people diagnosed with bipolar disorder about what had been helpful—and what had been harmful—during different phases of the condition.

This initiative is addressed to multiple audiences.

- **For people with bipolar disorder and their families,** it offers a space to share lived experience and to feel represented in a way that is accurate, respectful, and free from distortion or oversimplification.
- **For mental health professionals,** it provides a free, practical training resource that is immediately applicable in clinical practice and grounded in real-world data.
- **For the general public,** it offers an opportunity to move beyond prejudice and misinformation, and to engage more closely with a reality that is often misunderstood.
- **For the media**, it proposes a different language for talking about bipolar disorder—one that is respectful, precise, and detached from stereotypes

The aim of the campaign is not only to raise awareness, but to contribute to a tangible shift in how bipolar disorder is perceived and addressed across different contexts—clinical, familial, social, and educational. The title itself points to what so often remains unseen: unspoken emotions, difficult communication, and the invisible wounds that accumulate beneath the surface.

Method and Analytical Framework

The analysis presented in this chapter is based on textual materials collected through open-ended questions and spontaneous contributions shared via the social media channels of the Associazione Italiana Bipolari. This mode of data collection made it possible to capture a wide range of lived experiences, language patterns, and expressed needs directly voiced by people with bipolar disorder, in an anonymous format and without mediation through structured researcher–participant interaction. The material was analysed using a qualitative thematic analysis approach, aimed at identifying recurring elements, interpretative categories, and communicative patterns that are emotionally and relationally salient. The focus was not placed on clinical content in a narrow sense, but on the meanings attributed to words received and on the impact that specific communicative styles can have across different phases of the disorder (depression, mania or hypomania, mixed states, psychosis, and suicidal ideation).

The exploratory and unstructured nature of the data collection carries important methodological implications. In particular, the analysis is strongly dependent on how participants chose to formulate and position their responses. Linguistically similar phrases may appear across different macro-themes—for example, within both harmful and protective forms of communication—not due to analytical inconsistency, but because they were used with different intentions, emotional contexts, and meanings by participants themselves. This type of material does not always allow for the detection of subtle nuances related to tone, irony, prior relational history, or the situational context in which a statement was delivered. A more in-depth reconstruction of these dimensions would require the use of semi-structured interviews or other more formal qualitative methods specifically designed to explore intentionality, context, and meaning in a systematic way.

Consequently, the themes presented in this chapter should not be understood as rigid or exhaustive categories, but as interpretative groupings derived from recurring patterns within the collected narratives. The reappearance of similar elements across different sections reflects the complexity of lived experience and the inherently relational nature of language in psychiatric care. The aim of this analysis is not to provide a definitive taxonomy of communication in bipolar disorder, but to make visible those linguistic practices that, from the perspective of the people involved, are most frequently associated with experiences of protection or harm. In this sense, the chapter is conceived as a practical and educational tool, grounded in lived experience, intended to support listening, relational practice, and communicative awareness within care settings.

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

Depression – “Talk to Me. Don’t Let Me Disappear.

The depressive phase of bipolar disorder represents one of the most complex, painful, and fragile expressions of the condition. It is not merely a lowering of mood, but a systemic collapse of vital energy, sense of self, and the ability to make meaning of reality. In this state, communication—from family members, friends, healthcare professionals, or colleagues—takes on a critical role. It can function as a source of connection and containment, or become a disintegrating force that amplifies suffering, exclusion, and suicidal ideation.

The thematic analysis that follows is based on a systematic examination of first-hand accounts related to the depressive phase of bipolar disorder, with particular attention to forms of communication experienced as harmful or, conversely, as supportive. The themes identified do not emerge as static categories, but as interconnected systems that together convey a layered picture of depressive vulnerability. Words can invalidate subjective experience or restore its dignity; they can sever the bond—or help preserve it.

The analysis is structured around three main macro-themes, each subdivided into sub-themes that illustrate recurring communicative patterns. A final cross-cutting theme explores the role of identity and shame in relational dynamics during crisis. The aim is not merely descriptive, but interpretative: to illustrate the underlying mechanisms of each communicative mode, their psychological and relational consequences, and the ways in which they can shape the trajectory of suffering.

4.1. Phase 1: Depression – "Talk to Me. Don't Let Me Disappear."

Identified Themes

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
1	**Invalidating statements and harmful communication**	*Minimisation of pain*	Statements that appear reassuring but deny the depth of the depressive experience. They reinforce self-stigma and make the person feel that their pain is unseen.	"Come on, life is beautiful", "Everyone goes through this", "Others have it worse than you", "You're making a big deal out of nothing", "You can't always see everything in black"
1	**Invalidating statements and harmful communication**	*Blame and pressure to improve*	These messages turn depression into a moral failure, blaming the person who is suffering and intensifying emotional distress.	"You're not trying hard enough", "Pull yourself together", "You just need willpower", "Keep yourself busy", "You can't live like this"
1	**Invalidating statements and harmful communication**	*Devaluation of the diagnosis and of continuity of care*	These statements call the credibility of the suffering into question, undermine trust, and fuel shame and isolation.	"But you were better yesterday", "Well, it seemed to me like you were doing better", "Again? Are you always unwell?"
2	**Empathic communication and relational connection**	*Silent, non-judgmental presence*	Authentic listening does not require the right words, but a real, non-judgmental presence that conveys acceptance.	"I'm here with you", "We don't have to talk", "Do you want me to hold your hand?", "I'm here if you want, even if we don't talk"
2	**Empathic communication and relational connection**	*Acceptance and emotional validation*	These responses restore dignity to vulnerability, normalising pain and offering space for emotional openness.	"I don't judge you", "Cry as much as you need", "Other people cry too", "You're not abnormal", "You're not alone"
2	**Empathic communication and relational connection**	*Personal worth separated from the crisis*	These statements remind the person of their worth and identity even during crisis, helping to strengthen their sense of self.	"You're still the person I most like talking to", "We'll do everything together", "You're strong, you'll get through this"
3	**Relational fragility and fear of abandonment**	*Fragility of the bond*	Comments that are misaligned with the person's internal experience can generate fear of abandonment and reinforce isolation.	"When you tell me I'm better and it's not true, I'm afraid you'll abandon me."

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

MACRO-THEME 1: Invalidating statements and harmful communication

Communication perceived as harmful during the depressive phase is not necessarily openly aggressive. On the contrary, it often takes subtle, passive, or even seemingly well-intentioned forms. It is precisely this ambiguity that makes it particularly damaging: messages delivered with positive intentions but misaligned with a person’s inner experience can create a deep rupture between the self and the surrounding environment. The sub-themes that make up this macro-theme illustrate the different ways in which suffering may be denied, judged, or turned into a source of blame.

Sub-theme 1.1: Minimisation of pain

One of the most common forms of invalidating communication is the minimisation of pain. Phrases such as “Everyone goes through this,” **“Come on, life is beautiful,” or “Others have it worse than you”** often convey—implicitly rather than explicitly —*the idea that the pain expressed by the person is not serious enough to warrant attention or concern. The emotional impact is twofold: on the one hand, the person feels unseen; on the other, a sense of guilt emerges for experiencing emotions perceived as excessive or “out of proportion.”*

In a depressive context, where personal worth is already profoundly undermined, these statements reinforce a cycle of self-invalidation that can lead to further emotional withdrawal. Suffering is internalised as a sign of weakness, and future communication is often avoided for fear of being invalidated again. In some cases, this dynamic can contribute to the development of a self-destructive internal dialogue: “If even others think it’s nothing, then I really am overreacting—I’m the problem.”

4.1. Phase 1: Depression – "Talk to Me. Don't Let Me Disappear."

Phrases Frequently Reported by Users:

- "Come on, life is beautiful"
- "Everyone goes through this"
- "Others have it worse than you"
- "You're making a big deal out of nothing"
- "You can't always see everything in black"

These expressions, though seemingly reassuring or pragmatic, in fact devalue and minimise the person's genuine suffering. Denying or downplaying the severity of depression implies that the pain being experienced is not worthy of attention or understanding.

From a clinical perspective, such statements can reinforce self-stigma, leading individuals to perceive themselves as weak or inadequate, and increasing feelings of helplessness as well as passive suicidal ideation. From a relational standpoint, they convey an implicit message of disinterest or misunderstanding, further intensifying the sense of isolation.

Sub-theme 1.2: Blame and pressure to improve

This sub-theme highlights a form of communication that is deeply damaging to the individual: psychological pain is reframed as a personal or moral failure. Within this interpretative framework, depression is mistakenly understood as a lack of willpower or a deliberate negative choice, rather than as a complex neurobiological and psychological condition. The immediate consequence is the intensification of paralysing guilt, which fuels self-contempt and further immobilises the person in a state of emotional and behavioural inertia. At a social level, such statements reflect a productivity-oriented culture that implicitly frames the depressed individual as lacking value.

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

Phrases Frequently Reported by Users:

- “You’re not trying hard enough”
- “Pull yourself together”
- “You just need willpower”
- “Keep yourself busy”,
- “You can’t live like this”

Another recurring form of harmful communication is one that turns the depressive crisis into a moral issue, placing responsibility for the condition onto the individual. Statements such as “You’re not trying hard enough,” “Pull yourself together,” or “It’s just a matter of willpower” imply that recovery from depression depends entirely on personal effort.

This type of message has particularly harmful effects when a person is experiencing a severe depressive episode, marked by loss of initiative, cognitive and emotional slowing, and a profound erosion of meaning. ***External pressure to improve is experienced as an accusation and ends up amplifying the self-blame already present in the depressive mindset.***

The result is a rigidification of negative thinking: “Not only am I unwell, but it’s also my fault.” *At a relational level, the bond of trust is broken. The implicit message received is that the pain is not understandable but inconvenient—not something to be held and supported, but something to be eliminated as quickly as possible.*

4.1. Phase 1: Depression – "Talk to Me. Don't Let Me Disappear."

Sub-theme 1.3: Devaluation of the diagnosis and of continuity of care

Bipolar depression often follows a non-linear course, alternating periods of apparent wellbeing with sudden relapses. Statements such as "But you were better yesterday," "Again?" or "You're always unwell" invalidate this discontinuity, implicitly suggesting that the person is exaggerating, pretending, or otherwise not deserving of full credibility. This form of communication not only denies the complexity of the disorder, but also undermines the narrative continuity of the person's identity.
The consequences are profound. The person in crisis—already disoriented by their internal state—finds themselves having to defend the legitimacy of their own suffering. This generates additional stress, deepens the sense of isolation, and reinforces the perception that there is no safe space in which to share lived experience. In more severe cases, it can lead to complete relational withdrawal, compromising even the closest bonds.

Phrases Frequently Reported by Users:

- "But you were better yesterday"
- "Well, it seemed to me like you were doing better"
- "Again? Are you always unwell?"

These comments, while they may appear harmless, have a significant impact because they invalidate the depressed person's subjective reality and undermine the relational bond of trust. ***Bipolar depression is characterised by often unpredictable fluctuations that can be confusing for external observers. Drawing attention to these shifts through doubtful or sceptical remarks increases the fear of not being believed and fosters feelings of shame and relational isolation, as the person may feel compelled to perform a sense of wellbeing that does not reflect their internal state.***

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

The depressive phase represents one of the most delicate and critical moments in bipolar disorder. It is marked by an intense sense of despair and invisibility, alongside a profound need to be met with understanding and acceptance. This phase calls for careful reflection on communication in both clinical and relational contexts, as the way a person is addressed can significantly influence the course of the crisis and their sense of self.

MACRO-THEME 2: Empathic communication and relational connection

In contrast to the invalidating communication described in the previous macro-theme, a second thematic cluster emerges clearly: that of empathic, authentic, and regulating communication. During the depressive phase—and especially in its most severe forms, when suicidal ideation may be present—human presence, even when only implicit, can function as a relational intervention with a very high therapeutic impact. It is not necessarily the words themselves that are healing, but the quality of the relationship those words convey: acceptance, listening, non-judgement, and continuity.

This macro-theme is articulated into three sub-themes, illustrating how, in conditions of profound suffering, it is often the simplest forms of communication—free from corrective intent—that exert the strongest effect in terms of containment, recognition, and support of the person’s sense of self.

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

Sub-theme 2.1: Silent, non-judgmental presence

Many participants reported that, in the midst of a depressive crisis, their primary need was not to be reassured or encouraged, but simply not to be left alone. The experience of silent presence—knowing that someone is there, without asking for explanations or demanding improvement—is described as deeply reassuring and regulating.

Expressions such as “I’m here with you,” “Do you want to sit in silence together?” or “Can I hold your hand?” do not operate through specific semantic content, but through what they symbolically represent: a relational space that asks nothing, does not judge, and offers containment without intrusion. In these moments, the person in crisis is not required to justify themselves, to appear “better,” or to be “functioning,” but is finally allowed to exist in their own fragility.

From a psychological perspective, silent presence allows for a lowering of internal alertness and a temporary suspension of inner conflict. There is no need to explain one’s pain in order to be received. This facilitates an internal reconnection between body, emotions, and mind—dimensions that are often fragmented or dissociated during depression.

Effective and Appreciated Phrases Reported by Users:

- I’m here with you”
- “We don’t have to talk”
- “Do you want me to hold your hand?”
- “I’m here if you want, even if we don’t talk”

Silent presence represents one of the highest forms of support during the depressive phase. In depression, the lack of mental energy makes verbal communication extremely demanding. Offering quiet, stable, and genuine human contact allows the depressed person to feel accepted in their fragility, without the pressure to perform emotionally or verbally. This relational approach—known in psychology as containment—enables essential emotional regulation during moments of crisis.

4.1. Phase 1: Depression – "Talk to Me. Don't Let Me Disappear."

Sub-theme 2.2: Acceptance and emotional validation

Accepting another person's pain without trying to change it or question it is a profoundly transformative relational act. Phrases that convey this acceptance—such as "I don't judge you," "You can cry as much as you need," "You're not abnormal," or "You're not alone"—serve a specific function: restoring legitimacy to emotional experience and counteracting the internalisation of stigma.

During the depressive phase, individuals often perceive their emotions as excessive, burdensome, or pathological. Empathic recognition from another person allows this perception to be temporarily de-pathologised, offering a context in which emotion can be experienced without shame. This does not mean "normalising" the crisis in the sense of minimising it, but rather making it speakable, communicable, and shareable.

Validation is a relational gesture that breaks isolation. When pain is acknowledged without conditions or reservations, a space is created in which the person can begin to recognise and accept it themselves, laying the groundwork for further emotional processing. It is a slow and fragile process, but an essential one for emerging from the silence that so often surrounds psychological suffering.

Effective and Appreciated Phrases Reported by Users:

- "I don't judge you"
- "Cry as much as you need"
- "Other people cry too"
- "You're not abnormal"
- "You're not alone"

Emotional validation restores dignity to experienced pain. These messages help normalise depressive suffering without trivialising it, allowing individuals to express their emotions freely. This form of communication strengthens a sense of human connection and provides a fundamental reassurance: vulnerability is not something to be ashamed of or concealed, but a shared and understandable human experience.

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

Sub-theme 2.3: Personal worth separated from the crisis

Another essential element that emerged from the analysis is the importance of messages that remind the person of their worth beyond the crisis. Statements such as “You’re still the person I most enjoy talking to,” “We’ll do everything together,” or “You’re strong—you’ll get through this” do not deny the suffering, but place it within a broader narrative in which the person continues to be recognised as a whole individual.

During depression, identity often becomes fragmented: the person no longer recognises themselves and may experience themselves as absent, wrong, or worthless. Receiving a message that affirms the existence and value of the self—even in this state—helps counteract the feeling of erasure. These messages function as a form of “healthy mirroring,” offering back a positive and coherent image of the person that depression has obscured.

When authentic and not forced, this type of communication can reactivate core identity elements, such as a sense of belonging, trust in the relationship, and memory of who one has been. In this way, it becomes an essential tool not only for support, but also for the prevention of suicidal ideation, which often arises precisely from the loss of meaning and personal worth.

During bipolar depression, personal identity becomes fractured and self-perception is profoundly damaged. Reminding a depressed person that their worth exists independently of their current suffering allows for a reconnection with vital, intact parts of the self—an essential process for maintaining an integrated sense of identity. These messages foster emotional resilience and help prevent self-stigmatisation.

4.1. Phase 1: Depression – "Talk to Me. Don't Let Me Disappear."

MACRO-THEME 3: Relational fragility and fear of abandonment

The depressive phase of bipolar disorder is marked by a constant relational ambivalence: on the one hand, an intense need for closeness emerges; on the other, a deep fear of rejection or abandonment. This dynamic is not merely emotional in nature, but constitutes a genuine structural vulnerability of the depressive phase, with significant consequences for interpersonal functioning and for the ability to receive support.

One of the most emblematic statements collected during the analysis is: *"When you tell me I'm better and it's not true, I'm afraid you'll abandon me."* This sentence encapsulates a set of complex dynamics: the discrepancy between inner experience and external perception; the fear that improvement is being prematurely attributed by others in order to reduce relational burden; and the anxiety that recognition of the crisis may be withdrawn too soon. In this context, even apparently positive words—when misaligned with the person's internal reality—can trigger distrust, disappointment, and further isolation.

The fragility of the bond becomes particularly evident when the depressed person feels emotionally transparent. Any external attempt to reframe reality or minimise the intensity of the pain is experienced as a profound denial of their very existence. *The perceived risk is not simply that of being "misunderstood," but of being left alone at the darkest moment. This gives rise to a defensive withdrawal that can compromise even the most stable relationships, leaving space for catastrophic interpretations ("they don't really care," "they just want me out of the way").*

Within this framework, the way communication is carried out—its tone, timing, and emotional consistency—can have a potentially life-saving impact. ***A positive relational experience is not built on avoiding pain or trying to correct it, but on staying. Authentic affective continuity represents a form of containment that helps regulate fear of abandonment.*** Communication must therefore become a protected space in which fragility can be expressed without fear of punishment or of the withdrawal of love and attention.

4.1. Phase 1: Depression – “Talk to Me. Don’t Let Me Disappear.”

Practical, actionable recommendations that emerged repeatedly from the analysed data include:

Do

- **Use open-ended statements that are aligned with the person’s lived reality, rather than imposed interpretations.**
- **Offer an authentic and continuous presence, including silent presence when appropriate.**
- **Validate emotions without attempting to force change or transformation.**
- **Communicate genuine, stable availability over time.**

Avoid

- **Generic or automatic motivational statements.**
- **Comparisons with other experiences** (e.g. “I’ve been through difficult times too”).
- **Minimising remarks** (e.g. “It won’t last long,” “It will pass”).
- **Comments on physical appearance as a form of reassurance** (e.g. “You’re beautiful, you can’t be depressed”).

Relational experience in depression does not call for complex explanations or immediate solutions. Instead, it requires time, consistency, and the courage to remain present in a condition that offers neither certainty nor immediate reward. This relational capacity—often underestimated—represents a fundamental therapeutic resource, even beyond formal clinical settings.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS - “Don’t tell me everything will be okay. Just stay. That’s enough”

Severe depression, particularly when accompanied by suicidal thoughts, represents the point of greatest clinical and relational vulnerability for people with bipolar disorder. In these moments, psychological pain becomes overwhelming, the sense of self disintegrates, and any future perspective appears meaningless or unbearable.

It is within this extreme scenario that communication takes on a potentially life-saving —or destructive—role. The quality of the verbal exchange, or even of the communicative stance alone, can enable a minimal yet vital movement toward connection, or instead push the person decisively toward silence, isolation, and withdrawal.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Identified Themes

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
1	**Communications that cause even more harm**	*Superficial encouragement disguised as support*	Statements that appear reassuring but, in severe depression, feel empty and disconnected from lived reality. They impose an unshared hope and intensify loneliness.	"Everything will be fine", "You'll see, it will pass", "You just need to think positive", "Keep yourself busy"
1	**Communications that cause even more harm**	*Moral judgement disguised as advice*	These messages turn pain into guilt. They imply that depression is due to a lack of willpower, worsening self-blame and increasing suicidal risk.	"You have to react", "You can't live like this", "Wake up", "You don't want to do anything at all"
1	**Communications that cause even more harm**	*Breakdown of the emotional bond*	Expressions that confirm the fear of being a burden, leading to emotional shutdown or isolation. They push the person toward withdrawal and abandonment of contact.	"You're always unwell", "You're driving me crazy too", "I can't do everything on my own"
2	**Phrases that keep the connection alive**	*Simple, genuine presence*	Brief statements that convey closeness and unconditional presence, without demands or solutions. They have a strong regulatory effect.	"I'm here", "I'm here if you want, even if we don't talk", "Do you want to sit in silence together?"
2	**Phrases that keep the connection alive**	*Worth that remains even during crisis*	These messages recognise the person beyond the pain, strengthening a fragmented sense of identity and counteracting self-erasure.	"You're still the person I most enjoy talking to", "We'll do everything together", "You're not abnormal—crying is human"
2	**Phrases that keep the connection alive**	*Shared vulnerability*	Normalising emotions that are often socially unacceptable—such as crying or helplessness—fosters relief and relational alliance.	"Do you want a hug?", "Other people cry too", "Cry as much as you need —you're not alone"

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Identified Themes

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
3	**Silent Stigma and the Language of Suicide**	*Silence imposed by stigma*	Fear of judgement leads people to conceal their pain. Even vague or indirect expressions may mask severe suffering.	Shame about the diagnosis; fear of being excluded; minimising one's pain in order not to alarm others
3	**Silent Stigma and the Language of Suicide**	*Suicide as escape, not death*	Suicidal ideation often reflects a desire for relief rather than a wish to die. This requires careful listening and the ability to name the crisis with sensitivity.	"I just want to disappear", "I feel like I'm a burden", "I can't take this anymore"

MACRO-THEME 4: Communications that cause even more harm

In the context of severe depression, the communicative approaches adopted by family members, friends, or professionals can carry particular weight. During phases of intense psychological vulnerability—when the sense of self is compromised and access to hope is severely reduced—every word acquires transformative potential: it can draw closer or push away, contain or fragment, create meaning or strip it away.

