Service users perspectives on psychosis-risk terminology: An Italian study on labeling terms preferences and stigma

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ABSTRACT

Aims: The current range of labeling terms—at-risk mental state (ARMS), ultra-high risk for psychosis (UHR), and attenuated psychotic syndrome (APS)—used to refer to the psychosis-risk concept is varied, and their acceptability and potential stigma are not well understood. By involving Italian youth with lived experience of mental ill-health, we aimed to generate new labeling terms for psychosis-risk, and to evaluate literacy, attitudes, and preferences regarding these and the existing terms. Additionally, we investigated opinions of disclosure of the at-risk concept in clinical practice.
Methods: Through a dual-moderator focus group, novel diagnostic terms were coined for the at-risk concept: *psychosis proneness* (PP), *change of personal reality* (CPR), and *hints of subjectivity dysregulation* (HSD). A specifically designed questionnaire was then completed by 47 help-seeking youths, 60 relatives, and 61 clinicians to test newly generated and already established at-risk terms.
Results: Literacy on already established terms was significantly lower among youth (mean= 42 %) and relatives (mean= 38 %). ARMS was the preferred and least stigmatizing term among young people and clinicians. UHR was considered the most stigmatizing label. Among newly generated terms, CPR was the least stigmatizing and most informative. Disclosure of at-risk terminology was generally preferred after establishing a trusting clinician-patient relationship.

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Conclusions: Findings support ARMS as a useful and acceptable term in clinical practice with young people, while UHR is associated with the highest stigma. CPR is promising and should be tested in cross-cultural studies. In Italy, there is an urgent need for improving literacy on prevention in mental health.

1. Introduction

The "ultra-high risk" (UHR) for psychosis criteria are used to identify adolescents and young adults with an "at-risk mental state" (ARMS, i.e., at elevated risk of developing a full-blown psychotic disorder) (Nelson and McGorry, 2020; Yung et al., 1996). The growing body of evidence in this field prompted the American Psychiatric Association to include the term "attenuated psychosis syndrome" (APS) among the "Conditions for Further Study" of the Third Section of the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5) (American Psychiatric Association, 2013) and Fifth Edition – Text Revision (DSM-5-TR) (American Psychiatric Association, 2022). Currently, UHR, ARMS, and APS are interchangeably used in clinical settings to identify help-seeking youths for whom preventive treatments may alter the course of the illness (Boldrini et al., 2024; Lo Buglio et al., 2024).

Evidence shows that although using the label "at-risk" may be clinically useful (e.g., relief of young people related to a greater understanding of their condition), it may also generate perceived discrimination and stigma (Colizzi et al., 2021). For example, Kim et al. (2017) found that UHR and APS were considered strongly stigmatizing among clinicians and that 42 % of young people believed that the term UHR should be changed.

The purpose of renaming potentially stigmatizing terms is not new in psychiatry. For example, several campaigns have been launched both in Europe and North America by associations of mental health users asking for the replacement of "schizophrenia" by a less stigmatizing term (Campaign to Remove the Label of Schizoprhenia WWW Document, 2006; Fernando et al., 2012; George and Klijn, 2013). Among Asian countries, "Togo-Shitcho-Sho" (integration disorder) (Sato, 2006), "Johyun-byung" (attunement disorder) (Lee et al., 2013), and "Si Jue Shi Tiao" (dysfunction of thought and perception) (Sartorius et al., 2014) have been successfully introduced in Japan, Korea, and Hong Kong respectively, to rename previous local translation of the etymological meaning of schizophrenia (i.e., split-mind). Interestingly, in these Asian studies, the generation of more appropriate diagnostic terms has not been conducted by involving mental health service users.

Accordingly, Polari et al. (2021) engaged with youths with lived experience of mental ill-health to generate new at-risk terms, namely, "pre-diagnosis stage", "potential of developing a mental illness", and "disposition for developing a mental illness". The first two terms were the preferred labels to describe the "psychosis-risk" concept in a sample of young people, relatives, and clinicians. In contrast, UHR and APS were associated with the most stigma. Moreover, Polari et al. investigated the preferences of clinicians, young people, and relatives in relation to the disclosure of early diagnosis, finding that most participants agreed that information about diagnosis should be disclosed as early as possible.

Further research in other cultural contexts is warranted. Based on this background, the overarching goal of the current study was to replicate the original Australian study (Polari et al., 2021) in the Italian context. Specifically, we aimed to: i) engage youth with lived experience of mental ill-health to generate new terms to describe the psychosis-risk state; ii) investigate clinicians, youth, and relatives' knowledge of already established at-risk terms (i.e., UHR, ARMS, APS); iii) explore participants' preferences about both established and newly generated terms regarding their informative and stigmatizing nature, and; iv) understand participants' opinions about early diagnosis, with regard to the best timing to introduce the at-risk concept, as well as the extent and context of the information presented.