The fourth macro-theme focuses precisely on those forms of communication that, while not overtly aggressive or violent, prove harmful at both the subjective and relational level. These are often expressions perceived by those who use them as "normal," "common sense," or even "encouraging," yet which, in the lived experience of the depressed person, are experienced as intrusive, devaluing, or invalidating. Their harmfulness lies not only in their content, but in the distance they create: they implicitly convey the message that pain is not legitimate, understandable, or tolerable.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

The thematic analysis identified three main critical communicative patterns: superficial encouragement, moral judgement disguised as advice, and the implicit rupture of the emotional bond. These forms of communication produce convergent effects: they intensify feelings of loneliness, disrupt or weaken available relational channels, and hinder access to care pathways or the ability to seek help. In some cases, they can act as direct triggers or aggravating factors for suicidal ideation, particularly when they impact an already fragile or compromised sense of identity.

Sub-theme 4.1: Superficial encouragement disguised as support

Across the analysed material, a recurring negative effect emerges in relation to apparently reassuring phrases such as ***"Everything will be fine," "You just need to think positive," or "You'll see, it will pass." Although these expressions are often spoken with protective or consoling intentions, they prove profoundly inadequate during the acute phase of depression.***

For the person receiving them, these statements are not experienced as signs of closeness, but as an implicit rejection of their emotional reality. The pain—as it is lived and communicated—finds no space or recognition: it is bypassed, neutralised, or minimised. This form of communication generates disconnection and emotional distance. The individual feels not only misunderstood, but effectively excluded from the very possibility of being heard.

The underlying message—"you shouldn't feel this way"—conveys the idea that there is a "right" way to respond, and that anyone who fails to conform to it is somehow inadequate. The relational effect is a rupture: those who are suffering may begin to avoid dialogue altogether, retreating into a form of protective silence that is deeply isolating. The relationship becomes strained, and the sense of loneliness intensifies. In some cases, this dynamic has led participants to withdraw from meaningful relationships or to discontinue therapeutic pathways that were perceived as ineffective or judgmental.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 4.2: Moral judgment disguised as advice

Another cluster of problematic expressions identified in the analysis concerns statements that present themselves as constructive advice but convey a normative and moralising message. Phrases such as "Wake up," "You have to react," or "You can't go on like this" not only fail to acknowledge the complexity of the suffering, but actively transform it into individual blame.

The primary effect of these forms of communication is a negative redefinition of identity: pain is no longer understood as a condition to be endured, but as a personal failure, a character flaw, or a lack of will. Those who receive these messages do not feel supported, but accused. The implicit message—"you are the problem, not the situation"—intensifies feelings of inadequacy and fuels shame and self-condemnation.

The pressure to "react" demands a movement that is impossible at a time when all psychological energy is absorbed by day-to-day survival. When the simple act of getting out of bed requires immense effort, being told that one merely needs to "want it more" becomes a form of subtle yet deeply penetrating violence. *Over time, the person internalises the belief that if they are unable to improve, it is because they are not strong enough, not motivated enough, not worthy enough.* In this way, a vicious cycle of guilt and despair is constructed, further depleting the already limited resources available to them.

Phrases frequently reported by users:

- "Wake up"
- "You have to react"
- "You can't go on like this"

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 4.3: Breakdown of the emotional bond

A third cluster of problematic communication concerns situations in which suffering is experienced as intolerable not only by the person living it, but also by those observing it. ***Expressions such as "You're driving me crazy," "I can't do everything on my own," or "You're always unwell" signal the emotional saturation of the interlocutor, while simultaneously placing the relationship itself under strain.***

These statements are not necessarily spoken with hostility; they are often driven by exhaustion, frustration, or a sense of helplessness. However, their impact on someone in crisis is deeply disruptive. The message received is unequivocal: "your suffering is too much for me—I can't cope with you anymore."

FPhrases frequently reported by users:

- "You're driving me crazy."
- "I can't do everything on my own."
- "You're always unwell."

At a moment when the person is seeking containment and acceptance, being experienced as an additional burden intensifies feelings of guilt and can give rise to the desire to disappear—not as an impulsive act, but as something perceived as "necessary" in order to relieve others. Identity contracts even further around a sense of inadequacy, and the ability to trust others diminishes sharply.

In these situations, what is lacking is not a rational understanding of the problem, but the emotional availability to hold—even temporarily—a form of pain that cannot be resolved through practical solutions. When the relational bond collapses precisely at the moment it is most needed, the result is not only a relational wound, but a tangible worsening of the clinical condition.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

MACRO-THEME 5: Phrases that keep the connection alive

This theme highlights a central relational dimension during the most critical moments of severe depression, particularly when suicidal thoughts emerge. ***In these phases, communication can become extremely difficult: speaking requires enormous effort, and even perceiving affection or feeling part of a relational bond may feel impossible. Yet it is precisely in these moments that certain simple phrases can have a profound impact.***

These are not elaborate statements or pieces of advice, but brief, authentic messages capable of conveying continuity, acceptance, and stability. Phrases that do not judge, do not demand reaction or change, but instead communicate that someone is present—and will continue to be present.

The value of these communications lies in their ability to interrupt the logic of doing —the logic that demands improvement, response, and "functioning"—and to make space for a different logic: that of staying alongside. At a time when the person perceives themselves as useless, guilty, or even harmful, feeling recognised and accompanied in their fragility can make a decisive difference.

This form of presence does not aim to resolve suffering, but to share it. The data suggest that this represents a significant shift at both cultural and clinical levels: moving from a results-oriented approach to one centred on relationship, co-presence, and shared emotional regulation

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 5.1: Simple, genuine presence

One element that emerges strongly is the importance of simple presence, even without words. Phrases such as "I'm here," "I'm here if you want, even if we don't talk," or "Would you like to sit in silence together?" reflect a different relational stance: they do not push the person to speak or explain themselves, but offer a space in which they can exist without having to be active, productive, or communicative.

In the most acute phase of depression, even speaking can feel overwhelmingly difficult. In these situations, the continuity of presence—without demands or expectations—becomes a powerful form of care. The person experiences that the other remains alongside them even in silence, withdrawal, and suffering.

This kind of presence communicates unconditional acceptance. It does not withdraw in the face of difficulty or a lack of response. The data suggest that it is precisely this quiet, non-intrusive stability that can become a source of emotional containment: it helps the person not feel alone, without asking anything in return.

In some cases, suspending verbal language allows for a more authentic connection, freed from the social pressure of "having to say something." It is a form of communication that is minimal, yet deeply human.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 5.2: Worth that remains even during crisis

Another strong theme concerns the perceived loss of personal worth that often accompanies the most severe depressive phases. In this context, phrases such as "You're still the person I most enjoy talking to," "You have value even now," or "Your presence matters" have a significant impact.

These statements do more than offer reassurance: they provide deep recognition, restoring a sense of identity and dignity precisely at a moment when the person can no longer see themselves in that way.

Such phrases help construct an alternative narrative to the destructive inner voice that is typical of depression. Affirming that someone has value "even now" helps preserve a thread of continuity between the self "before" and the self "during" the crisis. The pain is not denied, but placed within a relationship that can hold it and move through it together.

This dimension also carries broader implications. In a society that often ties personal worth to productivity, positivity, and efficiency, recognising value in vulnerability becomes a profoundly countercultural act. The data reveal a tension between the subjective experience of crisis—as a total loss of meaning—and the possibility, through relationship, of maintaining a gaze grounded in respect and recognition.**

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 5.3: Shared vulnerability

Finally, the importance of phrases that allow difficult emotions to be expressed safely emerges clearly. Statements such as "Would you like a hug?", "Cry as much as you need—you're not alone," or "Other people cry too" have a normalising and humanising effect.

These words help break isolation, counter feelings of shame, and make emotions that are often hidden or judged more acceptable. They are not merely comforting, but function as genuine acts of recognition: the other person sees me, accepts my pain, is not frightened by it, and does not reject me.

Effective and appreciated phrases reported by users:

- "Would you like a hug?"
- "Cry as much as you need—you're not alone."
- "Other people cry too."

Saying "other people cry too" creates a horizontal connection. Suffering is no longer framed as a sign of individual failure, but as something that can be shared. This helps the person feel part of a common humanity again, stepping out of the narrative that only those who are strong, rational, and in control have value.

The implications extend beyond the individual level. Here, pain is not treated as an error to be corrected, but as a legitimate human experience. The relationship becomes a space in which pain can be expressed, received, and moved through together—without the need for immediate solutions, but with the offering of authentic closeness.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

MACRO-THEME 6:Silent stigma and the language of suicide

The sixth macro-theme addresses one of the most delicate areas to emerge from the testimonies: the ways in which people communicate—or struggle to communicate—their suffering related to suicidal ideation. ***The data reveal a constant tension between the need to express pain and the fear of the reactions such expression might provoke. The language used is often indirect, nuanced, and positioned at the edges of what can be said. Suicide is evoked or suggested, but rarely stated outright.***

This communicative pattern is not driven by a genuine desire to conceal, but rather by a social and relational context that makes it difficult to openly name the wish to no longer exist. *The stigma surrounding suicide generates a double silence: the silence of those who suffer, who cannot find the words or do not feel authorised to speak them, and the silence of those who listen, who often avoid the topic out of fear, discomfort, or a sense of helplessness.*

Within this context, language becomes a survival tool. Words grow veiled and ambiguous, yet they remain crucial signals that must be recognised. When direct dialogue feels impossible, these implicit expressions are often the only way to attempt contact. Acknowledging and receiving them can make the difference between isolation and connection, between withdrawal and the possibility of opening up.

Many of the collected phrases do not explicitly express an intention to end one's life, but instead convey profound exhaustion, a need for respite, or a wish to disappear. These expressions reflect a form of "protected" language—more socially acceptable, yet at risk of being unheard or misinterpreted.

Stigma affects not only those who are suffering, but also those who listen: interlocutors often do not know what to say, fear making the situation worse, or retreat into silence. This shared silence, on both sides, can create a dangerous relational void. Interrupting it—even with a single question or a stance of availability—can constitute a decisive act of care and prevention.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 6.1: Silence imposed by stigma

Expressions such as ***"I feel like a burden," "I don't want to be a weight on anyone,"*** or ***"I just want to disappear"*** emerge in the data as recurring signals. They are often spoken softly—sometimes hinted at in passing, other times repeated insistently. ***These are not explicit statements of suicidal intent, but indicators of a form of pain that is difficult to articulate fully. They constitute an alternative language, often the only one available to those who feel unable to speak openly. At the root of this silence lies stigma, understood not only as social condemnation but as the emotional climate surrounding psychological suffering.*** People experiencing suicidal thoughts frequently internalise the belief that they are unacceptable, flawed, weak, or guilty. Fear of judgement—of being seen as selfish, ungrateful, dangerous, or even manipulative—leads them to conceal what they are feeling. The risk, however, is that this silence may also be reinforced by external responses

The data show that those who are listening often do not know how to respond: they change the subject, minimise what is being said, or become emotionally rigid. This is not due to a lack of empathy, but rather to a lack of tools, fear of "doing harm," or the emotional weight of the topic itself. As a result, a double silence emerges: the person who does not feel authorised to speak, and the other who is unable to receive what is being expressed.

This dynamic creates a communicative void charged with tension. The primary risk is that the signals being sent remain unheard or are trivialised, further intensifying feelings of invisibility and loneliness. Recognising the importance of these phrases —even when they are not explicit—means offering the person the possibility of being seen and received in their emotional reality, without forcing them into a form of communication that may not yet be possible.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

Sub-theme 6.2: Suicide as escape, not death

One central element that emerges is that expressions related to a wish to die need to be understood within the person's existential and relational context. Statements such as "I can't take this anymore," "I want to disappear," or "Enough, I don't want to feel anything anymore" should not be read literally, but understood as requests for relief, rest, or a pause from pain experienced as overwhelming.

In the data, suicide rarely appears as a genuine wish to die. Instead, it is more often described as an extreme way of imagining escape from ongoing suffering. What emerges most clearly is the desire "not to feel anymore," rather than "not to live anymore." From this perspective, suicidal thinking can be understood as a survival response: a way of imagining a way out—sometimes temporary—from the weight of lived experience.

Speaking openly about these thoughts, when done with care, respect, and genuine listening, can have a strong protective effect. The data indicate that direct questions such as "Are you having thoughts about ending your life?" do not increase risk; rather, they support a sense of connection. Naming the pain, instead of avoiding it, helps reduce isolation and makes it possible to create a more open and honest relational space.

Approaching the topic with honesty and presence communicates a clear message to the person: "we can talk about this too—it is not something I am afraid of." This openness, and the permission it gives to express what is usually left unsaid, can shift suicidal thinking from something carried in silence to something that can be spoken, listened to, and supported.

PHASE 2: SEVERE DEPRESSION AND SUICIDAL THOUGHTS -"Don't tell me everything will be okay. Just stay. That's enough"

CROSS CUTTING MACRO-THEME: Identity, shame, and sense of self

A common thread runs through the narratives: the way severe depression erodes personal identity. Many accounts describe a sense of the self coming apart. People speak of feeling empty, broken, unrecognisable—not simply sad, but absent, stripped of value and meaning. This lived experience has a deep impact on how people see themselves and often fuels shame, self-blame, and the wish to disappear.

Within this context, language—and more broadly, communication with others—plays a crucial role. The words people hear can directly affect their sense of self: some reinforce the belief of being flawed or "a burden," while others help preserve—or even restore—parts of the self that feel damaged or lost.

The data show that phrases which affirm connection and recognise dignity, even during crisis, can act as protective factors. Grand or reassuring speeches are not needed. What matters is the careful choice of words that acknowledge the other person's humanity, especially when they are no longer able to recognise it themselves. In this sense, communication becomes a form of identity support: it does not simply accompany suffering, but helps the person remember who they are beyond the pain.

By contrast, judgemental, impatient, or dismissive language deepens the fracture of the self. At a time when everything feels fragile, even remarks that appear neutral can have a destabilising effect. This theme highlights how the quality of communication can make the difference between an identity that falls apart and one that, even in crisis, retains a core that is seen, acknowledged, and respected.

Shame, when it is met with silence or dismissal, becomes destructive. When it is recognised and held within a relational space, it can instead become a point of contact and rebuilding. In this sense, every word is an ethical and relational choice, with the potential to shape the person's experience far beyond the moment in which it is spoken.

Stigma, fear, and suicidal ideation

Silent and internalised stigma plays a key role in shaping communication with people experiencing suicidal ideation. Many individuals tend to minimise or hide their distress out of fear of judgement, rejection, or social exclusion. This self-imposed silence adds to their suffering and creates a barrier—often a very strong one—to expressing distress openly and seeking help. For this reason, it is essential that mental health professionals and family members remain aware that vague or indirect statements may conceal much deeper and more serious suffering.

In this context, understanding suicidal thoughts as attempts to escape pain experienced as unbearable is crucial for effective, and potentially life-saving, communication. Indirect expressions such as “I want to disappear” or “I can’t cope anymore” require careful and attentive listening. Being able to name suicidal ideation respectfully and without alarm helps break the silence created by stigma and supports timely access to appropriate clinical and relational support. The thematic analysis shows that open, non-judgemental, and empathic communication functions as a strong protective factor in the management of severe depressive episodes accompanied by suicidal ideation. A conscious and genuinely human approach to communication is not simply helpful, but clinically necessary to preserve dignity, hope, and support during the most fragile moments of bipolar disorder.

From this perspective, the macro-themes and sub-themes emerging from the analysis of depressive episodes outline a complex and closely interconnected framework. Invalidating communication patterns—such as minimising pain, assigning blame, or questioning the legitimacy or continuity of suffering—do not occur in isolation. Instead, they reinforce one another, creating an environment in which the person experiencing depression does not feel heard, understood, or believed. This communicative climate undermines trust and has clear effects on the clinical course, increasing the risk that the depressive episode becomes prolonged and that passive suicidal ideation emerges or persists.

By contrast, sub-themes related to empathic communication—such as quiet presence, emotional acceptance, and recognition of personal worth independent of the episode—form an integrated network of support that can reduce loneliness, isolation, and fear of abandonment. These elements do not operate separately, but work together, shaping a therapeutic relationship that itself becomes a stabilising factor. Within this relational space, people can gradually begin to rebuild trust in themselves, in others, and in the possibility of moving beyond the crisis.

Stigma, fear, and suicidal ideation

In this respect, the analysis aligns with the survey data, which show that experiences of clinical gaslighting, low levels of empathy, medical paternalism, and silence or taboo around discussing suicide are recurring elements within care relationships. These factors contribute to reinforcing internalised stigma and make it harder for people to express suffering and suicidal ideation openly. In response to this evidence, the training model adopted by the Italian Bipolar Association places strong emphasis on reducing stigma and fear around talking about suicide.

Volunteers are trained not to avoid the topic, but to address suicidal thoughts in a direct, respectful, and non-judgemental way. This approach is based on the understanding that asking someone explicitly whether they are experiencing suicidal ideation does not increase suicide risk; rather, it can reduce isolation, support disclosure, and facilitate access to help. This perspective is consistent with international evidence and is reflected in the work of organisations with established effectiveness in suicide prevention, such as The Listening Place in the United Kingdom, whose approach is grounded in open, explicit, and taboo-free listening to suicidal ideation.

Looking at these issues with specific attention to the roles of mental health professionals and family members brings additional considerations into focus. Professionals carry the responsibility of building communication that is not only clinically appropriate, but also emotionally aware and relationally attentive. An empathic and respectful approach supports trust and therapeutic collaboration, while inadequate communication risks weakening the therapeutic relationship and contributing to mistrust and disengagement from care. Family members, in turn, often find themselves in a difficult and vulnerable position and may unintentionally use invalidating language out of fear, frustration, or lack of guidance. Understanding the importance of emotional validation and quiet presence helps them move beyond the fear of “not knowing what to say” and to offer genuine support, contributing to a safer and more protective home environment. Developing these communication skills does not mean becoming therapists, but learning how to remain present during moments of crisis.

Taken together, these elements show clearly that the connections among the identified themes point to one central conclusion: the quality of communication is not a secondary issue, but a key factor that shapes the success or failure of therapeutic and relational interventions. Recognising and valuing this dimension is an essential step toward the effective and genuinely humane management of bipolar depression.

PHASE 3: MANIA / HYPOMANIA – “Don’t assume I’m fine just because I’m smiling”

Manic and hypomanic episodes of bipolar disorder are often marked by irritability, accelerated thinking and behaviour, impulsivity, and an outward appearance of high energy. Behind this apparent vitality, however, there is often significant internal distress, extreme exhaustion, and vulnerability that tends to go unrecognised by others.

From an external perspective, manic and hypomanic episodes are among the most misunderstood aspects of bipolar disorder. Unlike depressive episodes—which often make suffering visible through withdrawal, tearfulness, or immobility—mania and hypomania frequently present as increased energy, talkativeness, rapid thinking, frequent smiling, and constant activity. For this reason, internal distress is often overlooked, minimised, or mistakenly interpreted as improvement.

The accounts collected describe a very different experience. Behind the behavioural activation, people often report intense internal tension, severe sleep disruption, cognitive overload, marked irritability, and a growing sense of loss of control. The person does not experience feeling “well,” but rather feels driven, overstimulated, disorganised, and often frightened by their own state. When present, a smile does not reflect wellbeing, but functions as a social mask that further hides distress.

In this context, communication plays a particularly sensitive role. The words a person receives can increase disorganisation, anger, or shame, or instead help contain activation and preserve the relational bond. The thematic analysis shows that misunderstanding within relationships is one of the most destabilising factors during manic and hypomanic episodes.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
1	**Communications that worsen the crisis**	*Devaluation and mockery of the manic experience*	Statements that ridicule the manic episode, undermine trust, and push the person toward withdrawal and relational closure.	“Come on, stop exaggerating”, “You’re just having one of your episodes”, “You’ve had too much sun”, “We’re all a bit bipolar”
1	**Communications that worsen the crisis**	*Pathologising labelling*	Harsh statements that reduce the person to a clinical object to be controlled, intensifying distress and escalating the crisis.	“You sound crazy”, “You need a psychiatrist right now”, “Take your drops and go”
1	**Communications that worsen the crisis**	*Offensive humour or paternalism*	Ironic or minimising comments that invalidate the lived experience and amplify internal suffering.	“Did you take all your meds?”, “Come on, just go for a walk”, “What amazing energy—you’re so lucky!”
1	**Communications that worsen the crisis**	*Superficial comments about appearance*	Superficial remarks about physical appearance that deny or obscure the internal distress.	“You look perfectly fine”, “But you weigh 36 kilos—how could you possibly be unwell?”

PHASE 3: MANIA / HYPOMANIA - "Don't assume I'm fine just because I'm smiling"

Identified Themes

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
2	**Empathic communication and containment**	*Non-judgmental validation of irritability*	Acknowledging irritability as a symptom rather than a character flaw, using a calm and non-reactive tone.	"It seems like there's a lot of tension inside you—would you like to talk about it?"
2	**Empathic communication and containment**	*Recognising the fatigue behind the energy*	Avoiding superficial praise and recognising the disorganisation and exhaustion underlying apparent hyperactivity.	"It sounds like you have a thousand thoughts racing", "Have you been able to sleep at all?"
2	**Empathic communication and containment**	*Gentle containment*	Offering calm, steady presence without imposing, to support emotional regulation and preserve connection.	"Would you like to go get something together?", "You're very agitated right now, but I'm here with you"
3	**Identity and post-episode shame**	*Statements that intensify post-mania shame*	Harsh comments that reduce the person's entire identity to episode-related behaviour, hindering recovery and self-forgiveness.	"You've only caused damage", "You ruined everything", "Look what you've done"

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

MACRO-THEME 7: Communications that worsen the crisis

During manic or hypomanic episodes, certain communication patterns are particularly harmful because they target a specific point of vulnerability: the gap between what the person is experiencing internally and what others see from the outside. When inner distress is mocked, medicalised in a dismissive way, or brushed aside because of outward appearance, the person may experience a deep break in the relationship. This rupture can lead to anger, withdrawal, or a further escalation of the episode.

Sub-theme 7.1: Devaluation and mockery of the manic experience

Phrases such as:

- “Come on, stop exaggerating.”
- “You’re just having one of your episodes.”
- “You’ve probably had too much sun.”
- “We’re all a bit bipolar, really.”

These interactions are experienced as deeply invalidating. They do not merely minimise the suffering, but actively ridicule it, turning a destabilising experience into a personality trait or a passing oddity. This kind of communication undermines relational safety and elicits intense emotional reactions, often in the form of irritability or anger, which are then further stigmatised.

Many participants describe a heightened sense of loneliness: the implicit message conveyed is that their experience does not deserve attention or respect. In a phase where internal self-regulation is already fragile, ridicule increases disorganisation and dramatically reduces the person’s ability to ask for help in a direct and explicit way.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Sub-theme 7.2: Pathologising labelling

A second group of harmful communication involves the use of clinical or pseudo-clinical labels in an aggressive or demeaning way.

Phrases such as:

- “You’re crazy.”
- “They should section you.”
- “Go take your drops / your meds.”

They turn the person into a problem to be managed, rather than an individual going through a phase of genuine suffering. *Even when spoken with irony or out of exasperation, these expressions carry a strongly dehumanising impact. The person no longer feels like a participant in a relationship, but like an object of control or a potential threat.* ***The testimonies show that this type of language increases confusion, fuels fear, and can significantly undermine trust in relationships, including therapeutic ones.*** In some cases, pathologising labels contribute to greater resistance to treatment or to avoiding contact with services altogether, because they become associated with experiences of humiliation or coercion.

Sub-theme 7.3:Offensive humour or paternalism

Seemingly light-hearted comments such as:

- *“Did you take all your pills?”*
- *“Wow, what great energy — I’m jealous!”*

are often used with the intention of easing the tension. However, ***during manic or hypomanic phases, humour can easily become a form of invalidation. The energy that is visible from the outside is celebrated or joked about, while the exhaustion, anxiety, and insomnia that accompany it remain unseen.*** This kind of communication reinforces the idea that the person should be feeling well, widening the gap between their internal experience and external recognition. The result is a profound sense of being misunderstood, which may lead the person to withdraw or to intensify their behaviour in an often unconscious attempt to finally be seen and acknowledged.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Sub-theme 7.4: Superficial comments about appearance

A further form of invalidation concerns comments based on physical appearance:

Phrases such as:

- “You look perfectly fine.”
- “You’re all made up.”
- “How can you be unwell?”

These statements implicitly deny the possibility that a person can be suffering while still appearing functional, well-groomed, or active. ***Their impact is particularly harmful because they reinforce a widespread stereotype: the idea that mental distress must be visible in order to be credible.***

People report feeling pressured either to perform their suffering so that it will be believed, or, conversely, to hide it completely. In both cases, communication focused on appearance contributes to a loss of authenticity and to an increased relational distance.

MACRO-THEME 8: Empathic communication and containment

In contrast to the communication patterns described above, a set of communicative practices emerges that is capable of reducing escalation, preserving the relationship, and offering genuine emotional containment. During manic or hypomanic phases, the goal is not to correct behaviour or suppress energy, but to create a relational context that is sufficiently stable to allow for gradual emotional regulation.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Sub-theme 8.1: Non-judgmental validation of irritability

One of the most recurrent elements in the testimonies is the need for irritability to be recognised as a symptom, not as a personal flaw.

Phrases such as:

- “It sounds like there’s a lot of tension inside you.”
- “I can feel how agitated you are — that must be exhausting.”

allow what is happening to be named without assigning blame. ***Validation does not imply approval of the behaviour, but recognition of the internal state.*** This type of communication reduces reactivity and opens up a space for mutual listening, which is essential to prevent conflict escalation.

Sub-theme 8.2: Recognising the fatigue behind the energy

Another central aspect is recognising the exhaustion that lies beneath the heightened activation.

Phrases such as:

- “You seem to have a thousand thoughts all at once.”
- “Are you managing to get any sleep?”

They shift the focus from outward performance to the inner experience. ***This helps the person feel seen in their full complexity, not just through the most visible manifestations of the episode.*** Acknowledging the fatigue legitimises the need to slow down, without imposing it.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Sub-theme 8.3: Gentle containment

Effective containment at this stage is conveyed through a calm, consistent, and non-intrusive presence. Expressions such as:

“You’re very agitated right now, but I’m here with you.”
“Would you like to do something simple together?”

communicate stability without exerting control. ***They do not impose rigid limits, but instead offer a relational anchor.*** This kind of communication supports shared emotional regulation and helps keep the bond intact, even when behaviour is disorganised.

MACRO-THEME 9: Identity and post-episode shame

A particularly delicate and often overlooked dimension concerns what happens after the manic or hypomanic phase. **Many participants describe a return to clarity accompanied by intense retrospective shame. Actions carried out during the episode are re-examined harshly, self-image feels damaged, and personal identity suddenly appears fragile, inconsistent, and difficult to put back together.**

At this stage, the greatest risk is not only immediate emotional distress, but a depressive relapse. Shame, guilt, and rumination over what was said or done during the episode can quickly turn into self-contempt, relational withdrawal, and loss of hope. **Many accounts show that the transition from mania to depression is not only biological, but deeply relational: the way the environment responds to the “after” can either support a gradual recovery or accelerate a depressive collapse.**

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Phrases such as:

- “You’ve only made a mess”
- “You’ve ruined everything”
- “Look at what you’ve done”

They act as risk factors. They amplify shame, freeze identity around the episode, and prevent any meaningful integration of the experience. Reducing the whole person to the behaviours displayed during the crisis reinforces self-contempt and makes it harder to distinguish between responsibility and blame, increasing a sense of global failure.

By contrast, *communication that clearly separates the person from the episode—acknowledging the impact of what happened without turning it into an identity-level condemnation—supports the reconstruction of dignity and functions as a protective factor against a subsequent depressive phase.* ***The testimonies show how crucial it is, at this stage, to be able to rely on words that help to “put the pieces back together”: not absolving words, but words capable of holding together complexity, responsibility, and humanity.***

The ability to forgive oneself rarely develops in isolation. It often emerges through the gaze of another—a gaze that does not deny what happened, but does not reduce the person to what happened. In this sense, post-episode communication is not only reparative at a relational level, but also serves a fundamental preventive function, reducing the risk that shame will turn into silence, isolation, and depression.

PHASE 3: MANIA / HYPOMANIA - “Don’t assume I’m fine just because I’m smiling”

Practical, actionable guidelines that emerged consistently from the analysed data include:

Do

- **Recognise irritability as a signal of distress, not as a character flaw.**
- **Use a calm, steady, non-reactive tone, even when the situation feels tense.**
- **Make space for the person’s inner experience, not only for their outward behaviour.**
- **Offer presence without control, coercion, or threat, maintaining the relational bond.**

Avoid

- **Irony, sarcasm, or jokes about the person’s mental state**
- **Comments based on outward appearance**
- **Clinical labels used in a demeaning or dismissive way**
- **Reproaches or punitive reminders after the episode**

The relational experience during a manic or hypomanic phase does not call for immediate correction or reactive interventions. What it requires, rather, is a presence capable of recognising the suffering that expresses itself through irritability, heightened activation, and disorganisation, without reducing it to a behavioural problem. In this phase, what truly makes a difference is not “calming the person down,” but offering a stable emotional context in which intensity can be contained without being judged or ridiculed. A calm tone, attention to the person’s inner experience, and a non-controlling availability help preserve the bond precisely when it is most fragile. This relational quality—often tested by fatigue and misunderstanding—acts as a crucial protective factor: it reduces the risk of escalation, limits relational ruptures, and creates the conditions for the crisis to be lived through without turning into guilt, shame, or isolation.

The interconnection of themes of manic and hypomanic phases

During manic and hypomanic episodes, the themes that emerge from the analysis are not centred on a denial of suffering—as often happens in depressive episodes—but on a more subtle and potentially harmful break: the gap between what the person is experiencing internally and what others perceive from the outside. It is this gap that makes communication a central clinical factor, with the ability to guide the crisis either toward gradual regulation or toward emotional and relational escalation.

Mockery, pathologising labels, and superficial remarks are not simply expressions of stigma; they are forms of communication that directly affect the experience of mania or hypomania. Irony and sarcasm, often used with the intention of "lightening the mood," tend to have the opposite effect: they increase emotional intensity and reactivity, reinforcing the message that the distress is not serious or not legitimate. Pathologising language—especially when used in a threatening or anticipatory way—disrupts the person's sense of continuity and turns the relationship into one of control, often triggering defensive or oppositional reactions. Comments focused on appearance or visible energy deny the internal suffering and place the person in a false dilemma: either escalating behaviour in order to be taken seriously, or withdrawing to avoid being mocked.

These communication patterns do not act in isolation, but reinforce one another. The person feels exposed in their behaviour while remaining unseen in their inner experience—noticed, but not understood. In this context, communication becomes an additional destabilising factor, layered onto an already heightened state of activation, increasing the risk of loss of control, relational breakdowns, and impulsive decisions.

By contrast, empathic communication and gentle containment function not as generic "good practice," but as real regulatory tools. Non-judgemental acknowledgement of irritability, clear recognition of the exhaustion underlying the activation, and a stable relational presence help reduce the intensity of the episode without relying on correction or punishment. In this context, the value of communication lies not in explaining or normalising the experience, but in maintaining a relational anchor that limits disorganisation and preserves the bond.

The interconnection of themes of manic and hypomanic phases

A key point that emerges concerns time. The words spoken during manic or hypomanic episodes do not lose their impact once the episode ends, but continue to shape what follows. Post-episode shame represents a critical moment. As the person regains awareness, mocking, judgemental, or dismissive remarks are often taken in and reinterpreted as proof of being "wrong" or "unmanageable." At this stage, the risk of a depressive relapse increases markedly, as shame turns into withdrawal, self-criticism, and loss of hope.

By contrast, communication that clearly separates the person from the episode plays an important preventive role. This does not mean ignoring the impact of behaviours, but avoiding the reduction of the whole person to the crisis itself. Maintaining this distinction between the self and the symptoms is a key condition for repairing identity and supporting a move toward greater stability.

Within this framework, the role of mental health professionals and family networks takes on specific importance. For professionals, communication is not only a way to build a therapeutic alliance, but a core element of risk management. Rushed, ironic, or prematurely pathologising language can increase instability as much as an inappropriate clinical decision. For family members, the challenge is not simply to "say the right thing," but to stay present during a phase that strains the relationship, without responding through control, mockery, or emotional withdrawal.

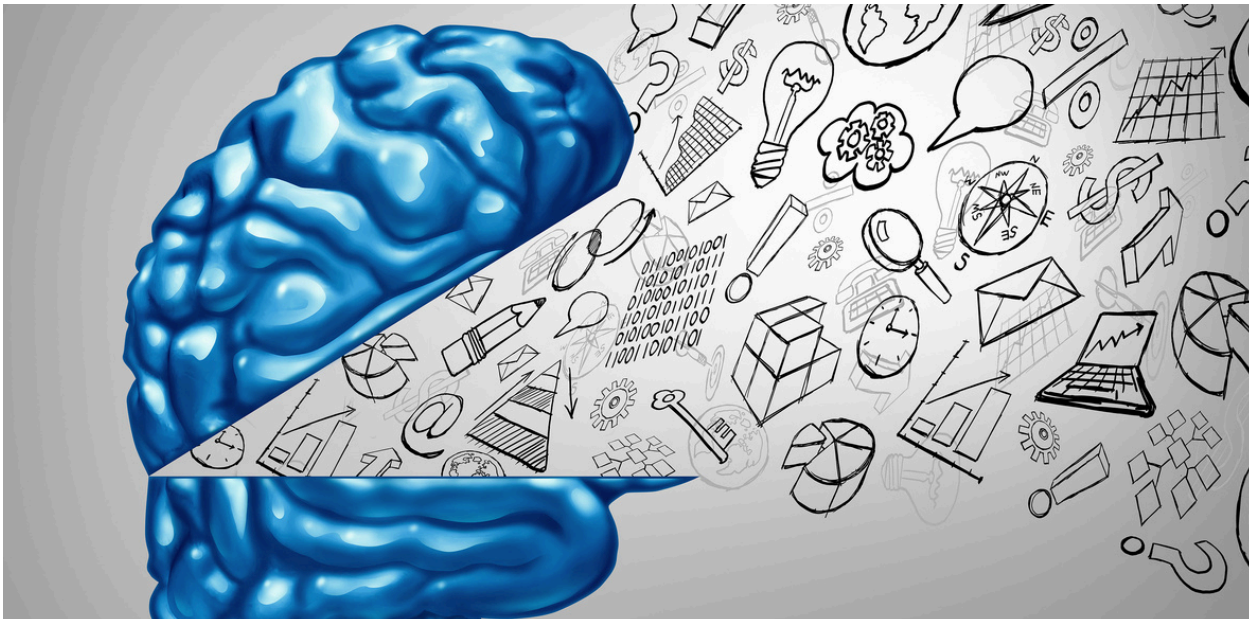
Taken together, the themes analysed point to a clear picture: during manic and hypomanic episodes, communication is neither neutral nor secondary. It directly interacts with emotional activation, identity, and the course of the illness that follows. A thoughtful and containing approach that respects internal complexity not only reduces immediate harm, but also helps prevent shame, relational rupture, and the depressive downturn that may come next. It is in this continuity—between the acute episode and what follows—that communication shows its full clinical and human importance.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Mixed episodes in bipolar disorder represent one of the most complex and high-risk clinical situations, both from a diagnostic and a relational point of view. Unlike more clearly defined episodes, they are not simply characterised by the presence of both depressive and manic features at the same time, but by how these features interact. Energy does not relieve despair, activation does not reduce emptiness, and impulsivity exists alongside a deep loss of hope.

The lived experience is marked by strong internal confusion, in which opposing emotional states do not alternate in a clear or predictable way, but overlap. A person may feel driven to act while also feeling completely unmotivated, irritable and desperate, briefly clear and then suddenly overwhelmed. This creates an experience that is very hard to describe and easy to misunderstand from the outside, where visible activation may be read as “energy” or “determination,” while the underlying depressive suffering remains unseen.

In this context, clinical risk does not arise only from the intensity of symptoms, but from their combination: high impulsivity, severe depressive distress, and a lack of relational containment. It is in relation to this last element that communication becomes crucial, as it can either contribute to escalation or act as a key protective factor.



PHASE 4: MIXED EPISODE - "Inside the storm: euphoria and despair together"

Identified Themes

Macro-Tema	Nome Tema	Sotto-Tema	Descrizione	Esempi
1	**Destabilising communication**	*Minimisation of inner conflict*	The person feels deeply divided internally; statements that dismiss or invalidate this contradiction deny the lived experience and increase isolation.	"You're being contradictory," "You're exaggerating," "I don't understand what you want"
1	**Destabilising communication**	*Fear-driven reactions*	Fearful or impulsive reactions from others are experienced as judgment or abandonment and can rapidly escalate the crisis.	"We need to call the psychiatrist," "You need help," "Enough, I can't handle this anymore"
1	**Destabilising communication**	*Harmful Oversimplification*	Telling the person to calm down or make a decision reduces an inherently complex and contradictory state to something manageable, increasing feelings of inadequacy.	"Calm down," "Make up your mind," "Stop acting like this"
2	**Regulating and validating communication**	*Acknowledging inner chaos*	People in a mixed episode look for words that make their experience easier to express. Acknowledging ambivalence helps create a sense of containment.	"It sounds like there's a conflict inside you," "You can feel anger and fear at the same time — that's valid"
2	**Regulating and validating communication**	*Slowed, steady communication*	A calm tone, short sentences, and no immediate demands help the person feel held without being overwhelmed.	"Let's breathe together," "You don't have to decide right now," "I'm staying here"
2	**Regulating and validating communication**	*Help without control*	Offering presence without pressure or coercion creates space to breathe and supports emotional regulation.	"Would you like to sit in silence?" "Is it okay if I sit with you?"
3	**The Relationship as a protective factor**	*Fear of being a burden and fear of abandonment*	In moments of crisis, people often fear that they are too much to handle. What they need is a clear relational message: I see you, even like this.	"I'm destroying everything," "No one will ever tolerate me like this," "I see you — not just the storm"

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

MACRO-THEME 10: Destabilising communication

During a mixed episode, communication carries particular clinical weight because it takes place in a state where the person is both activated and overwhelmed, impulsive and without hope. In this context, words are not simply received — they are intensified. Requests for coherence, reactions driven by fear, or attempts to simplify the situation echo the internal conflict already in place, increasing emotional disorganisation and reinforcing the feeling of being “too much” or unmanageable.

Unlike depressive or manic episodes, a mixed episode offers neither the slowing of depression nor the one-directional momentum of mania. Communication that asks the person to choose, calm down, or clearly explain what they feel assumes a level of integration that is temporarily unavailable. The result is not just relational misunderstanding, but a real increase in clinical risk: emotional escalation, impulsive actions, loss of containment, and a deeper sense of despair.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Sub-theme 10.1: Minimisation of inner conflict

Phrases such as:

- “You’re being contradictory”
- “You’re overreacting”
- “I don’t understand what you want”

They are particularly harmful in mixed states because they strike at the most fragile point of the experience: the simultaneous presence of opposing internal states. **A person going through a mixed episode is not indecisive or confused in the everyday sense of the word. Rather, they are experiencing, at the same time, intense emotional activation and profound depressive suffering, without either of the two being able to offset or regulate the other.**

From the person’s point of view, this is experienced as a deep inner split: the urge to act exists alongside loss of hope, urgency alongside helplessness, anger alongside emptiness. *When the surrounding environment responds by framing this experience as confusion or “overreaction,” the implicit message is that the problem lies within the person, rather than in the clinical episode they are going through.*

This kind of communication has clear consequences. Internally, it increases the sense of being “wrong” and unable to explain oneself. ***The person may begin to question the validity of their own experience and feel completely alone in the distress they are living. From a clinical perspective, this form of invalidation can intensify despair and make the mixed episode more dangerous, because it undermines the person’s ability to name what is happening and to ask for help in a way that feels possible or acceptable.***

For both professionals and loved ones, it is essential to recognise that during a mixed episode there is no single, consistent emotional state to choose or prioritise. *Asking for coherence in this context is equivalent to asking for something that, in that moment, is simply not available.*

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Sub-theme 10.2: Fear-driven reactions

Phrases such as:

- “We need to call the psychiatrist right now.”
- “That’s enough, I can’t handle this anymore.”
- “You need immediate help.”

They often stem from genuine concern, but during a mixed episode they are experienced as signals of a rupture in the relationship. **People in this state are often, at least intermittently, aware of how difficult they may be to handle and carry a deep fear of being a burden or a threat to others.**

When the other person responds with fear, urgency, or visible exhaustion, this fear is reinforced. The person may feel that their presence has become unmanageable and that the relationship can no longer hold them. In a state already marked by strong emotional instability, this perception can quickly push the crisis further.

The loss of relational containment is one of the most serious risk factors during a mixed episode. Emotional activation can escalate rapidly, leading to impulsive actions, rushed decisions, or behaviours that place the person at risk. In more severe situations, these dynamics can end in coercive interventions that are experienced as traumatic and that leave lasting effects on trust and on the willingness to seek or accept help in the future.

For professionals and family members, this does not mean ignoring risk. It means maintaining a presence that is not overtaken by fear. Safety also depends on the ability to stay emotionally present during the crisis, without communicating withdrawal, rejection, or the need to escape.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Sub-theme 10.3: Harmful oversimplifications

Phrases such as:

- “Calm down”
- “Make up your mind”
- “Don’t act like this”

They are particularly problematic during a mixed episode because they assume a level of emotional regulation that is temporarily unavailable in this phase. Asking someone to “calm down” implies that the person can voluntarily reduce their internal activation; asking them to “decide what they want” presupposes a stable orientation toward the future. Both expectations are unrealistic in a mixed episode, where intense activation and profound despair coexist and interfere with one another.

The subjective effect is often a sense of total failure. The person is not only suffering, but also unable to do what they are being asked to do in order to “get better.” This increases frustration, anger, and feelings of worthlessness, and can push the person either toward oppositional reactions or toward complete emotional shutdown.

At a relational level, these simplifications communicate a lack of understanding of the complexity of the episode. At a clinical level, they can worsen emotional disorganisation and make any further intervention harder, because the person begins to feel consistently inadequate in relation to others’ expectations.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

MACRO-THEME 11: Regulating and validating communication

In a mixed episode, “regulating communication” does not mean speaking nicely or being kind in a generic way. It means performing a very specific function: reducing the intensity and speed of the crisis without adding pressure, without demanding coherence, and without turning the relationship into a power struggle. In this phase, the person is living two opposing forces at the same time: an energy that pushes them to act, and a depressive pain that pushes them to disappear. It is precisely this combination that makes mixed episodes so dangerous.

For this reason, many habitual communication strategies fail. Explaining, persuading, “trying to reason,” asking the person to choose or to calm down all presuppose an inner stability that is not available in that moment. Regulating communication, by contrast, works with what is available: tone, pace, simplicity, presence, and above all the implicit message: “You don’t have to fix this right now, you’re not alone, I’m not judging you.”

For professionals, this also means avoiding conversations that turn into reality testing or immediate negotiation. In a mixed episode, the priority is to lower emotional and decisional load. For loved ones, it means learning not to respond to urgency with more urgency. Mixed episodes tend to pull everyone into reacting quickly—and it is precisely this speed that often fuels the crisis rather than containing it.

PHASE 4: MIXED EPISODE - "Inside the storm: euphoria and despair together"

Sub-theme 11.1: Acknowledging inner chaos

Phrases such as:

- "It sounds like there's a conflict going on inside you."
- "You can feel anger and fear at the same time."

They work because they do something very specific: they remove the obligation to be coherent. **In a mixed episode, the person is often desperately trying to explain themselves, but every sentence may sound contradictory even to the one speaking.** When the other person acknowledges this ambivalence without judging it, the need to defend oneself drops, and the person can begin to stay with the experience instead of having to make it immediately logical or consistent.

This is not just an emotional relief. It is a clinically significant step, because it reduces one of the main drivers of escalation: the struggle to be understood and believed. For clinicians, it is also a way to gather meaningful information without cornering or overwhelming the person; for family members, it helps prevent the conversation from turning into an interrogation.

Sub-theme 11.2: Slowed, steady communication

Phrases such as:

- "You don't have to decide right now."
- "Let's take this one step at a time."
- "I'm here. I'm staying with you."