2. Methods

2.1. Study design

A focus group was conducted involving young people with a previous experience of mental ill-health to discuss the concept of "psychosis risk" and to propose new diagnostic terms. Subsequently, a questionnaire was administered in digital or paper format to three groups of participants: help-seeking youth at risk for psychosis, their relatives, and clinicians. All procedures comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by the University of Padua (protocol n° 4393) and "Milano Area 3" (register n° 274–20042022). Prior to engaging the study, all participants and their parents (when the participant was a minor) provided written consent.

2.2. Generation of new labeling terms

The dual-moderator (moderators: TB, EC) focus group was held on March 8, 2022 at an early intervention service in Milan—i.e., outpatient center of the Department of Mental Health and Pathological Addictions of the ASST Grande Ospedale Metropolitano Niguarda. Ten adolescents with a previous experience of mental ill-health (i.e., 6 remitted from psychosis-risk status, 4 recovered from brief psychotic disorder), after providing informed consent, took part in a discussion focused on the concept of "psychosis risk" and were asked to propose alternative terms that they considered informative and non-stigmatizing. The group generated and found an agreement on three terms: *tendenza alla psicosi* (psychosis proneness; PP) *alterazione della realtà personale* (change of personal reality; CPR), and *accenni di disregolazione della soggettività* (hints of subjectivity dysregulation; HSD).

2.3. Sample

In a two-center study, 47 help-seeking youth at risk for psychosis, 60 relatives, and 61 clinicians from Niguarda Hospital (Milan) and the Child and Adolescent Neuropsychiatry Unit, Children Hospital Bambino Gesù (Rome) responded to a questionnaire, after consent.

Inclusion criteria for youth involved an at-risk mental state for psychosis, assessed by one validated measures—Structured Interview for Psychosis-Risk Syndromes (SIPS; (McGlashan et al., 2001; Miller et al., 2002)), Comprehensive Assessment of At-Risk Mental States (CAARMS; (Yung et al., 2005)), Checklist ERIraos (Maurer et al., 2018)—excluding those with a present or past history of treated or untreated psychotic episode, any organic brain disease, any physical illness with a psychotropic effect, a history of delayed developmental or intellectual disability, and current attenuated symptoms secondary to acute intoxication.

"Relatives" referred to young people's mothers, fathers, guardians, or other relatives providing care to the young person. "Clinicians" were practitioners working in mental health services.

2.4. Questionnaire and data

A 17-item questionnaire was translated and adapted from Polari et al. (Polari et al., 2021) to assess literacy (i.e., exposure to and understanding of each labeling term), attitudes (i.e., to what extent each term was considered frightening or shameful, stigmatizing, unnecessary, and useless), preferences (the most preferred term, the least stigmatizing

and the best in explaining youth's difficulties), and opinions on the best timing to introduce the at-risk concept, extent, and context of the information disclosure. Further information is reported in S1.

2.5. Statistical analyses

Differences between the groups in literacy were tested employing a logistic regression model approach, since variables were dichotomous. In all models, we included each dependent variable (level of exposure, level of understanding), indicating group (clinicians, young people, relatives) and terms (APS, ARMS, UHR in the model on "exposure" to terms; APS, ARMS, UHR, CPR, HSD, PP in the model on "understanding" terms) and their interaction as fixed effects measures (in Wilkinson notation: Dependent Variable ~ Group * Terms). For the participants' ratings of the four statements in the questionnaires about attitudes, we ran a linear model (LM) that included the reported scores as the dependent variable and the type of attitude investigated (frightening or shameful, stigmatizing, unnecessary, useless) as fixed effects. Finally, to assess whether there were any differences in each group evaluated each term, we implemented separate models including terms and type of attitude and the interaction between them as fixed effects. All analyses were conducted with the software R (2.13) using the lmer function from the lme4 package (Bates et al., 2015). Significance levels for fixed effects were computed using the "anova" function in the lmerTest package, which uses Satterthwaite's approximation for degrees of freedom. In addition, significant effects have been explored using post-hoc pairwise contrasts, corrected for multiple comparisons using false discovery rate (FDR (Benjamini and Hochberg, 1995)). Finally, the χ^2 test was used to compare opinions on the at-risk concept disclosure between groups. In case of cells with a number of cases lower than five, we performed simulated Fisher test via permutation.

3. Results

3.1. Participants

Young people had a mean age of 22 years (SD=2.88), and most of them (80.1 %) were recruited in Milan. Among relatives, 33 (55 %) were mothers, 17 (28.3 %) were fathers, and 2 (3.3 %) were guardians, while this information for 8 relatives (13.3 %) was missing. Distribution of professional roles is reported in S2. The response rates were 65 % for young people, 43 % for relatives, and 89 % for clinicians.