They are not "nice" or comforting phrases in the usual sense: they are phrases that change the pace. *In a mixed episode, the internal rhythm is often fast and painful—racing thoughts, urgency, irritability, combined with despair and emotional emptiness.* **A slowed-down, steady way of communicating introduces an external rhythm that the person can latch onto.**

For professionals, this means avoiding the urge to overload the person with long explanations, lists, multiple options, or demands for immediate decisions. *Short sentences, simple questions, and—above all—the willingness to postpone choices when they are not strictly necessary are far more effective. For family members and loved ones, it means stepping back from arguments, not chasing every contradiction, and not trying to "correct" things in the moment. The goal is to stabilize, not to win the discussion.*

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Sub-theme 11.3: Help without control

Offering help without imposing solutions or conditions—for example:

Phrases such as:

- “Would you like to sit in silence?”
- “Would it be okay if I sat with you?”

They work because they combine two essential elements: availability and respect. **During a mixed episode, external control can feel intrusive or aggressive, while a complete absence of guidance can feel like abandonment. Help without control sits in the middle.** *It offers support without coercion and leaves room for small, manageable choices that help restore a minimal sense of agency and safety.*

For professionals, this also means introducing interventions in a non-threatening way (“we can look at this together,” “I’ll explain what I’m doing”) and maintaining consistency in the messages conveyed by the team. For family members, it means avoiding ultimatums and pressure (“if you don’t do X, then…”), because during a mixed episode pressure often leads to withdrawal or open conflict rather than cooperation.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

MACRO-THEME 12: The Relationship as a protective factor

In a mixed episode, the relationship is not just a source of “support”: it is often the thin line between containment and loss of control. This is because the person is simultaneously experiencing depressive suffering (which pulls toward isolation and thoughts of death) and activation or impulsivity (which pushes toward urgency and rapid action). In other words, in a mixed episode, pain does not stay still — it can turn into action.

In this context, the fear of being unbearable is not merely an emotional concern, but a concrete lived experience: the person sees their own irritability, confusion, and disarray, and fears that those close to them will stop being there. When the other becomes frightened, angry, withdraws, or makes threats, this confirms the sense of being “too much” and can dramatically increase risk: the person may feel driven to do something “to end the storm,” to punish themselves, or to stop being a burden to others.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Sub-theme 12.1: Fear of being a burden and fear of abandonment

FPhrases such as:

- “I’m ruining everything.”
- “They’ll never be able to put up with me like this.”

They show that during mixed episodes, suffering also takes the form of a judgment against the self. The person does not fear the episode alone; they fear their own identity within the episode. This fuels shame and despair and can lead either to withdrawal or to extreme behaviours aimed at “bringing the experience to an end.”

For professionals and family members, it is essential to recognise that, in this phase, the person often interprets every relational cue (tone of voice, silence, distance, sighs, nervousness) as evidence of rejection. Not because they are “overreacting,” but because the mixed episode alters the capacity to feel safe.

Messages that separate the person from the storm (repair and prevention)

Phrases such as:

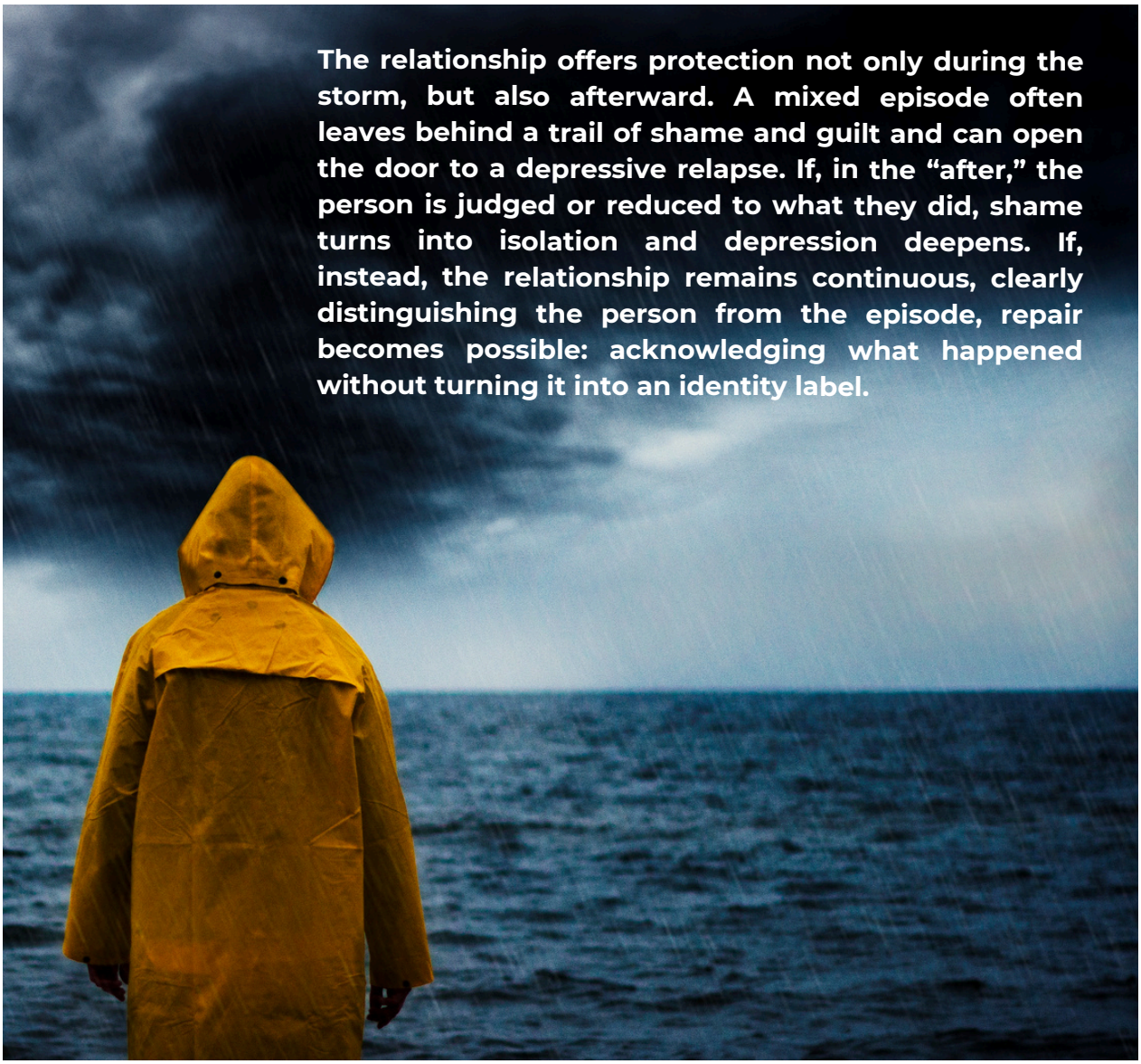
- “I see you, not just the storm.”
- “This phase will pass, and I’m here.”
- “You are not a problem; you are going through a very difficult time.”

They are not meant to “cheer the person up.” They are meant to separate identity from symptoms, preventing the crisis from turning into a personal condemnation. This distinction is a protective factor because it reduces shame and self-contempt and helps preserve the relational bond, which in a mixed episode is an integral part of safety.

For professionals, this means maintaining a non-punitive stance even when behaviour is difficult, and communicating consistently within the care team. For loved ones, it means a very concrete task: staying present without arguing, without humiliating, without reproach. Even a simple, calmly spoken “I’m here” can be more effective than any explanation.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

The “after” as part of safety (shame and depressive risk)



The relationship offers protection not only during the storm, but also afterward. A mixed episode often leaves behind a trail of shame and guilt and can open the door to a depressive relapse. If, in the “after,” the person is judged or reduced to what they did, shame turns into isolation and depression deepens. If, instead, the relationship remains continuous, clearly distinguishing the person from the episode, repair becomes possible: acknowledging what happened without turning it into an identity label.

PHASE 4: MIXED EPISODE - “Inside the storm: euphoria and despair together”

Useful operational guidance, recurring consistently in the analysed data, includes:

Do

- **Recognise internal conflict as a signal of distress, not as inconsistency**
- **Use a calm, steady, and slowed tone, reducing urgency and demands**
- **Make space for emotional ambivalence without requiring clarity or decisions**
- **Offer a stable, available presence, without control or pressure**

Avoid

- **Phrases that demand choosing, calming down, or “making up one’s mind”**
- **Frightened, alarmist, or rushed reactions**
- **Oversimplifications of the lived experience (“you’re overreacting,” “decide what you want”)**
- **Ultimatums or explicit or implicit relational threats**

The relational experience in a mixed episode does not call for linear explanations or immediate solutions. It requires the capacity to tolerate a complexity that cannot be resolved in the moment. In this phase, the goal is not to restore order, but to provide containment; not to clarify, but to slow things down. Stable communication that does not demand coherence or decision-making helps reduce emotional escalation and preserves the bond precisely when the person fears losing it. This relational quality represents an essential factor of clinical safety, as it limits the risk that depressive suffering, combined with impulsivity, turns into irreversible actions.

Between activation and despair: a cross-sectional reading of the mixed episode

The mixed episode is one of the least known and most misunderstood phases of bipolar disorder, and for this very reason, one of the most dangerous. Unlike depression, in which suffering tends to slow the person down, and mania, in which activation is often accompanied by little awareness of risk, in a mixed episode suffering and energy coexist. Pain is not static: it moves, pushes, agitates. Despair does not paralyse; it runs alongside impulsivity. This combination makes the mixed episode particularly insidious. A person may feel hopeless while simultaneously having the energy to act. It is in this space that suicide risk increases significantly—not necessarily because the wish to die is stronger, but because suffering does not remain still long enough to be contained. In this context, communication is not a relational detail: it becomes an element that can either slow down or accelerate the crisis.

The macro-themes that emerged show how many habitual responses prove ineffective or even harmful. Communications that demand coherence, calm, or decision-making are based on a false assumption: that, in a mixed episode, there is a clear internal direction to follow. In reality, the person experiences opposing emotions at the same time, without being able to integrate them. When this is interpreted as contradiction, exaggeration, or avoidable confusion, the implicit message is that the problem is not the episode, but the person. Suffering thus turns into shame as well.

Fearful or rushed reactions have a similar effect. Even when they stem from genuine concern, they may be experienced as signals of rejection: “you’re too much,” “I can’t handle you,” “I can’t be with you like this.” In a mixed episode—where the fear of losing relationships is already intense—this type of response can precipitate the crisis. The person no longer feels only distressed, but also like a burden, and may try to “end everything” quickly in order to stop causing pain to those around them.

What emerges strongly, then, is the role of regulating communication. In a mixed episode, there is no need to clarify, explain, or persuade. What is needed is containment. Acknowledging the internal chaos without demanding order, slowing the pace of interactions, reducing demands, and offering a stable, non-threatening presence. This type of communication does not resolve the internal conflict, but it makes it more tolerable. It allows the person not to feel forced to choose one part of themselves in order to be believed or accepted.

Between activation and despair: a cross-sectional reading of the mixed episode

In this phase, the relationship becomes a true factor of safety. Many accounts show how the fear of being unbearable runs through the mixed episode from within. Statements such as “I’m destroying everything” or “they’ll never be able to put up with me like this” are not merely emotional expressions, but attempts to make sense of a crisis that calls one’s very identity into question. Messages that distinguish the person from the episode — “I see you, not just what is happening” — have a concrete protective value: they reduce self-contempt, contain the risk of relational rupture, and help slow down escalation.

A crucial cross-cutting aspect concerns what happens afterward. A mixed episode often leaves behind shame, guilt, and the fear of having irreparably damaged relationships. If this phase is followed by judgment, reproach, or by reducing the person to what they did during the crisis, the risk is a slide into a deep, silent depression. By contrast, communication that acknowledges the difficulty of the episode without turning it into an identity label allows for repair: it makes it possible to talk, to understand, and to rebuild, without erasing the person’s dignity.

Taken together, the themes analysed show that in a mixed episode there is no “coherence to be restored,” but rather a complexity that must be navigated with care. Communication, when it is aware and regulating, does not eliminate the crisis, but it can prevent it from becoming overwhelming. For mental health professionals and for loved ones, developing this capacity is not optional: it is a concrete form of prevention, care, and protection of life.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

Psychotic episodes in bipolar disorder are among the most destabilising and misunderstood experiences, both for those who go through them and for those who witness them. **During these episodes, the shared sense of reality is deeply altered. Thoughts, beliefs, images, and voices are experienced as absolutely true, even when they appear irrational or incomprehensible to others. Delusions and hallucinations are not just “strange ideas,” but experiences lived as real, urgent, and personally meaningful.**

Unlike other psychotic conditions, psychosis in bipolar disorder is often closely tied to mood. During manic episodes, it may involve grandiosity, special missions, or a sense of power. During depressive episodes, it may centre on guilt, punishment, ruin, or hopelessness. This link with mood makes bipolar psychosis especially difficult, ***because the beliefs feel consistent with how the person experiences themselves at that moment.***

From the person’s point of view, psychosis is not simply a loss of contact with reality. It is a deep change in how the self and the world are experienced. The person may feel chosen, persecuted, watched, responsible for disasters, or guilty of unforgivable acts. The boundary between thoughts, emotions, and external reality becomes very thin. Doubt disappears. What is thought or perceived is experienced as fact, not as interpretation.

This makes communication extremely fragile. Direct attempts to correct beliefs, argue with them, or “bring the person back to reality” are usually ineffective. They may be experienced as threatening or hostile. The person does not feel helped, but attacked or misunderstood. Relational risk is high. Psychosis can break trust, create fear on both sides, and lead to distance that may remain even after the episode has ended.

PHASE 5: PSYCHOSIS -“You don'thave to understand. Just stay with me”

In this phase, clinical risk does not come only from delusions or hallucinations, but from how they interact with the relational context. Loss of trust in others, the feeling of not being believed or of being blocked, and the resulting isolation can increase agitation and fear. In some cases, this can raise the risk of behaviours that are dangerous to oneself or to others. When psychotic content is shaped by guilt, punishment, or despair, suicide risk can become particularly high—especially if the person feels alone, misunderstood, or abandoned.

In this context, communication plays a central role. It cannot be based on logic, persuasion, or direct contradiction. Its aim is to preserve the relationship, reduce the sense of threat, and provide emotional containment. Acknowledging the person’s experience without confirming the delusional content, separating suffering from the factual truth of beliefs, and maintaining a steady, non-judgemental presence are key elements in navigating a psychotic episode without creating further breaks.

In bipolar disorder, psychosis is not just an acute clinical event. It is an experience that can leave lasting effects on identity and relationships. Understanding it in its full complexity—without reducing it to a simple “loss of contact with reality”—is a necessary step toward communication and relational responses that limit harm and support safety, trust, and recovery.

PHASE 5: PSYCHOSIS -"You don'thave to understand. Just stay with me"

Identified themes

Macro-Theme	Theme Name	Sub-Theme	Description	Examples
1	**Phrases that amplify the crisis**	*Denial of subjective reality*	Denying the psychotic experience—even when it is incongruent with shared reality—creates isolation and fractures trust.	"It's not real," "It's all in your head," "Come on, what are you talking about?"
1	**Phrases that amplify the crisis**	*Stigma and aggressive pathologisation*	Using stigmatising or offensive labels undermines dignity and reinforces shame, increasing the risk of dissociation.	"They need to section you," "You're losing it," "You're not normal," "You belong in hospital."
1	**Phrases that amplify the crisis**	*Clinical language used inappropriately*	Diagnostic terms used without relational context can feel threatening, cold, or invalidating.	"You're delusional," "You're psychotic," "You're having an episode."
2	**Human connection and anchoring**	*Validating without confirming*	Accepting subjective reality without reinforcing psychotic content helps preserve the relationship and contain distress.	"I understand that this feels real to you. I'm here." "Even if I don't understand everything, I'm here."
2	**Human connection and anchoring**	*Acknowledging fear and shame*	Making space for the fear and shame that accompany the crisis, including post-episode, reinforces personal worth.	"I know this can be frightening," "Your experience matters," "You're not alone in this."
2	**Human connection and anchoring**	*Anchoring in the relationship*	Maintaining the relationship even when shared reality is lost can help regulate and reassure.	"I'm here and I'm listening," "You don't need to be afraid of me."
3	**Restoring dignity**	*Reclaiming identity beyond the crisis*	Recognising continuity of the person even within delusion helps rebuild a sense of self after the crisis.	"What you went through does not define you," "Even during the crisis, you were still you."

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

MACRO-THEME 13: Phrases that amplify the crisis

During a psychotic episode, communication has a particularly strong impact because it enters an experience in which the person’s subjective reality is felt as completely true. In this context, certain phrases are not just unhelpful, but can actively increase fear, confusion, and damage the relational bond. Ways of speaking that deny the experience, stigmatise it, or treat it in a cold and purely medical way tend to intensify the crisis, making containment and support harder to achieve.

Sub-theme 13.1: Denial of subjective reality

Phrases such as:

- “It’s not real.”
- “It’s all in your head.”
- “Come on, what are you talking about?”

They deny the person’s lived experience, even when the intention is to reassure or correct. **During psychosis, however, what is said or perceived is not experienced as an interpretation, but as a fact. Directly challenging this subjective reality produces a powerful sense of isolation: the person does not feel helped, but excluded from any possibility of understanding.**

On a relational level, this denial can lead to withdrawal, mistrust, and loss of confidence. On a clinical level, it can increase distress, reinforce persecutory experiences, and make the person less receptive to any form of intervention—precisely because they feel disbelieved or ridiculed.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

Sub-theme 13.2: Stigma and aggressive pathologisation

Phrases such as:

- “They need to section you.”
- “You’re losing it.”
- “You’re not normal.”
- “You belong in hospital.”

They do not communicate care or protection, but judgment and threat. *Even when spoken in moments of fear or exhaustion, these expressions undermine the person’s dignity and reinforce stigma, which is often already internalised.* The crisis is transformed into guilt—or into an identity-based blame: not “you are unwell,” but “you are wrong.”

This mode of communication increases shame and may lead to withdrawal, opposition, or despair. In more severe cases, it contributes to making the psychotic experience more traumatic and undermines future trust in services and helping relationships.

Sub-theme 13.3: Clinical language used inappropriately

Phrases such as:

- “You’re having delusions.”
- “You’re psychotic.”
- “You’re having an episode.”

When used without relational mediation, they can feel cold, threatening, or invalidating. In a phase of great vulnerability, direct and decontextualised clinical language risks reducing the person to a diagnosis, making them feel observed and classified rather than accompanied.

This type of communication deepens emotional distance and can increase confusion and the sense of loss of control. The person no longer feels like a subject in relationship, but an object of intervention, with a negative impact on both clinical course and the possibility of rebuilding a therapeutic alliance.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

MACRO-THEME 14: Human connection and anchoring

During a psychotic episode, communication cannot be based on the same assumptions used outside of psychosis. When shared reality is no longer accessible, attempts to confront beliefs, explain rationally, or correct content are ineffective. In this context, the main purpose of communication is not to decide what is true or false, but to reduce fear, preserve the relationship, and offer a sense of continuity within an experience that is deeply disorganising.

The data show that when external reality cannot be shared, the relationship becomes the main—and sometimes the only—anchor available. The quality of the other person’s presence directly affects the level of distress, the sense of threat, and the possibility of moving through the episode without further relational breaks or traumatic consequences.

Sub-theme 14.1: Validating without confirming

Phrases such as:

- “I understand that this feels real to you. I’m here.”
- “Even if I don’t understand everything, I’m staying with you.”

They represent one of the most delicate and complex communicative skills in the management of psychosis. **Validating without confirming means acknowledging the subjective reality of the experience without reinforcing delusional content.** *This distinction is crucial: the person is neither contradicted nor ridiculed, but neither are they trapped in a form of confirmation that would make the delusion more rigid and pervasive.*

From a clinical perspective, this type of communication reduces tension and emotional hyperarousal by interrupting the struggle to be believed or disproved. From a relational perspective, it preserves trust and keeps a channel of contact open, which will be essential in later phases of the care pathway as well. For the person, feeling recognised without being “indulged” makes it possible to remain in relationship without perceiving the other as a threat or an antagonist.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

Sub-theme 14.2: Acknowledging fear and shame

Phrases such as:

- “I know this can be frightening.”
- “Your experience matters.”
- “You are not alone in this.”

They give voice to two central emotional dimensions in psychosis: fear and shame. **Fear is often already present during the acute phase,** linked to a sense of loss of control, threat, or persecution. **Shame, by contrast, may emerge gradually,** especially as the person begins to regain awareness and to come to terms with what has happened.

Openly acknowledging these emotions has significant clinical and human value. It helps prevent fear from being read solely as a “symptom” and shame from remaining silent and unprocessed. The data show that *failure to legitimise these experiences increases the risk of emotional isolation, withdrawal, and communicative shutdown, creating conditions for subsequent depressive relapses or for a lasting rupture in the relationship with care providers.*

Sub-theme 14.3: Anchoring in the relationship

Phrases such as:

- “I’m here and I’m listening to you.”
- “You don’t need to be afraid of me.”

They intentionally shift the centre of communication from shared reality to the relationship as a space of safety. **In a phase in which the world may appear threatening, fragmented, or incomprehensible, the other’s consistent presence becomes a stable reference,** capable of containing distress even when psychotic content persists.

This type of communication is not aimed at “resolving” psychosis, but at preventing the crisis from becoming an irreparable relational rupture. The relationship—maintained over time and carried through without judgment—forms the ground on which a more integrated recovery of both reality and self can later take place.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

MACRO-THEME 15: Restoring Dignity

A psychotic episode does not end when acute symptoms reduce. Even after delusions and hallucinations fade, many people are left with a deep impact on their sense of self. Shame, confusion, fear of being defined by the episode, and worry about how others see them are common and often underestimated. In this phase, communication has an important reparative role.

How the episode is named, talked about, or remembered by those around the person can either support integration or reinforce internalised stigma. The words used can help the person reconnect their experience to who they are, or instead fix the episode as a defining mark that is hard to move beyond.

Sub-theme 15.1: Reclaiming identity beyond the crisis

Phrases such as:

- “What you went through does not define you.”
- “Even when you were in crisis, you were still you.”

They act directly on the level of identity. Separating the person from the episode makes it possible to rebuild a sense of continuity of the self, *preventing the psychotic experience from being lived as proof of a definitive loss of worth, reliability, or dignity.*

From a clinical perspective, this process of identity repair is fundamental to long-term recovery: it reduces self-stigma, facilitates engagement with care pathways, and makes the idea of seeking help in the future less threatening. From a relational perspective, it allows the bond to be repaired and the experience of the crisis to be reintegrated into the personal narrative—without erasing it or turning it into a permanent mark.

PHASE 5: PSYCHOSIS - “You don'thave to understand. Just stay with me”

Useful operational guidance, recurring consistently in the analysed data, includes:

Do

- **Acknowledge the subjective experience without confirming delusional content**
- **Maintain a calm, consistent, and non-judgemental presence**
- **Anchor communication in the relationship rather than in correcting reality**
- **Protect dignity and identity, including in the post-episode phase**

Avoid

- **Denying or ridiculing what the person experiences as real**
- **Using cold or threatening clinical language**
- **Stigmatising labels or punitive references to hospitalisation**
- **Pressuring the person to “return to normal” or to recall the episode in a forced way**

The relational experience in the psychotic phase does not require convincing or correcting. It requires preserving the bond when shared reality is temporarily lost. In this phase, communication cannot rely on logic or refutation, but on reducing perceived threat and maintaining continuity of presence. Anchoring communication in the relationship makes it possible to contain fear and disorganisation without increasing distance or trauma. Even after symptoms have resolved, words that clearly distinguish the person from the crisis are essential for rebuilding dignity, trust, and a sense of self. This relational function represents a central component of care, not an ancillary one.

When reality fractures: psychosis, relationship, and the invisible risk

The cross-cutting analysis of the macro-themes emerging in psychotic episodes of bipolar disorder highlights one central point: psychosis is not only a change in thought or perception, but also a deeply relational experience. How the surrounding environment responds—through words, tone, silences, and reactions—directly influences the course of the crisis, the level of distress, and the possibilities for recovery afterwards.

Unlike other episodes of the disorder, in psychosis the core problem is not simply "feeling unwell," but no longer sharing the same reality as others. This break creates a state of extreme vulnerability. The person lives experiences that feel completely real to them, yet are often denied, corrected, or mocked by others. When this happens, the crisis is not contained, but intensified. Denial of subjective experience, stigma, and the cold or aggressive use of clinical language are not just communication failures, but real relational and clinical risk factors.

The macro-themes show that these communication patterns build on one another. Denying lived experience damages trust. Aggressive pathologising undermines dignity. Unfiltered clinical language reduces the person to a diagnosis. Together, these responses create an environment in which the person feels not only confused, but also disbelieved, unseen, and potentially dangerous. This climate promotes isolation, fear, and withdrawal, and can increase the risk of defensive reactions, opposition, or despair-driven behaviour.

By contrast, communication focused on connection and human anchoring emerges as a strong protective factor. Acknowledging experience without confirming delusional content, recognising fear and shame, and grounding communication in the relationship rather than in shared reality does not mean giving up on care or safety. It means choosing a different starting point. When shared reality is no longer available, the relationship itself can become that ground. A stable, non-judgemental, and non-threatening presence reduces perceived danger and allows the crisis to unfold without becoming a deeply isolating or traumatic experience.

A particularly important cross-cutting aspect concerns suicide risk during psychotic episodes. This risk is not always expressed in a direct or easily recognisable way, especially when psychotic content is shaped by guilt, punishment, or delusional missions.

When reality fractures: psychosis, relationship, and the invisible risk

This risk is not always expressed in a clear or easily recognisable way, especially when psychotic content is shaped by guilt, punishment, or delusional missions. In these situations, the person may act under beliefs experienced as unavoidable or necessary, without being able to express suicidal intent in the way others expect. When isolation, stigma, and loss of trust are added, the risk can increase further—and often remains silent.

The post-psychotic phase is another critical point. Symptom reduction does not mean that suffering has ended. Many people are left with strong feelings of shame, fear of judgement, confused or fragmented memories, and concern about being permanently defined by the episode. When the environment responds with silence, avoidance, embarrassment, or punitive reminders, the injury to identity deepens. Psychosis is then not understood as an episode of illness, but taken in as proof of personal failure or loss of worth.

By contrast, the themes that emerge highlight the importance of communication that helps restore identity beyond the crisis. Separating the person from the episode, recognising continuity of self even during the most disorganised moments, and using non-stigmatising ways to talk about what happened are key steps in recovery. This reparative role is not secondary, but part of care itself, because it directly affects trust, help-seeking, and the ability to face future crises without fear.

Taken together, the macro-themes point to a clear conclusion: during psychosis, communication is not neutral. It can increase harm, trauma, and rupture, or it can support containment, safety, and repair. For mental health professionals, this involves a responsibility that goes beyond technical skill and includes how the psychotic experience is named, discussed, and accompanied. For loved ones, it means having support and guidance to remain present without being overwhelmed by fear.

From Listening to Action: Integrating Emerging Communication Needs into Clinical, Family, and Public Practice

The previous sections of the report have presented, phase by phase, the main macro-themes and sub-themes that emerged from the qualitative thematic analysis of the collected testimonies. These findings consistently describe what people with bipolar disorder experienced as helpful, harmful, or decisive in communication across the different phases of the condition.

This final section does not introduce new data nor does it reformulate results that have already been presented. Its purpose is to offer a cross-cutting, operational translation of the findings, with the aim of supporting stakeholders, professionals, family members, and institutional actors in the concrete implementation of these indications in everyday practice. The shift from listening to action does not imply a reduction of complexity, but rather an intentional effort to integrate lived experience, existing practices, and real-world care contexts.

Despite the specificity of the different phases of the disorder, the analysis highlighted a number of recurring principles that cut across all the experiences collected:

- the distinction between the person and the clinical condition as a central element in preserving a sense of identity;
- the explicit recognition of emotional experience, distinct from endorsing symptoms or behaviours;
- the direct impact of communication on shame, guilt, and isolation;
- the role of communication as either a risk factor or a protective factor during moments of heightened vulnerability;
- the need for relational continuity before, during, and after a crisis.

These principles do not constitute abstract recommendations, but rather represent the common ground on which people experienced a greater possibility of being heard, understood, and supported.

From Listening to Action: Integrating Emerging Communication Needs into Clinical, Family, and Public Practice

The gap between expressed needs and everyday practice

The testimonies clearly show what people with bipolar disorder would like to receive in terms of communication. At the same time, family members and professionals often operate in contexts characterised by stress, urgency, high emotional load, time constraints, and clinical responsibility. The gap between expressed needs and everyday practice arises largely from these conditions, rather than from a lack of care or competence. This distance between communicative needs and real-world practices is also reflected in the quantitative survey data, where a substantial proportion of respondents report systematic difficulties related to lack of time, continuity, and listening within services—indicating that the issue does not concern isolated incidents, but recurring structural conditions of the care context.

Many of the phrases perceived as harmful do not stem from ill intent, but from entrenched communicative automatisms that tend to emerge particularly in situations of pressure, helplessness, or perceived risk. Making this mechanism explicit allows the focus to shift from judging intentions to identifying opportunities to transform existing communicative practices. The survey data reinforce this interpretation, showing that communicative practices perceived as blaming, minimising, or judgemental are reported with significant frequency, often in association with crisis contexts, urgent interventions, or fragmented care pathways —suggesting that such modes emerge primarily when the system is operating under pressure and resource scarcity.

Bridging this gap means recognising that the communicative needs expressed by service users are legitimate and informative, and that the difficulties faced by those who provide care or support are real and structural. The goal is not to choose between these two dimensions, but to build operational approaches that can hold them together. In this sense, survey responses indicate that failure to integrate communicative needs does not only result in experiences of subjective invalidation, but is also associated with concrete outcomes such as loss of trust in the care system, reduced engagement with treatment pathways, and fear of seeking services again—making this gap a clinically and organisationally significant issue.

From Listening to Action: Integrating Emerging Communication Needs into Clinical, Family, and Public Practice

Implementation strategies: making the emerging indications workable

The indications that emerged from the thematic analysis do not require the creation of new protocols, but rather the conscious adaptation of practices already in use. Effective implementation involves three fundamental steps:

- making the most frequent communicative automatisms visible;
- recognising their impact from the perspective of the person who receives them;
- identifying realistic alternatives that are compatible with the operational context and with the roles involved.

The need to make these steps concretely workable is reinforced by the survey data, which show that a substantial proportion of participants reported not feeling adequately informed, involved, or listened to during decision-making moments, describing care pathways perceived as standardised, impersonal, or insufficiently attentive to subjective experience. Responses also indicate that communicative practices perceived as cold, judgemental, or dehumanising have effects not only at a clinical level, but are associated with increased stress, mistrust, and emotional withdrawal, with repercussions that often extend into relational and family domains. In this sense, the quantitative data confirm what emerged from the qualitative analysis: communication is not an ancillary element of care, but a central lever that directly affects the sustainability of helping relationships, the therapeutic alliance, and the overall stability of care pathways.

In clinical settings, this may translate into a review of the language used during assessment phases, diagnostic feedback, or follow-up, without altering technical content or clinical decisions. Even brief communicative adjustments can reduce experiences of guilt, shame, or invalidation, thereby strengthening the therapeutic alliance. In family and informal contexts, implementation involves greater awareness of how concern is expressed: recognising the boundary between care and pressure makes it possible to maintain support without turning it into implicit demands for improvement or attributions of responsibility. The testimonies further show that more respectful and containing communication protects not only the person experiencing depressive phases, but also those who support them, by reducing emotional escalation, mutual frustration, and the sense of relational failure among family members and professionals. From this perspective, implementing the emerging indications does not represent an additional burden, but rather a strategy for the sustainability of the caring relationship—one that can help prevent burnout, emotional shutdown, and the gradual disengagement from helping roles.

From Listening to Action: Integrating Emerging Communication Needs into Clinical, Family, and Public Practice

Differences in context and responsibility

The indications that emerged take different forms depending on the context in which they are applied. In family and informal settings, communication primarily serves a function of accompaniment and of maintaining the bond. In clinical settings, the same principles are integrated with specific responsibilities related to risk assessment, care planning, and the person's safety. In public and media contexts, language contributes to shaping social representations that can either reduce or reinforce stigma.

Making these differences explicit helps avoid inappropriate applications of the emerging indications and allows them to be adapted coherently to different roles, without betraying their underlying meaning.

The report as a training and institutional tool

The findings presented in this report can serve as a foundation for:

- training and continuing education pathways for health professionals;
- support and orientation materials for family members and caregivers;
- awareness-raising initiatives for the general public and the media;
- co-design processes involving services, associations, and people with lived experience.

Anchoring training in people's direct experience makes it possible to translate expressed needs into concrete communicative skills, strengthening the quality of caring relationships and the sustainability of support systems. Integrating what people with bipolar disorder ask for in terms of communication does not mean pursuing an unrealistic ideal, but recognising that the quality of words and relationships is a structural component of care.

This section aims to offer a shared framework for transforming listening into action, keeping users' lived experience at the centre while realistically supporting those who, every day, work within the complex contexts of care, support, and public representation of mental health.

From Listening to Action: Integrating Emerging Communication Needs into Clinical, Family, and Public Practice

The implementation of the emerging communicative indications does not require abandoning existing practices, but rather their conscious integration.

01

A first level of intervention concerns the systematic inclusion of elements of validation and recognition within interactions that are already part of routine practice. Even in contexts characterised by limited time, brief communicative exchanges can significantly alter the perception of being heard and respected, without interfering with clinical assessment or operational decision-making.

02

A second level concerns awareness of communicative automatisms. Many phrases perceived as harmful emerge in situations of stress, helplessness, or urgency. Making their impact visible—as shown by the testimonies—makes it possible to replace them with alternative formulations that are compatible with the context and with the speaker's role.

03

A third level concerns support for those who provide support. Adopting less blaming and more containing communicative approaches does not benefit only the person in distress, but also helps reduce emotional burden, relational conflict, and the sense of failure experienced by family members and professionals. In this sense, implementing the emerging indications also represents a strategy for preventing burnout and emotional disengagement.

05. BODY, STABILITY, AND INTEGRATED CARE

In bipolar disorder, the bodily dimension is an integral part of clinical assessment and long-term management, and is explicitly highlighted in major international guidelines as an element to be monitored alongside psychopathology[8]. Clinical recommendations emphasise that optimal treatment requires not only the assessment of affective symptoms, but also regular monitoring of physical health, sleep–wake rhythms, treatment side effects, and lifestyle factors, as these aspects influence safety, quality of life, treatment adherence, and overall clinical outcomes[9] [10].

Within this framework, certain bodily domains take on particular clinical relevance. Sleep and circadian rhythms, for example, are recognised in the literature as dimensions closely linked to mood regulation and functional stability: disruptions in sleep continuity or regularity may precede changes in mood state and are associated with greater mood instability. For this reason, the management of rhythms is indicated as a relevant component of integrated clinical practice[11].

A second domain concerns side effects and, more broadly, the “bodily cost” of treatments. The need to proactively monitor body weight, metabolic parameters, sexual functioning, and other adverse events recurs across clinical recommendations, in part because side effects perceived as burdensome are among the factors most frequently associated with non-adherence or discontinuation of mood-stabilising medications[12] [13].

A substantial body of literature also indicates that people with bipolar disorder show a high prevalence of physical comorbidities and cardiometabolic risk, with direct implications for daily functioning, clinical outcomes, and treatment management[14] [15]. These findings reinforce the need for care models that consider the body as part of the overall clinical picture, rather than as a separate or secondary domain.

All of these elements align with the principles of patient-centred care and integrated care models, which emphasise the value of listening to individual needs, continuity of care, and shared decision-making between the person and the professional. In psychiatric practice, this implies not only recognising in theory the relevance of sleep, rhythms, physical health, and side effects, but translating this knowledge into clinical practices that are genuinely person-oriented, avoiding fragmented or purely pharmacocentric approaches. Despite these recommendations, in everyday clinical practice many of these dimensions are still addressed in a medicalised way or reduced to abstract prescriptions[16]:

05. BODY, STABILITY, AND INTEGRATED CARE

Sleep may be addressed primarily through pharmacological adjustments without considering patterns or life context; weight gain may be managed through generic advice such as “you need to lose weight”; and recommendations regarding diet or physical activity rarely take into account material barriers, social context, or individual preferences. This gap between the theoretical knowledge embedded in clinical guidelines and their practical application can reduce the overall effectiveness of care and fail to fully address the real bodily needs of people with bipolar disorder.

Within this framework, the present section of the report offers a structured reading of the experiential data collected by AIBP on early bodily warning signs, sleep, eating, movement, side effects, and material or relational barriers to bodily care.

The sections focused on the body do not describe secondary aspects of the bipolar disorder experience. Instead, they make it possible to see how care is translated into everyday life. When the data on early bodily signals, sleep, nutrition, movement, side effects, and material inequalities are considered together, a clear issue emerges: the main problem is not a lack of clinical knowledge, but a structural difficulty in making care sustainable over time. This reading is consistent with what emerges in the earlier sections of the report. Communication problems, fragmented care pathways, lack of clear follow-up, and loss of trust in the system form the context in which the bodily dimension takes on clinical relevance. In this sense, the body becomes a cross-cutting indicator of the same systemic weaknesses that run through the entire care pathway.

[8] National Institute for Health and Care Excellence, Bipolar disorder: assessment and management (NICE Clinical Guideline 185, updated 2025) https://www.nice.org.uk/guidance/cg185 accessed 28 Jan 2026.

[9]National Institute for Health and Care Excellence, Bipolar disorder: assessment and management (NICE Clinical Guideline 185, updated 2025) https://www.nice.org.uk/guidance/cg185 accessed 28 Jan 2026.

[10]Goodwin GM et al, Evidence-based guidelines for treating bipolar disorder (BAP Guideline 2016) – physical health to be considered in clinical assessment and treatment planning (monitoring of weight, cardiovascular risks).

[11]Jonathan Scott et al, A systematic review and meta-analysis of sleep and circadian rhythm disturbances in bipolar disorders (2022).

[12]National Institute for Health and Care Excellence, Bipolar disorder: assessment and management (NICE Clinical Guideline 185, updated 2025) https://www.nice.org.uk/guidance/cg185 accessed 28 Jan 2026.

[13]Goodwin GM et al, Evidence-based guidelines for treating bipolar disorder (BAP Guideline 2016).

[14]D E Kemp and colleagues, Cardiometabolic health in bipolar disorder: metabolic syndrome, obesity and cardiovascular disease (2012).

[15]D Vancampfort et al, A Meta-Analysis of Prevalence Rates and Moderators of Metabolic Syndrome in Bipolar Disorder (2013).

[16]K N Fountoulakis et al, Challenges in the development of treatment guidelines for bipolar disorder: gaps between research recommendations and clinical practice (Frontiers in Psychiatry, 2025) — evidenzia il gap tra evidenze e implementazione pratica.

5.1. Methodology and data collection context

Study design and data collection procedures

The data presented in this section derive from an experiential data collection conducted by the Associazione Italiana Bipolari (AIBP) through online surveys disseminated via the association's communication channels. The data collection was carried out in the context of preparing the presentation "Body, mind, and bipolar disorder: from crisis to integrated care," delivered at the National SIMA Congress (Italian Society of Adolescent Medicine), with the aim of exploring the relationship between the bodily dimension, mood stability, and the sustainability of care in bipolar disorder.

Participation in the surveys was voluntary and anonymous. The sample consists of approximately 30 respondents, a size consistent with the exploratory and non- epidemiological nature of the initiative. The questions were designed to investigate several areas considered clinically relevant on the basis of the literature and clinical practice: early bodily warning signs, sleep and daily rhythms, eating, movement, side effects of pharmacological treatments, and the presence of material or relational barriers in bodily care.

Data collection did not include formal clinical selection criteria or external diagnostic verification, and relied exclusively on participants' self-report.

Exploratory nature and limitations of the data

The data presented are exploratory and descriptive in nature. The sample size and data collection methods do not allow for generalisation or causal inference. The percentages reported serve an illustrative purpose and are intended to make the distribution of experiences within the group visible. The value of the data lies in their ability to highlight recurring patterns, practical critical issues, and areas of discrepancy between theoretical recommendations and everyday lived experience, offering useful insights for clinical reflection and for the improvement of care practices.

Explored areas and structure of the questions

The questions were organised into thematic areas, each introduced by a key statement designed to contextualise the clinical focus.

01

The body as an early warning signal of instability

- Perception of bodily signals before a crisis
- The role of the body as an early warning system

02

Sleep

- Changes in sleep as a signal of instability
- Perceived difference between sleep quantity and sleep quality

03

Food, energy, and the mood-body cycle

- Real freedom of choice around food
- Stress, guilt, and accessibility

04

Movement and realistic accessibility

- Perceived failure in relation to exercise
- The role of the presence of others
- Economic and environmental accessibility

05

Side effects of treatments

- Most difficult side effect
- Thoughts about discontinuing medication

06

Material inequalities

- Economic and environmental barriers
- Real freedom of choice

5.2 The body as an early warning signal of instability

In bipolar disorder, the ability to identify early warning signs of instability represents a central element for relapse prevention and long-term management. Beyond subjectively reported mood changes, the body can function as an early alert system, through physical and somatic signals that precede or accompany changes in mood state. However, these signals are not always recognised, valued, or systematically integrated into clinical assessment.

This section explores the extent to which people with bipolar disorder report the presence of bodily signals prior to a crisis, and how these signals are perceived and interpreted.

In response to the question, “Do you experience physical signals before a mood episode?”, the large majority of respondents reported the presence of anticipatory bodily signals:

- Yes, often: 80%
- Always: 5%
- Almost never: 12%
- Never: 3%

Overall, 85% of the sample reported experiencing physical signals often or always prior to a mood episode.

A complementary finding emerges from the question, “Have you ever experienced physical pain or somatic symptoms that were dismissed as ‘just psychological’?”

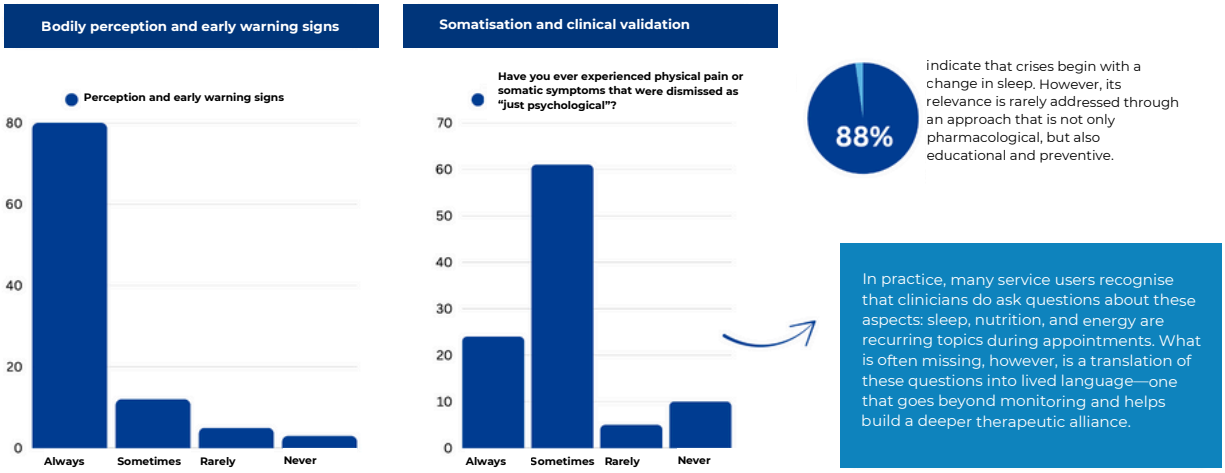
- Always: 24%
- Sometimes: 61%
- Rarely: 5%
- Never: 10%

Overall, 85% of respondents reported having experienced at least occasional dismissal or minimisation of their physical symptoms.

5.2 The body as an early warning signal of instability

Interpretation of the findings

The data show that, for the vast majority of participants, the body functions as an early warning system for mood instability. The frequency with which anticipatory physical signals are reported indicates that these signals are not episodic, but integrated into the subjective experience of the crisis.



AIBP proposes starting from this shared ground to strengthen the connection between clinical dimensions and subjective meaning, through simple and accessible tools: shared monitoring sheets, spaces for experiential listening, and routines co-built together. In this way, the body can become a shared resource—observed and understood together—in a more effective and humane way.

Alongside this finding, a second critical issue emerges: many people report that their physical symptoms are minimised or dismissed. This gap between what the body signals and how the care system responds is not neutral. When bodily symptoms are labelled as "just psychological," people are less likely to report them early or to use them as part of ongoing clinical monitoring.

This reading is reinforced by the national survey data. Loss of trust in the system and avoidance of seeking care appear as common consequences of repeated experiences of invalidation. In this context, the body is often "listened to" by the person long before it is taken seriously by the care system, leading to missed opportunities for early intervention and relapse prevention.

5.2 The body as an early warning signal of instability

Implications for clinical practice

- **Systematically integrating bodily signals into clinical assessment:** actively asking about the presence of early physical signs can enrich the understanding of an individual's clinical course and support the development of personalised prevention strategies.
- **Recognising the legitimacy of somatic signals:** avoiding the devaluation of physical symptoms as "merely psychological" can foster greater trust and more open communication between the individual and the professional.
- **Building a shared language around the body:** working collaboratively with the person to identify and name their bodily signals can transform the body from a source of confusion or shame into a shared monitoring tool.
- **Using bodily signals as a clinical resource rather than background noise:** integrating them into care plans can contribute to more timely, sustainable, and person-centred care.

During clinical visits or follow-up appointments, it may be useful to systematically include a brief, standardised question about bodily signals—for example, asking whether the person has noticed physical changes that, in the past, have preceded periods of instability. This type of question can be incorporated into routine clinical assessment without significantly extending consultation time.

A second concrete intervention concerns the documentation of bodily signals that are relevant for the individual patient. Recording, in a concise form, one or two recurring physical signals reported by the person allows a shared reference point to be developed over time, supporting both ongoing monitoring and the early identification of potential changes in clinical state.

The data also highlight the importance of avoiding the minimisation of physical symptoms. Explicitly acknowledging that bodily signals may carry clinical value—even in the absence of immediately identifiable objective markers—can encourage more open communication and reduce the tendency to withhold symptom reporting in the early phases of instability.

Finally, the use of aggregated feedback materials—such as summaries of recurring experiences collected by user associations—can support clinical practice by providing a shared framework for discussing bodily signals and experiences that are difficult to verbalise. This approach makes it possible to integrate lived experience without placing the burden of extensive qualitative data collection on individual professionals.

Taken together, these recommendations aim to make bodily signals an integral part of routine clinical assessment, improving the timeliness of interventions and continuity of care without introducing additional complexity into care settings.

5.3 Sleep

In bipolar disorder, sleep represents one of the bodily dimensions most closely linked to mood regulation and long-term stability. Changes in sleep duration, continuity, or quality may precede shifts in mood and accompany periods of instability. Despite this theoretical recognition, in clinical practice sleep is often approached as a symptom to be "corrected" rather than as a dynamic indicator of balance or imbalance.

This section explores how people with bipolar disorder perceive the role of sleep in their lived experience of crisis and instability, with particular attention to its value as an early warning signal.

In response to the question, "Do your episodes often begin with a change in sleep?", the answers show a strong concentration around a shared experience:

- Absolutely yes: 88%
- Rarely: 11%
- Never: 2%

Overall, 88% of respondents report that changes in sleep represent a recurring and recognisable feature at the onset of a crisis phase.

The wording of the question and the responses suggest an implicit distinction between sleep quantity and sleep quality. The relevant change is not simply about sleeping more or less, but often involves a loss of regularity, continuity, or the feeling of being rested.

The data show that for most respondents, sleep is one of the first bodily areas to change around the onset of a mood episode. The high number of affirmative responses indicates that sleep is experienced as a clear and recognisable signal, rather than as a secondary or incidental symptom.

This finding reinforces the view that sleep is not merely a target of pharmacological intervention, but an informative clinical variable that can be used to monitor the course of the disorder over time. The discrepancy between the importance attributed to sleep by individuals and the way it is sometimes handled in clinical practice—as a parameter to be rapidly normalised—may contribute to the loss of clinically relevant information about individual trajectories.

5.3 Sleep

Implications for clinical practice

- **Valuing sleep as a signal, not only as a symptom:** actively asking whether and how sleep has changed relative to the individual's usual pattern can provide meaningful insight into the evolution of mood state.
- **Distinguishing between sleep quantity and sleep quality:** targeted questions about continuity, perceived restfulness, and regularity are often more informative than the number of hours slept alone.
- **Integrating sleep monitoring into routine follow-up:** sleep can function as a stable indicator to be reviewed over time, without the need for technical tools or structured rating scales.
- **Avoiding an exclusively pharmacological approach:** medication adjustments may be necessary, but they risk being insufficient if not accompanied by an understanding of the role sleep plays in the person's overall balance.

During clinical visits, it may be helpful to explicitly ask whether sleep has changed compared to the person's usual functioning, rather than simply whether they are "sleeping enough." Questions focused on change allow early identification of signs of instability.

A second practical intervention involves defining an individual "sleep baseline" together with the person, even in descriptive terms (for example: typical schedules, continuity, perceived rest). This reference point can be revisited in subsequent follow-ups to assess meaningful deviations.

It is also useful to document any recurring sleep-related patterns that, for that individual, have preceded crisis phases in the past. Even minimal notes can support early recognition of situations associated with increased risk.

Finally, the data highlight the importance of recognising sleep as a subjective experience, rather than reducing it to a purely quantitative parameter. This approach can foster more effective communication and greater adherence to agreed strategies, contributing to a more timely and person-centred management of care.

5.4 Eating, Energy, and the Mood-Body Cycle

In bipolar disorder, eating and bodily energy represent dimensions that are closely intertwined with daily functioning and mood stability. Beyond nutritional aspects in the strict sense, the relationship with food is shaped by emotional, cognitive, environmental, and material factors, which may vary across different phases of the disorder. In this context, eating is not merely a behavioural variable, but a bodily and relational dimension that influences perceptions of control, freedom, and wellbeing.

This section explores perceived freedom in food choices and the emotional burden associated with eating as indirect indicators of the sustainability of care in everyday life.

In response to the question, "How free do you feel to choose what to eat based on what makes you feel well?", the answers show a differentiated distribution:

- Completely free: 29%
- It causes me stress: 30%
- Very little: 23%
- Not at all: 18%

Overall, 71% of respondents report some degree of limitation, stress, or lack of freedom in their food choices, while fewer than one third describe having full decision-making autonomy.

The responses suggest that, for a substantial proportion of the sample, the relationship with food is marked by strain, constraint, or effort, rather than being a neutral or wellbeing-supportive part of daily life.

The data indicate that many people with bipolar disorder experience eating as a demanding and stressful domain, rather than as an easily available resource for self-care. The high frequency of responses referring to stress, restriction, or lack of choice points to barriers that extend beyond access to nutritional information alone.

These findings are consistent with an interpretation of eating as a space where bodily energy, emotional experience, and material conditions intersect. Difficulty in "choosing what to eat based on what feels beneficial" may reflect economic constraints, fluctuations in energy levels, treatment-related side effects, or implicit normative pressures around what constitutes "appropriate" eating. The data therefore suggest that the issue lies less in a lack of guidance and more in the limited real-world accessibility of food choices that are compatible with wellbeing and with the resources available to individuals.

5.4 Eating, Energy, and the Mood-Body Cycle

Implications for clinical practice

It is important to **avoid abstract or overly standardised prescriptive approaches. Dietary advice focused on "what to eat" that fails to take into account stress levels, available energy, and material conditions risks being ineffective and may increase feelings of pressure or inadequacy.** Nutritional recommendations—often derived from evidence produced in controlled samples—require ongoing adaptation in order to be applicable in real-life contexts.

A central issue concerns **recognition of the emotional burden associated with eating. Food may become a source of guilt, frustration, or perceived failure, interfering with adherence and overall wellbeing.** In this context, it is essential to avoid moralising interpretations of eating difficulties and to refrain from automatically attributing them to lack of motivation or poor compliance.

During clinical encounters, it may be more useful to **orient assessment towards practical feasibility, by asking whether the dietary guidance received is sustainable in everyday life, rather than focusing exclusively on its theoretical correctness.** This approach allows sources of stress or perceived failure to be identified at an early stage.

A further relevant intervention involves **recognising and valuing non-ideal improvements, by explicitly validating intermediate or partial steps—for example, reducing a single food perceived as harmful or occasionally introducing a nourishing food.** While these changes may fall short of theoretical standards, they represent meaningful progress within the care pathway.

Accordingly, it is advisable to **work towards minimal, cumulative, and flexible goals, agreed with the person and responsive to fluctuations in energy, mood, and available resources, rather than rigid plans that are difficult to sustain over time.** From this perspective, it becomes useful to redefine the concept of adherence to include partial, intermittent, or informal forms of self-care when these constitute an improvement relative to the individual's starting point.

Finally, the data highlight the importance of **placing eating within a broader mood–body cycle, recognising that variations in energy and bodily wellbeing directly shape the relationship with food and the capacity to care for oneself through eating.**

5.5. Movement and realistic accessibility

In bipolar disorder, movement is frequently recommended as part of care, both for its potential benefits to physical wellbeing and for its role in everyday functioning. However, there is often a substantial gap between recommendation and the actual possibility of engaging in movement. Factors such as available energy, environmental conditions, financial resources, and emotional experience directly shape whether movement can be practiced in a regular and sustainable way.

This section examines how movement is experienced by people with bipolar disorder, with particular attention to feelings of failure, material barriers, and the role of the relational context.

In response to the question, “Has the idea of exercising ever made you feel like a failure?”, the answers were distributed as follows:

- Yes, because others point it out to me: 30%
- Yes: 12%
- Sometimes: 27%
- No: 32%

Overall, 69% of respondents report having felt—at least occasionally—a sense of failure in relation to movement or physical exercise.

In response to the question, “Have you ever wanted to follow a diet or be physically active but found yourself limited by financial or environmental barriers?”, responses were as follows:

- Yes, definitely: 66%
- Sometimes: 19%
- Never: 15%

Overall, 85% of respondents report the presence of financial or environmental barriers.

In response to the question, “Is it easier for you to go for a walk if someone is waiting for you?”, the answers were distributed as follows:

- Yes: 79%
- No, never: 18%
- I have no one: 3%

The majority of respondents indicate that the presence of another person significantly facilitates engagement in movement.

5.5. Movement and realistic accessibility

The data indicate that, for many people with bipolar disorder, movement is not a neutral or easily accessible domain, but one marked by pressure, judgement, and perceived failure. The frequency with which feelings of failure are reported suggests that recommendations around physical exercise may be difficult to integrate when they do not take into account the person's real-life conditions.

At the same time, the high proportion of respondents reporting financial or environmental barriers highlights that difficulties with movement cannot be reduced to a lack of motivation, but instead reflect concrete structural constraints.

Findings related to the presence of others further suggest that engagement in movement is strongly shaped by relational context: the likelihood of moving increases when the activity is shared or supported, while the absence of support may represent an additional source of exclusion.

Taken together, these results indicate that the issue is not movement itself, but the real-world accessibility of movement-related opportunities.

5.5. Movement and realistic accessibility

Implications for clinical practice

There is a need to rethink how movement is proposed in care. ***Generic, performance-driven, or high-standard recommendations can increase feelings of failure rather than support wellbeing.*** Movement should not be treated as a neutral behaviour, but as a domain that is often shaped by judgement, pressure, and comparison.

A central issue concerns the ***recognition of material and environmental barriers, which should be considered an integral part of the clinical picture***. Economic, logistical, or contextual obstacles concretely limit access to movement and cannot be interpreted as a lack of will or motivation. ***During clinical appointments, it may be helpful to explore how movement recommendations are experienced***, including any feelings of failure, pressure, or comparison with unrealistic standards. This allows guidance to be adjusted and helps prevent counterproductive effects on the therapeutic alliance.

It is also important to ***redefine movement in more inclusive terms, valuing minimal, non-performative forms that are integrated into everyday life and compatible with available energy. Activities such as walking for a few minutes, moving around the house, or carrying out domestic tasks can represent meaningful forms of bodily activation.***

As observed in relation to eating, it is clinically relevant to recognise and validate non-ideal improvements, treating intermediate or discontinuous steps as legitimate parts of the care process. Minimal, cumulative, and flexible goals—agreed upon with the person—can support greater long-term sustainability.

Assessment should explicitly include economic and environmental barriers, avoiding the suggestion of activities or services that are not realistically accessible. Where possible, it is useful to orient people towards free options or forms of movement embedded in daily routines. Finally, the data point to the importance of relational support, recognising that movement is more feasible when it is shared or supported by others. **Encouraging accompanied or group-based forms of movement, when consistent with the person's context, can be a concrete way to reduce isolation and make physical activity more sustainable.**

Pilot Experiences and Applied Perspectives: A Gentle Eating Approach

Building on the findings related to the real-world accessibility of eating and movement, the Italian Bipolar Association piloted a gentle eating education programme, initially offered to volunteers and motivated participants. The programme was not designed as a diet or a set of prescriptions, but as an educational space aimed at reducing the emotional burden associated with food, supporting realistic choices, and fostering habits that are sustainable over time. Eating was framed as a source of wellbeing, variety, and enjoyment, rather than as a normative or performance-driven domain.

From an operational perspective, the programme prioritised:

- simple, non-judgemental visual tools (for example, colour-based reference models);
- concrete examples of flexible, modular meals;
- accessible, ready-to-use recipes supported by step-by-step visual instructions;
- the absence of prohibitions or rigid targets, in favour of small, cumulative choices.

Informal feedback collected during the pilot phase suggests good engagement and a perceived increase in accessibility, particularly among individuals who had previously experienced stress, guilt, or feelings of failure in response to conventional dietary guidance.

Along similar lines, the Association is currently reflecting on the development of collective motivational tools for movement, inspired by models of gradual reinforcement and based on minimal, cumulative, and symbolic goals. The aim is to value everyday micro-goals that are compatible with available energy—such as a few minutes of walking or forms of movement integrated into domestic life—potentially shared within a group context, in order to reduce isolation and perceived failure.

These initiatives should be understood as experimental and complementary projects, not as substitutes for clinical guidance. The overarching goal is to develop practical tools that can increase the real-life sustainability of recommendations, while maintaining an open dialogue with professionals in nutrition, movement, and mental health who are interested in co-designing interventions grounded in the needs emerging from the data.

One theme that emerges indirectly from the data concerns how change over time is recognised. ***Recommendations around eating and movement are often oriented towards complete or ideal standards of adherence, which do not reflect the gradual and non-linear ways in which people actually modify their behaviour in real life.***

Giving value to even small or partial improvements can represent an important protective factor. Acknowledging these forms of progress helps reduce feelings of failure, supports motivation, and counteracts "all-or-nothing" patterns, which are frequently counterproductive in bipolar disorder.

5.6. Treatment side effects

In bipolar disorder, pharmacological treatments are a cornerstone of clinical management. At the same time, medication-related side effects can have a substantial impact on quality of life, body image, everyday functioning, and willingness to continue treatment over time. In this sense, the body can become the site where the clinical benefits of stabilisation come into tension with costs that are experienced as burdensome or difficult to accept.

This section examines which side effects are perceived as most problematic and how these bodily changes shape individuals' relationships with pharmacological treatment.

In response to the question, "Which side effect has been the most difficult for you to accept?", responses were distributed as follows:

- Weight gain: 51%
- Sedation: 29%
- Acne: 3%
- Other: 17%

Weight gain emerges as the side effect most frequently identified as difficult to accept, followed by sedation.

In response to the question, "Have you ever considered stopping your medication because of changes you noticed in your body?", responses were as follows:

- Yes, and I did: 30%
- I thought about it but did not stop: 32%
- Sometimes: 14%
- No, never: 24%

Overall, 76% of respondents report having considered stopping medication at least once due to bodily changes, and 30% state that they actually discontinued treatment.

The data indicate that bodily side effects are a central element in the experience of pharmacological treatment. The prominence of weight gain and sedation as difficult-to-accept effects suggests that the perceived costs of treatment are concentrated in domains that directly affect energy levels, bodily identity, and everyday functioning.

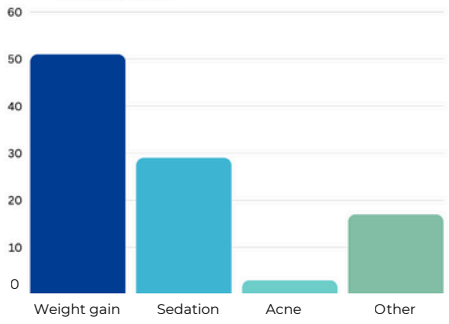
5.6. Treatment side effects

The high proportion of individuals who have considered stopping medication—and, in a substantial share of cases, have actually done so—highlights how the body can become a critical factor in the sustainability of care, rather than a secondary concern. These findings suggest that non-adherence should not be interpreted solely as a lack of insight or poor collaboration, but also as a response to bodily changes experienced as intolerable.

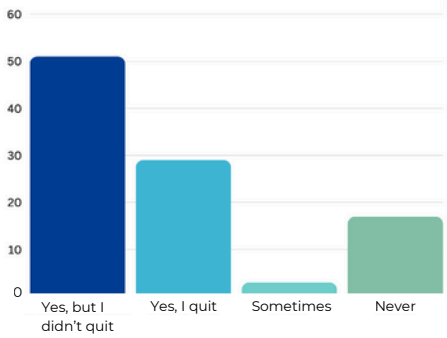
Taken together, the results indicate that the management of side effects is an essential component of therapeutic continuity, and that failure to integrate this dimension can undermine the overall effectiveness of treatment.

Side Effects: When the Body Becomes a Reason for Discontinuation

Which side effect was the most difficult to accept?



Have you ever considered stopping medication because of changes you noticed in your body?



This is not only a clinical issue, but also a relational and identity-related one. The body—already marked by the disorder—can become a site of conflict, shame, or distancing. Many people report not feeling heard when they talk about side effects, or having learned to minimise them in order not to appear "uncooperative".

AIBP proposes the systematic integration of bodily experience into the therapeutic relationship—not only as a matter of monitoring, but as a space for dialogue. Acknowledging these experiences, exploring therapeutic alternatives together, and co-designing strategies to improve tolerability can strengthen the therapeutic alliance and reduce the risk of treatment discontinuation.

5.6. Treatment side effects

Implications for clinical practice

The findings point to several important implications for clinical practice:

- **Treat side effects as an integral part of clinical assessment,** rather than as secondary concerns subordinate to mood stabilisation.
- **Acknowledge the subjective impact of bodily changes,** avoiding minimisation or interpretations limited solely to pharmacological tolerability.
- **Understand non-adherence as a multifactorial phenomenon,** including the role of the body and bodily identity in the individual's relationship with treatment.
- **Integrate side effects into routine clinical communication,** reducing the risk that they remain unspoken or are addressed only during crisis phases.

During clinical encounters, it may be helpful to explicitly ask whether bodily changes are affecting the person's relationship with treatment, including direct questions about weight, sedation, and energy levels. This allows early identification of distress that might otherwise lead to unplanned discontinuation.

It is important to **normalise discussion of side effects, making them a stable part of clinical dialogue rather than an issue addressed only when they become critical.** Open and explicit communication can reduce the likelihood of stopping medication without consultation.

When significant difficulties emerge, it is useful to jointly **explore possible adaptive strategies. These may include treatment adjustments, targeted monitoring, or a redefinition of care goals, taking into account the balance between clinical benefits and bodily costs.**

Finally, the data underscore the importance of recognising the body as a central site of treatment experience, integrating side-effect management into a broader perspective on treatment sustainability and continuity of care.

5.7. Material inequalities

In bipolar disorder, the ability to take care of one's body does not depend solely on individual motivation or clinical awareness, but is strongly shaped by the material resources available. Financial costs, access to services, living conditions, and the availability of support all have a direct impact on the feasibility of clinical recommendations and on continuity of care.

This section examines the extent to which people with bipolar disorder encounter economic or environmental barriers when attempting to follow body-related care recommendations, and how these barriers affect the long-term sustainability of therapeutic pathways.

In response to the question, "Have you ever wanted to follow a diet or be physically active but encountered financial or environmental barriers?", responses were as follows:

- Yes, definitely: 66%
- Sometimes: 19%
- Never: 15%

Overall, 85% of respondents report having encountered financial or environmental barriers at least occasionally when trying to take care of their bodies.

In response to the question, "Has a clinician ever suggested something that you could not afford?", responses were distributed as follows:

- Yes: 54%
- Rarely: 25%
- No: 21%

Overall, 79% of respondents report having received clinical recommendations at least once that were not compatible with their economic or material circumstances.

The data indicate that material inequalities constitute a structural variable in the care experience of many people with bipolar disorder. The frequency with which financial or environmental barriers are reported suggests that difficulties in following recommendations related to eating, movement, or support are not occasional, but recurrent.

Findings related to economically inaccessible recommendations highlight a gap between clinical guidance and real-life living conditions, which may translate into frustration, feelings of inadequacy, or disengagement. In this context, non-adherence does not necessarily reflect poor collaboration, but rather a concrete inability to implement what is being recommended. The results therefore suggest that material inequalities are not external to care, but directly shape its effectiveness and long-term sustainability.

5.7. Material inequalities

Implications for clinical practice

The findings point to several relevant implications for clinical practice:

- **Integrate the assessment of material resources into clinical care,** recognising that economic and environmental accessibility directly affect adherence and outcomes.
- **Avoid standard, decontextualised recommendations,** which may increase feelings of failure or distance from the care pathway.
- **Acknowledge inequalities as clinically relevant determinants,** rather than as marginal or purely "social" variables external to healthcare competence.
- **Strengthen the therapeutic alliance by offering guidance** that is compatible with the person's real-life possibilities.

In light of the data, integrating material inequalities into clinical practice can be achieved through concrete and sustainable actions.

During clinical encounters, it may be helpful to explicitly ask whether proposed recommendations are economically and logistically feasible, normalising the possibility that they may not be. This type of question can help prevent misunderstandings and unspoken disengagement.

Priority should be given to low-cost options or approaches embedded in everyday life, avoiding suggestions that require unavailable resources. Where possible, orienting people towards free or publicly available alternatives can make recommendations more realistic and actionable.

A further step involves treating inequalities as clinical information to be documented and reviewed over time, recognising that material conditions may change and influence care in different ways.

Finally, the data highlight the value of structured collaboration with local services and user-led associations, which can provide information, guidance, and complementary resources, contributing to more equitable and sustainable care pathways.

The Body, Care Implementation, and Sustainability of Care Pathways: An Integrated Reading of the Data

The sections dedicated to the body do not merely describe additional aspects of the experience of bipolar disorder; rather, they offer a concrete lens through which to observe how clinical recommendations are actually translated—or fail to be translated—into everyday practice. When read together, the data on bodily signals, sleep, eating, movement, side effects, and material inequalities suggest that the central issue is not a lack of clinical knowledge, but the structural difficulty of making care sustainable over time.

This picture is consistent with what emerges in other parts of the report. Barriers to access, discontinuity of care, fragmentation of services, and communication difficulties described in previous sections constitute the context within which bodily data acquire meaning. In this sense, the body becomes a cross-cutting indicator of the same systemic fragilities that run through the entire care pathway.

The body as a point of intersection between prevention, continuity, and trust

The data show that bodily signals and changes in sleep are frequently recognised by individuals as early markers of impending instability. This finding directly intersects with the issues of continuity of care described in the report: when clinical points of reference change frequently, follow-up is inconsistent, or access is irregular, it becomes difficult to build a shared, longitudinal understanding of individual early warning signs.

In the absence of continuity, the body loses its preventive function and becomes visible only once a crisis is already fully developed. This contributes to a sense of unpredictability surrounding the disorder and reinforces the perception—reported in other sections of the report—of a system that intervenes late and in a reactive manner, rather than proactively. The bodily dimension, therefore, cannot be separated from the issue of continuity of care: without relational and organisational stability, even the clearest signals remain clinically underutilised.

Sleep and clinical oversimplification: an emblematic example

Sleep represents a paradigmatic case of the gap between evidence and implementation. International literature and clinical guidelines have long recognised the central role of sleep–wake rhythms in mood regulation and relapse prevention. However, the data show that, in practice, sleep tends to be managed primarily as a variable to be rapidly normalised—often through pharmacological intervention—rather than as a dynamic signal to be monitored over time.

This approach intersects with other critical issues identified in the report, including excessive sedation, difficulties in managing side effects, and communication perceived as poorly attuned. Within this framework, sleep ceases to function as a preventive tool and instead becomes a point where problems accumulate: increased polypharmacy, reduced energy,

The Body, Care Implementation, and Sustainability of Care Pathways: An Integrated Reading of the Data

deterioration in quality of life, and—particularly in more severe cases—a growing sense of mistrust towards therapeutic decisions.

Side effects and discontinuity: when the body signals a breakdown in care

The data on side effects and thoughts of discontinuing medication highlight a theme that runs throughout the report: the fragility of the therapeutic alliance over time. The proportion of individuals who have considered stopping, or have stopped, medication for bodily reasons is directly connected to sections describing communication difficulties, a perceived lack of person-centredness, and limited shared decision-making.

From this perspective, non-adherence cannot be understood as an individual problem, but rather as a signal of a therapeutic balance that fails to hold over time. The body becomes the first place where this imbalance is expressed, often before it is articulated at a psychological or relational level. Ignoring or minimising these signals means losing an early indicator of a potential rupture in the care pathway.

Eating, movement, and inequalities: the blind spot of implementation

The sections devoted to eating, movement, and material barriers make visible another cross-cutting issue already present in the report: the gap between standard recommendations and real-life conditions.

The data show that a substantial proportion of individuals encounter economic, environmental, and social obstacles when attempting to follow clinically sound recommendations. This finding intersects with the analyses on access and inequality: when the system fails to take available resources into account, recommendations risk producing counterproductive effects, such as shame, feelings of failure, and gradual disengagement. In this sense, the body becomes a point of friction between clinical norms and social reality, making visible how material inequalities translate into concrete clinical outcomes.

Professionals and the system: the issue is not knowledge, but translatability

It is important to emphasise that the data do not point to a lack of competence or concern on the part of professionals. On the contrary, the picture that emerges is consistent with what is described elsewhere in the report: high care burdens, limited time, service fragmentation, and coordination difficulties make it challenging to consistently apply person-centred models of care. In this context, the bodily dimension functions as a stress test for the system: when the system is under strain, it is precisely the body—sleep, energy, side effects, accessibility—that tends to be managed in a more reductive or standardised way. This is not due to lack of commitment, but to structural constraints that shape everyday clinical decision-making.

The Body, Care Implementation, and Sustainability of Care Pathways: An Integrated Reading of the Data

The role of local networks and user-led organisations

The integrated reading of the data suggests that part of care sustainability necessarily lies beyond the clinical encounter itself. Community contexts, informal networks, and user-led organisations can help bridge the gap between clinical recommendations and everyday life, offering support, orientation, and continuity that the healthcare system struggles to provide on its own.

In this sense, the contribution of such organisations is not a substitute for clinical care, but a complementary one: making recurring patterns visible, facilitating dialogue between lived experience and professional practice, and supporting continuity during the most fragile phases of the care pathway.

Final conclusions

Taken together, the data show that the body is not an additional or secondary dimension in the care of bipolar disorder, but the place where the limits and potential of care pathways become visible at an early stage. The gap between available evidence and real-world practice is less about "knowing what to do" and more about "being able to do it" within complex contexts. Systematically integrating the bodily dimension therefore means working on sustainability, continuity, and trust—core elements that run throughout the report and represent a necessary condition for improving long-term outcomes.

06. REAL ACCESS TO CARE: THE MENTAL HEALTH SERVICES CENSUS

This section presents the preliminary findings of an operational mapping of mental health services conducted by the Associazione Italiana Bipolari over the past two years.
Unlike analyses based on administrative sources or institutional databases, this mapping is grounded in direct and systematic contact with services, carried out centre by centre and region by region, including both urban settings and small municipalities.

The aim of the mapping is not purely descriptive, but twofold:

- **to observe the real structure of care provision across the territory, as it appears from the perspective of concrete access;**
- **to assess services' willingness to collaborate with the third sector—specifically with a national user-led association—as an indirect indicator of openness, integration, and system sustainability.**

The mapping was therefore conceived as a tool to analyse real-world access, understood not only as formally informing services of the existence of a free, collaboration-oriented offer—designed in part to alleviate pressure on centres—but also as the concrete possibility of building effective support networks around the person.

Methodology: a relational and standardised census

The mapping was carried out by a team of trained volunteers, using a uniform contact protocol applied consistently across all services, regardless of region or type of facility.

Each centre was contacted individually by email using a standardised communication, designed to serve a dual purpose:

- to introduce the Associazione Italiana Bipolari, its national role, and the services it provides;
- to propose a structured form of collaboration aimed at easing the burden on services while offering patients and families free, accessible, and ongoing resources.

The introductory message was intentionally non-evaluative and non-advocacy-oriented. It was framed as an offer of support rather than a request for formal affiliation, in order to observe—without coercion—the level of responsiveness and interest expressed by services.

Scope of coverage and current status of the mapping

The mapping was designed with the aim of covering 100% of the national territory. At the time of writing this report, the project is still ongoing, but it has already achieved broad and meaningful coverage.

To date, the mapping has involved services in the following regions:

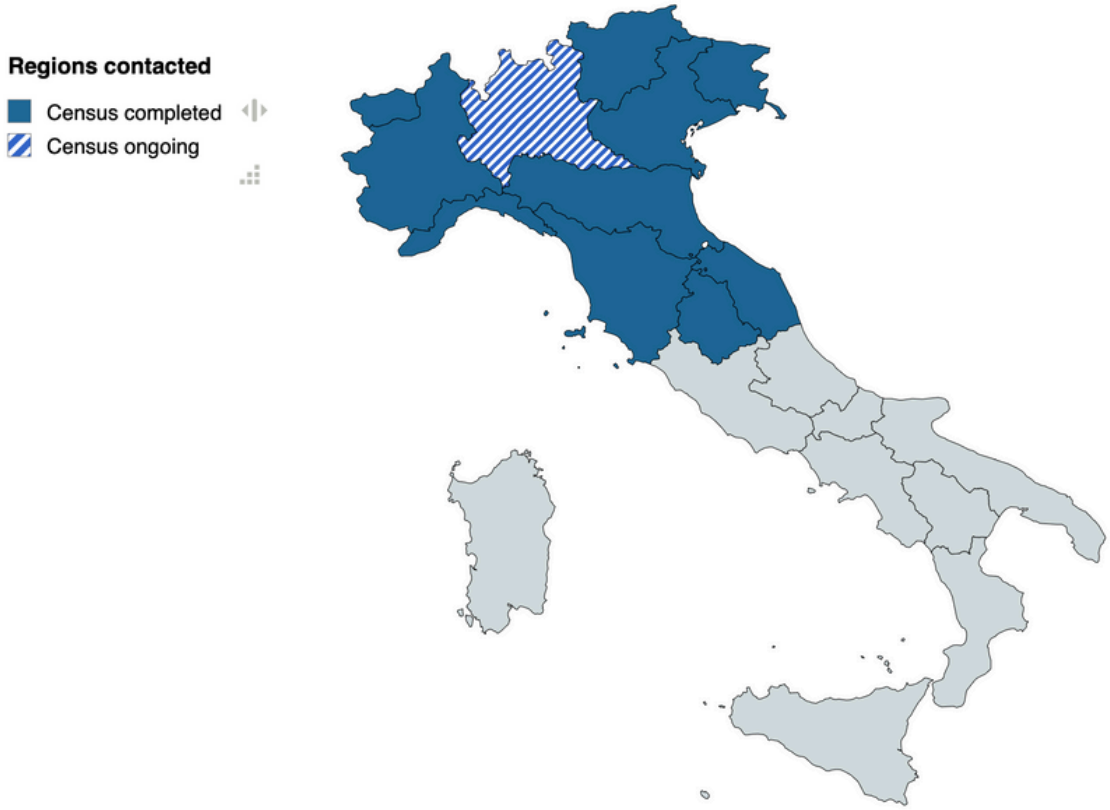
- Liguria
- Emilia-Romagna
- Friuli Venezia Giulia
- Marche
- Piedmont
- Trentino–Alto Adige
- Tuscany
- Valle d'Aosta
- Veneto
- Lombardy

For each region, all identifiable services were contacted, including:

- Community Mental Health Centres (CPS / CSM equivalents)
- Inpatient psychiatric units (SPDC)
- Public outpatient mental health services
- Hospitals and clinics providing psychiatric care

Methodology: a relational and standardised census

The outreach included both large urban centres and smaller local settings, allowing for an analysis that is not skewed by an exclusively urban perspective.



Data collected

For each service contacted, the following variables were systematically recorded:

- type of service
- name of the centre
- address and city
- date of contact
- presence or absence of a response
- stated willingness to collaborate

The mapping does not assess the clinical quality of interventions, nor does it make evaluative judgements about individual services. The data collected relate exclusively to the relational and organisational accessibility of services in response to a collaboration proposal aimed at supporting patients.

Methodology: a relational and standardised census

The mapping project allows for up to three contact attempts for each service before a facility is classified as non-responsive or unavailable for collaboration. At the time of writing, all services included in the database have been contacted at least once, and the follow-up process is currently underway.

This point is methodologically relevant. The data presented in this section represent an interim snapshot; however, they are already sufficiently extensive to provide a detailed and meaningful picture of the system's current state and its patterns of response.

Why this mapping is relevant for access analysis

The mapping makes it possible to observe dimensions of access that are rarely captured by institutional or administrative data, including:

- the actual traceability of services in practice;
- their responsiveness to qualified external contacts;
- their willingness to engage in collaboration with actors who can support patients and families beyond the confines of the clinical encounter.

From this perspective, lack of response or systematic refusal to collaborate is not interpreted as a failing of individual services, but as an indicator of organisational strain, workload pressure, or structural isolation. This interpretation is consistent with findings reported elsewhere in the report, particularly in relation to resource shortages, service fragmentation, and challenges in territorial integration.

Methodology: a relational and standardised census

Link to previous sections of the report

The preliminary findings of the mapping provide a structural framework for the experiences described in earlier sections of the report:

- the access and continuity difficulties reported by individuals are reflected in the uneven distribution of services and variability in service responsiveness;
- the workload perceived by professionals is mirrored in the limited capacity to activate external collaborations, even when these could help relieve clinical pressure;
- territorial inequalities emerge not only in the availability of services, but also in their relational openness and ability to work within networks.

The mapping therefore makes visible a level of access to care that is often overlooked: the possibility of building operational alliances around the person, beyond the formal clinical encounter.

Strategic value of the mapping

Within the Italian context, this mapping represents an innovative tool because it:

- integrates bottom-up analysis with a system-level perspective;
- observes the system in action, rather than only as described on paper;
- generates data that are useful not only for advocacy, but also for planning, collaboration, and policy development.

The findings are thus intended to support a deeper understanding of the real-world conditions in which patients, professionals, and services operate, providing a concrete basis for reflecting on more sustainable models of integration.

6.1. Preliminary results of the mental health services census

As of 21 January 2026, **18 services out of 725 (corresponding to 2.48% of contacted services)** have expressed an explicit willingness to collaborate. Although this represents an interim snapshot of the mapping exercise, the figure is already sufficient to highlight meaningful patterns in service responsiveness.

Regional distribution of willingness to collaborate

Willingness to collaborate shows marked regional variability, with overall response rates remaining low across all areas included in the mapping.

- **Tuscany** records the highest number of services expressing willingness to collaborate (4 out of 74), corresponding to a response rate of 5.4%.
- **Lombardy** and **Liguria** follow, with 3 services each indicating availability, out of 62 (4.8%) and 67 (4.5%) services contacted, respectively.
- **Veneto** reports 3 services willing to collaborate out of 128 contacts (2.3%).
- **Friuli Venezia Giulia, Emilia-Romagna,** and **Piedmont** each report one service expressing availability, with response rates below 1–3%.
- In **Marche, Trentino–Alto Adige, Umbria,** and **Valle d'Aosta,** no positive responses to collaboration were recorded during the first phase of the mapping.

Note
In the case of Valle d'Aosta, a single expression of interest in collaboration emerged through an external request rather than as a result of the standardised contact procedure used in the mapping. For this reason, the information is reported qualitatively and is not included in the quantitative count of collaborating services.

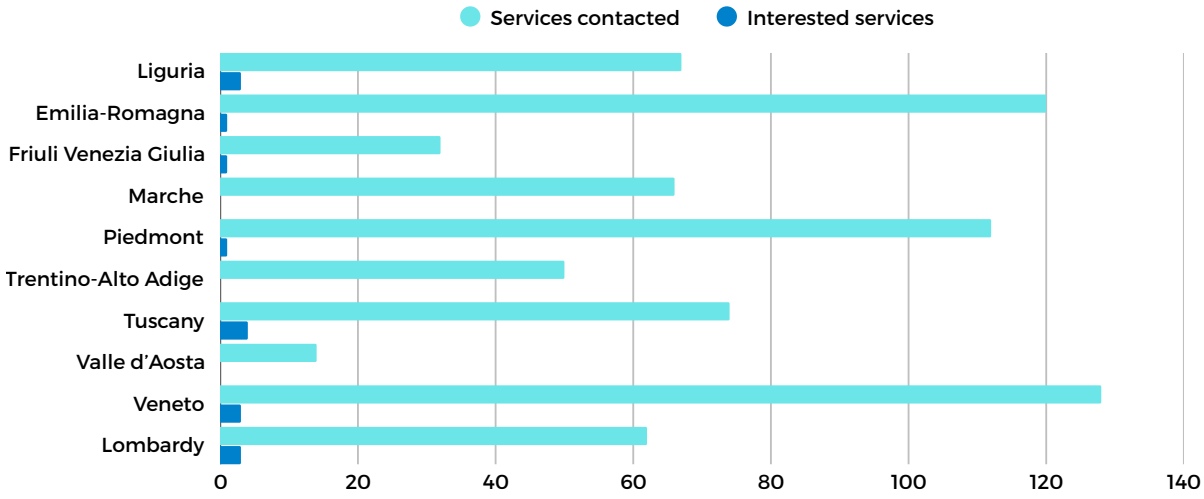
6.1. Preliminary results of the mental health services census

SERVICES CONTACTED ONCE, WITH TWO FOLLOW-UP ATTEMPTS PLANNED

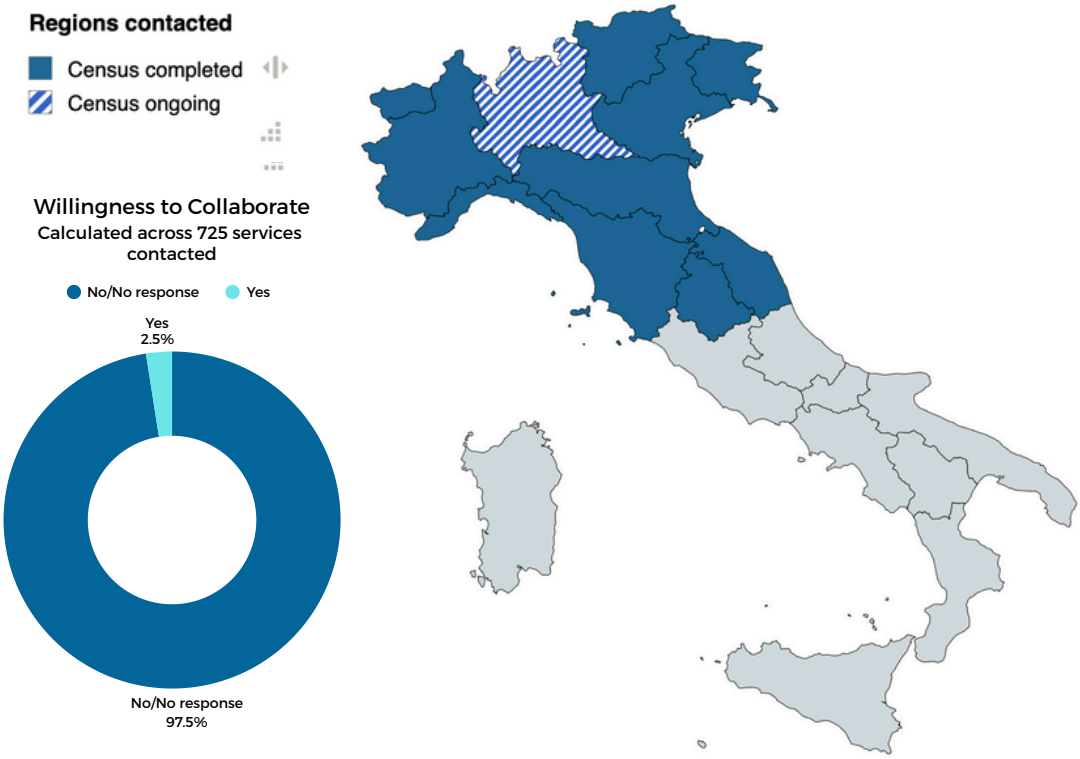
Region	Services contacted (N)	Services willing to collaborate (N)	% Response rate	Census status
Liguria	67	3	**4.5%**	Completed
Emilia-Romagna	120	1	**0.8%**	Completed
Friuli Venezia Giulia	32	1	**3.1%**	Completed
Marche	66	0	**0.0%**	Completed
Piedmont	112	1	**0.9%**	Completed
Trentino-Alto Adige	50	0	**0.0%**	Completed
Tuscany	74	4	**5.4%**	Completed
Valle d'Aosta	14	0	**0.0%**	Completed
Veneto	128	3	**2.3%**	Completed
Lombardy	62	3	**4.8%**	Ongoing

Percentage of Collaborating Services by Region

Percentage calculated based on the number of services contacted in each region.



6.1. Preliminary results of the mental health services census



In all regions where at least one response was received, the majority of responding services declared a willingness to collaborate. This suggests that the primary challenge may not lie in a lack of interest on the part of services, but rather in the likelihood of eliciting a response at the initial point of contact.

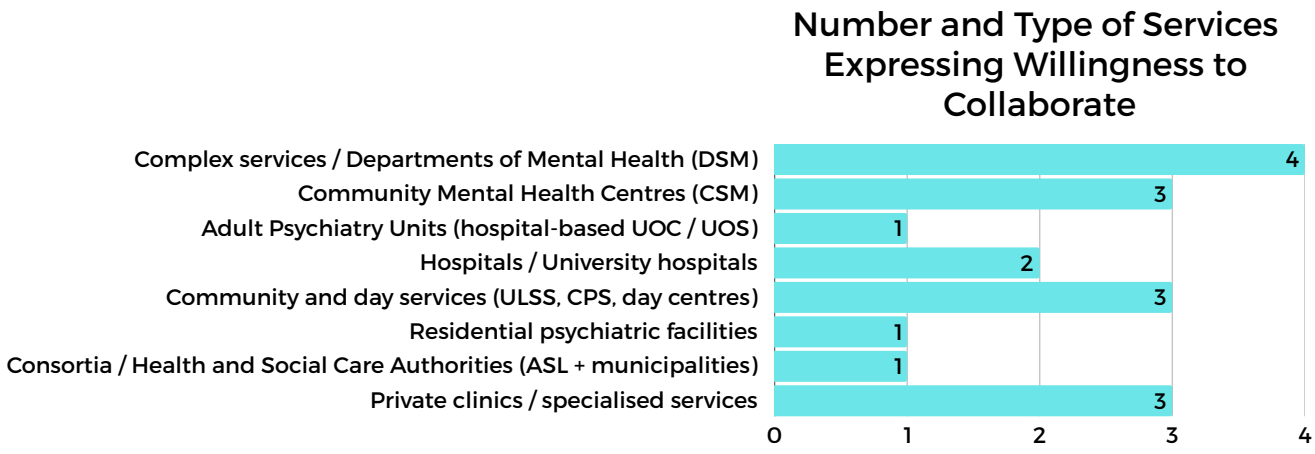
Potential confounding factors and alternative explanations
Several factors should be considered when interpreting these findings:

- **Communication channels and deliverability:** the use of generic institutional email addresses, inboxes that are not regularly monitored, spam filtering, or the absence of internal protocols for handling external requests may all reduce the probability of a response.
- **Identification of the recipient:** responsiveness may depend on whether a named contact person is available, or whether the message is received by an administrative office without decision-making authority.
- **Regional and organisational differences:** some regions or healthcare organisations may have more formalised frameworks for collaboration with the third sector, while others may require more complex authorisation processes, slowing down or discouraging responses.
- **Type of service:** community-based, hospital-based, residential, and private services may differ in their degree of autonomy and in the procedures required to initiate collaborations, generating variability that is independent of clinical interest.
- **Project phase and incomplete follow-up:** as this represents an interim snapshot, a proportion of non-responses may convert into responses following subsequent contact attempts. Initial outreach often underestimates delayed engagement.
- **Perceived ambiguity around the scope of collaboration:** some services may interpret the request as a formal institutional communication, requiring administrative clearance before responding; others may have concerns about reputational or liability implications.

6.1. Preliminary results of the mental health services census

NUMBER AND TYPE OF SERVICES EXPRESSING WILLINGNESS TO COLLABORATE

Type of service	Number of services	Regions involved
Complex services / Departments of Mental Health (DSM)	4	Liguria, Tuscany
Community Mental Health Centres (CSM)	3	Liguria, Piedmont
Adult Psychiatry Units (hospital-based UOC / UOS)	1	Emilia-Romagna
Hospitals / University hospitals	2	Tuscany
Community and day services (ULSS, CPS, day centres)	3	Veneto, Lombardy
Residential psychiatric facilities	1	Friuli Venezia Giulia
Consortia / Health and Social Care Authorities (ASL + municipalities)	1	Tuscany
Private clinics / specialised services	3	Veneto, Lombardy
Total collaborating services	**18**	–



6.2. Response and silence as indicators of real access: an integrated reading

The findings of the mental health services mapping acquire clearer meaning when read alongside the data emerging from the National Survey on Malpractice and Improper Practices in Psychiatric Patient Care, which systematically documents recurring difficulties in access, continuity, and quality of care, as well as significant consequences for trust and the long-term sustainability of care pathways. The survey highlights a pattern of access that is formally available but not fully practicable in real life. Reported issues include insufficient orientation, fragmented pathways, discontinuity between phases of care, and difficulties in identifying territorial resources and non-clinical forms of support. Within this context, the mapping does not constitute an assessment of the clinical quality of individual services. Rather, it provides complementary evidence on the system's capacity to respond and to activate support networks around the person, including through external collaborations that can sustain patients between one clinical contact and the next.

A cross-cutting element emerging from the mapping results is the low likelihood of receiving an explicit response at the initial point of contact, despite a standardised collaboration proposal that entailed no additional burden for services. Out of more than seven hundred services contacted, only a very small proportion provided a formal reply, whether positive or negative. Among those that did respond, the majority expressed willingness to collaborate, while a minority explicitly declined. Numerically, however, the most substantial component of the data consists of non-responses, which represent the predominant outcome of the outreach process.

From an analytical perspective, silence cannot be interpreted in a single or unambiguous way. It may reflect organisational overload, lack of time, or absence of dedicated resources, but it may also indicate a deliberate choice not to engage in external collaborations without issuing a formal refusal. In the absence of an explicit response, it is not possible to distinguish between these explanations. What can be observed, however, is the systemic effect of this dynamic: the difficulty of activating structured collaborations between mental health services and user-led or associative resources that provide continuity, information, and accompaniment outside the strictly clinical setting. Regardless of the underlying reasons, non-response results in the non-activation of these resources, with direct consequences for continuity of care and for the lived experience of people followed by services. From this perspective, response—or lack thereof—becomes a relevant indicator of real-world access to care, not in terms of formal service availability, but in terms of the concrete possibility of building support networks around the person.

When considered together, the mapping and the survey converge on a central point: real access does not coincide with the mere existence of a service, but with the effective possibility of entering a continuous and sustainable care pathway, in which information, support, and orientation are available also beyond the boundaries of the clinical encounter. The mapping captures a specific and often invisible dimension of this process: the relational and organisational permeability of services in response to a collaboration proposal aimed at addressing needs that the survey identifies as recurrent—continuity, support, accompaniment, orientation, and trust.

6.2. Response and silence as indicators of real access: an integrated reading

At the same time, it is important to clearly delimit the meaning of the data. Non-response, on its own, does not allow for a distinction between lack of availability, inadequate communication channels, or organisational overload. The aim is not to infer intentions, but to describe the practical outcome: regardless of the underlying reason, the result is the non-activation of a complementary support network. This lack of activation is consistent with the negative outcomes and experiences of discontinuity reported in the survey.

Even when potential confounding factors are taken into account, one central issue remains. When non-response represents the predominant outcome, the system demonstrates a structural difficulty in translating an available resource into support that is actually activated. From the perspective of patients, this is not an administrative detail. It means that free tools for support, orientation, and continuity often remain "outside the care pathway", precisely at the points where the survey identifies the greatest vulnerability—loss of trust, discontinuity, feelings of abandonment, and difficulties in maintaining adherence and stability.

In other words, the mapping makes visible a potential mechanism that helps explain, at a systemic level, why many of the critical issues described in the survey persist even when complementary resources exist. These resources are not absent; they are simply not activated, because the interface between services and the territory is fragile, uneven, or insufficiently structured.

Taken together, these findings suggest that a significant component of real access to care depends on a network infrastructure that is often missing or functions intermittently: minimal procedures for responding, signposting, integrating, referring to resources, and co-constructing continuity. When this infrastructure fails, care tends to contract around the clinical encounter and the reactive management of acute phases, leaving uncovered those domains that the survey identifies as central to sustainability—ongoing support, orientation, practical empowerment, and the rebuilding of trust.

Overall, the data indicate that the key issue is not simply how many services exist, but how effectively the system is able to build continuity around the person, including through operational alliances that can reduce clinical burden and improve the care experience. The mapping provides a concrete and replicable indicator of this capacity: the presence—or absence—of a response to a standardised collaboration proposal aimed at supporting patients.

6.3. Operational implications for services, communities, and models of care

When the mapping findings are read in conjunction with the national survey data, they suggest that a substantial share of the difficulties in real-world access to care does not stem solely from service availability or from the quality of clinical interventions in the narrow sense. Rather, these difficulties are closely linked to challenges in building continuity and sustained support networks around the person over time.

This section does not aim to propose new clinical protocols or standardised solutions. Instead, it seeks to identify realistic areas for improvement that are consistent with the evidence presented and with the organisational constraints faced by services.

01

Making Collaboration with Local Networks Visible and Traceable

The mapping shows that collaboration with user-led and ongoing support resources is neither systematically structured nor easily activated. A first practical step involves making these collaborations explicit, traceable, and recognisable within services, including through minimal procedures (such as designated contact persons, dedicated communication channels, or shared informational materials). From the patient perspective, this can translate into greater clarity about where to find support between clinical contacts, reducing the sense of fragmentation and abandonment reported in the survey.

02

Integrating External Resources as Part of the Care Pathway, Not as "Extras"

The data suggest that many of the difficulties experienced by people with bipolar disorder arise outside the confines of the clinical encounter: day-to-day management of the condition, early warning signs, adherence, orientation, and emotional and practical support. In this context, user-led and associative resources should not be treated as optional or informal add-ons, but as complementary components of the care pathway, capable of supporting areas that services—by their very nature—struggle to address on a continuous basis. More structured integration of these resources can help reduce the burden on professionals while simultaneously improving the overall patient experience.

6.3. Operational implications for services, communities, and models of care

03

Improving Informational Continuity and Orientation

The survey reveals widespread difficulty in navigating services, interventions, and available resources. Even when individuals are formally under clinical care, many report not knowing whom to contact for needs that are non-urgent or not strictly medical. A concrete operational response involves strengthening orientation within services by systematically providing information about reliable community and user-led resources, with particular attention to transition points such as diagnosis, discharge, and changes in care setting.

04

Recognising the Clinical Value of Non-Medical Support

The survey findings show that emotional support, peer exchange, accessible information, and practical accompaniment have a significant impact on perceived safety, trust in the system, and the long-term sustainability of care pathways. These elements do not replace clinical intervention, but rather strengthen its effectiveness over time. Recognising the value of these dimensions requires moving beyond a view of care limited to the clinical act alone and considering mental health as a process that is also shaped within the person's everyday life.

6.3. Operational implications for services, communities, and models of care

05

Reducing the Gap Between Theoretical Recommendations and Real-World Practice

Clinical guidelines and people-centred care models have long advocated for integrated, person-centred approaches. However, data from both the mapping and the survey indicate that the practical translation of these principles remains uneven. Addressing this gap does not necessarily require new evidence or additional models, but rather an operational reflection on how to make existing recommendations workable in real-world settings, taking into account available resources, workload pressures, and organisational constraints.

06

The Role of Associations as an Infrastructure for Continuity of Care

Within this framework, user and family associations can play a specific role: not as substitutes for clinical services, nor merely as advocacy actors, but as infrastructures for continuity, capable of providing stable support, information, and accompaniment over time. The mapping indicates that this potential remains only partially explored or not fully integrated. Strengthening dialogue between services and associations may therefore represent a concrete lever for improving real-world access to care, without increasing clinical workload and without introducing unrealistic solutions.

07. CONCLUSIONS - CROSS-CUTTING ANALYSIS AND FUTURE DEVELOPMENTS

This chapter brings together the findings of the AIBP Report 2025 into a single analytical framework, connecting three levels of evidence: the quantitative survey data, the qualitative analysis of lived experiences, and the preliminary results of the mental health services mapping. The aim of this cross-cutting reading is not to repeat what has already been described in the individual sections, but to clarify how the identified critical issues are linked across the full care pathway, and how they produce secondary—often avoidable—effects that weaken the very elements needed for stabilisation: trust, continuity, adherence, timely access, and the everyday sustainability of treatment.

This analysis builds directly on the AIBP Report 2024, which serves as its starting point. In 2024, the association brought attention to issues that are often marginal or poorly structured in institutional documents, including rights, informed consent, the therapeutic relationship, territorial inequalities, the gap between care and everyday life, and the role of associations as support infrastructures. The 2025 work does not simply repeat these themes. Instead, it tests them against empirical data and, importantly, shows how they develop over time. What emerges is that many critical issues do not remain limited to isolated moments, but tend to spread and persist, shaping how people relate to services, what they feel able to disclose, when they seek help, and with what emotional attitude. From this perspective, “quality of care” is not an abstract concept, but a concrete factor that directly influences outcomes.

7.1 From the 2024 Report to the 2025 Report: From Denunciation to Measurability

The 2024 Report articulated a clear demand: to recognise that mental health care cannot be reduced to diagnostic accuracy or the prescription of treatment alone, but also depends on rights, continuity, equitable access, coordination between services, quality of communication, and the involvement of competent community-based resources, including associations. In that context, integration between the healthcare system and external resources was identified as a necessary direction, yet one that remained fragile and often dependent on individual goodwill.

The 2025 Report takes this analysis a step further. It shows that the critical issues described in 2024 are not merely matters of "lived experience" or "relational difficulties", but factors that measurably affect key elements of the care trajectory. When a substantial proportion of respondents report having avoided or delayed access to care due to concerns about the quality of treatment (44.8%), or when 70% indicate that they did not receive clear instructions or follow-up plans after treatment, it becomes evident that care does not fail only because of a lack of interventions, but also because of the absence of minimal conditions of continuity and clarity. In other words, care may formally exist, yet be difficult in practice to follow, to understand, and to sustain over time.

The comparison between 2024 and 2025 therefore clarifies a crucial point: what was described in 2024 as a "space for collaboration" or a "need for integration" in 2025 also emerges as a "space of risk" when it remains unfilled. The question shifts from "who is right" to "where care breaks down in real life, and with what predictable consequences".

7.2 From Subjectivity to Structure: When Experience Becomes Data

One of the most important differences between the two reports concerns how lived experience is treated. In the 2024 Report, testimonies mainly served to make visible what is often missing from standard indicators: invalidation, confusion, fear, loss of trust, and isolation in interactions with services. In the 2025 Report, lived experience is no longer treated as anecdotal or "purely subjective," but is analysed as a signal of how the system actually works.

The combination of quantitative data and qualitative analysis shows that certain issues recur with enough consistency to form clear patterns. These include communication problems, limited listening, perceived paternalism, lack of explanations, poor clarity around risks and benefits, absence of follow-up, incomplete management of side effects, and difficulties linked to navigation and coordination of services. The repetition of these elements is not just a narrative detail. It indicates that some problems are not randomly distributed, but tend to appear at the same points along the care pathway and to produce predictable responses in how people adapt to the system.

This shift has concrete operational implications. When people's reported experiences consistently point to a weakening of alliance and trust, the data do not merely describe "how people feel"; they identify a critical point along the care trajectory. Individuals adapt by protecting themselves—reducing disclosure, delaying contact, selectively reporting information, or accessing services only at more advanced stages of crisis. In 2024, this dynamic could be inferred; in 2025, it becomes observable through indicators of access and continuity.

From this perspective, experiential data do not compete with clinical indicators; they complement them. They make visible central dimensions of care—such as comprehensibility, relational safety, and continuity between contacts—that remain invisible unless they are deliberately observed.

7.3 Communication, Consent, and the Therapeutic Relationship as Determinants of Outcomes

The AIBP 2025 Report clearly shows that communication and the therapeutic relationship are not "soft" or secondary aspects of care. They are practical elements that directly influence adherence, trust, continuity, and how resources are used. The data point to a recurring pattern. For many respondents, consent exists in formal terms, but often does not translate into real understanding, time for discussion, or the possibility to ask questions. Within the sample, 38% report receiving treatments or tests without explanations of why they were needed. Fifty-nine per cent felt pressured to accept care or medication they were not comfortable with. In many cases, care is perceived as focused on medication alone (50%), while alternative options are not discussed (39%). These issues are accompanied by clear relational difficulties: 61% report poor listening or lack of empathy, many feel treated more as a set of symptoms than as a person, and more than one in three describe having their experiences questioned or minimised.

These are not matters of communication "style." They shape outcomes because they affect a critical point: whether people are willing to stay engaged in care and to share meaningful information. When contact with services feels unsafe, unclear, or not participatory, people are more likely to hold back early warning signs, delay asking for help, or access services only when a crisis has already escalated. In mental health care—where trust and continuity are central—this cumulative effect also affects system sustainability. Care becomes fragmented, reactive, and more expensive over time. What emerges most clearly in the 2025 data is that these dynamics are strongest during moments of increased vulnerability. At the very times when careful language, clear explanations, and genuinely informed consent are most needed, routine communication and organisational habits tend to take over, increasing distance instead of providing containment.

7.4 The Body as a Fracture Point Between Theory and Practice (and as a Factor of Continuity)

A cross-cutting axis of the 2025 Report concerns the bodily dimension as the space in which the gap between theoretical principles and everyday practice becomes particularly visible. Sleep, energy, nutrition, movement, side effects, and metabolic impacts are widely recognised as central to the management of bipolar disorder; however, the data show that their integration into real-world care pathways often remains partial, standardised, or treated as secondary to prescription-based interventions.

What is decisive in 2025 is that the body does not emerge only as a domain of wellbeing, but as a driver of continuity. The reported outcomes describe physical, cognitive, and emotional–relational consequences with varying degrees of duration and severity. On the side of long-term harm, a substantial proportion report persistent cognitive impairment (33% of responses in this area), alongside permanent physical disability (20%) and medication-induced metabolic dysfunction (14%). On the side of temporary harm, the most frequently reported issue concerns reversible but highly debilitating side effects (42%), followed by temporary alterations in cognitive or motor functioning (30%). At the emotional and relational level, identity-related impacts emerge strongly: worsening self-esteem or self-image (34%), reduction or loss of libido and sexual desire (27%), and increased or experience-driven social isolation (20%).

These figures do not simply describe “side effects”; they describe factors that reshape the relationship with care itself. When people are not prepared for what to expect, when risks and benefits are not discussed clearly, and when bodily impacts are minimised or treated as inevitable, the likelihood of disengagement and unplanned treatment discontinuation increases, with direct consequences for stability and relapse prevention. From this perspective, integrating the body into care does not mean adding an extra chapter; it means safeguarding adherence and making treatment sustainable over time.

7.5 Real-World Access to Care: When the System Is Difficult to Navigate

The 2025 Report shows that access cannot be understood only in terms of the formal presence of services. Real access means being able to move through the system: knowing who to contact, understanding what to expect, being able to rely on a minimal network between one point of contact and the next, and encountering a system that is readable and coordinated.

From the perspective of people using services, concrete and recurring barriers emerge. Among those who reported difficulties in accessing care, lack of availability of specialised services was indicated by 44.8%, financial constraints by 39.7%, and long waiting times by 36.2%. Stigma and fear of judgement continue to play a significant role (32.8%), showing that access is also a relational and cultural issue. Added to this is a less visible but decisive factor: system fragmentation. Among those who reported systemic problems, lack of coordination between professionals was indicated by 46.6%, and lack of clear information about available services by 44.8%. These data describe a system in which access can fail even when services formally exist, because people cannot find their way, do not understand the steps involved, or do not know how to maintain continuity.

The most critical issue across all areas is the lack of a clear “continuation structure.” Seventy per cent report receiving no instructions or clear plans for follow-up after treatment. In psychiatry, where continuity is part of the intervention itself, this absence is not neutral. It creates an operational gap that people often fill with withdrawal, passive waiting, or delayed re-entry into care. In this sense, access is not just an initial step, but a dimension that runs through the entire care pathway.

7.6 Mapping Mental Health Services: Real-World Access Viewed from the System Side

The services mapping adds a structural layer to the report by looking at how the system works in practice—that is, how it responds and connects, not just how it exists on paper. Preliminary results show that out of 725 services contacted, 18 expressed a clear willingness to collaborate (2.48%). Although this figure varies by region, overall levels of expressed availability remain low across all areas examined. In some regions, no positive responses were recorded during the first phase of the mapping.

This finding should not be read in a moral or accusatory way, nor does it allow clear conclusions about the reasons behind it. It may reflect organisational overload, the absence of clearly identified contact points, unmonitored institutional communication channels, technical barriers, lack of internal procedures for handling external requests, or informal organisational choices. Regardless of the reasons, the observable outcome is the same: lack of response prevents the activation of resources that could be valuable for both people using services and professionals working within them.

When considered together, the mapping and survey data point to the same issue. Many experiences described as “difficult access,” disorientation, or lack of continuity reflect a structural difficulty within the system to build working alliances around the person. The mapping highlights a level of access that is often overlooked: the system’s ability to engage in dialogue, connect resources, and activate local networks.

7.7 Associations and the Territory: From Informal Resources to Infrastructures of Continuity

The comparison between 2024 and 2025 allows a clearer understanding of the role of associations and local networks. In 2024, this role was described as a potentially useful resource, but one that was often marginal. In 2025, it becomes evident that territorial functions are not secondary. They operate exactly where care most often breaks down.

Many difficulties do not arise within a single clinical encounter, but in the spaces between contacts. These include waiting periods, uncertainty about next steps, day-to-day management of side effects, the need for orientation, the processing of negative experiences, and the need for non-judgemental support that helps people stay engaged in care without shame or withdrawal. When these spaces are left uncovered, distrust, avoidance, and discontinuity increase, with clear consequences for stability.

In this context, the role of associations does not replace clinical care, nor does it compete with it. It is complementary and strategic. Providing accessible information, peer support, orientation, continuity, spaces to reflect, and ongoing accompaniment helps reduce the gap between “prescribed care” and care that is actually workable in everyday life. However, the mapping shows that this integration is still weakly formalised. Stable dialogue between services and associations remains uncommon, suggesting that the main limitation is not the lack of territorial resources, but the absence of practical mechanisms to use them in a systematic and repeatable way.

The key change compared to 2024 is therefore clear. What previously appeared as a possibility now emerges as a structural necessity. When the system does not take care of the spaces between clinical contacts, those gaps become clinically relevant, because they increase the risk of rupture along the care pathway.

7.8 Systemic Responsibility and the Limits of Blame Attribution

The findings of the 2025 Report call for a clear clarification of responsibility. The critical issues identified cannot be understood as isolated events or as the result of individual shortcomings. Instead, the data point to systemic conditions that make certain dynamics more likely: formal consent without real understanding, communication compressed by organisational pressure, lack of structured follow-up, fragmented coordination, and territorial integration left to personal initiative.

Clarifying responsibility does not reduce the seriousness of these findings. On the contrary, it helps shift attention to what can actually be changed. If the problems were only individual, responses would remain occasional and limited. The fact that clear patterns recur opens concrete paths for action: focused training on communication during phases of increased vulnerability; minimum standards for informed consent and clarity; clear and shared follow-up plans; structured monitoring of side effects; and simple but stable ways to support territorial coordination and collaboration.

From this point of view, systemic responsibility is not an accusation. It is a tool. It means identifying the conditions that produce avoidable suffering and turning them into clear targets for improvement.

7.9 Conclusions and Future Perspectives

Taken as a whole, the AIBP 2025 Report offers a coherent picture of how care for people with bipolar disorder actually works in Italy. It shows that many critical issues run across the entire care pathway: from assessment, to the therapeutic relationship, to the management of the body and treatment side effects, and through to real access and the system's ability to ensure continuity. The comparison with 2024 confirms strong continuity in the issues identified, but also highlights an important shift. What emerges today is not a series of isolated problems, but a trajectory through which these problems lead to hesitation, disengagement, loss of trust, and breaks in care over time.

One cross-cutting message stands out clearly: the gap between stated principles and everyday practice is not abstract, but has direct effects on outcomes. When people do not understand what is happening, are not meaningfully involved in decisions, do not receive clear guidance about what comes next, or experience poor management of bodily effects and side effects, care becomes hard to sustain. When these experiences repeat, their cumulative impact reshapes how people access services and how they relate to the system as a whole.

In this context, local networks and associations emerge as a strategic resource that is still largely underused. Many critical issues arise in spaces that fall outside clinical appointments. When these spaces are not supported, the risk of rupture increases and continuity becomes more fragile. Strengthening territorial connections and building stable, replicable partnerships is therefore not an optional addition, but a necessary condition for making care pathways workable in everyday life.

Looking ahead does not mean searching for simple solutions, but setting a clear direction. This includes investing in independent tools to collect and analyse experiential data, linking these data to indicators of continuity and quality of the therapeutic relationship, and using the resulting evidence to co-design realistic improvements with services, policymakers, and local actors. In mental health care, systematically listening to people's experiences is not an extra gesture. It is part of care itself, and part of how quality should be governed.

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