3.2. Literacy on labeling terms

3.2.1. Exposure to terms
We found a main effect of the group ($F(495) = 60.38$, $p < 0.001$), indicating that clinicians were significantly more exposed (M= 0.93) to terms than both youth (M= 0.42) and relatives (M= 0.38). We also found a significant main effect of terms ($F(2, 495 = 24.68$, $p < 0.001$), showing that UHR was the term to which all groups were most exposed (M= 0.72), followed by ARMS (M= 0.66), while APS was the least exposed to (M= 0.40). Moreover, we found a significant interaction between group and terms ($F(4, 495 = 4.10$, $p = 0.002$). Planned comparisons revealed that clinicians were always more exposed to all terms than both relatives and youth (see Fig. 1), while the latter two groups never differed from each other in any term.

3.2.2. Understanding of terms
Concerning perceived understanding of the terms, we found a main effect of group ($F(2, 990) = 37.14$ p < 0.001), indicating that clinicians were significantly more able to understand (M= 0.86) each terms than youth (M= 0.53) and relatives (M= 0.63). We also found a significant main effect of terms ($F(5, 990) = 8.47$, $p < 0.001$), showing that UHR is the most understood term among all (M= 0.80), followed by ARMS (M= 0.78). Among the newly generated terms, the most understood term was
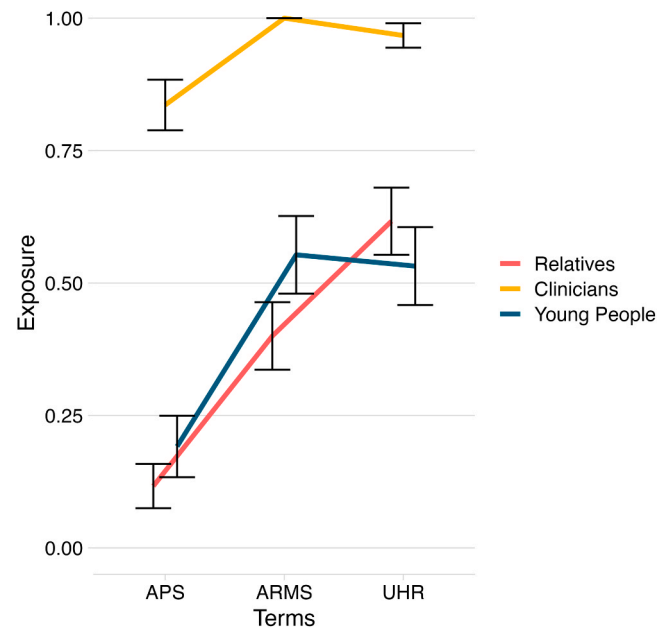

Fig. 1. The plot shows the marginal means of "exposure" to each term within individual groups. The bars also represent the standard error of the mean. Legend: APS, attenuated psychosis syndrome; ARMS, at risk mental state; UHR, ultra high risk for psychosis.

PP (M= 0.76), while HSD (M= 0.43) was overall the least understood. In addition, we found a significant interaction between group and terms (F (10, 990 = 3.55, $p < 0.001$). Planned comparisons revealed that clinicians understood all terms better, apart from PP, as their performance did not differ from that of relatives and youth. Relatives and youth differed in understanding only for the terms APS ($F(1, 990 = 6.11$, p 0.03) (M_{diff}= 0.21) and UHR ($F(1, 990 = 4.37$, p 0.05) (M_{diff}= 0.17) (see Fig. 2 and the Table S1 for all planned comparisons).

3.3. Attitudes towards terms

The questionnaire asked participants to express their attitudes by rating to what extent they considered each term frightening or shameful, stigmatizing, unnecessary, and useless. Concerning the full model (i.e.,
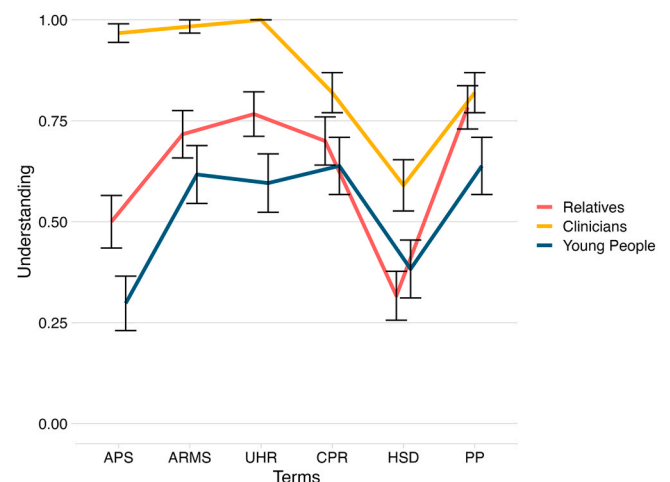

Fig. 2. The plot depicts the marginal means of understanding levels of each term within the three groups. The bars also represent the standard error of the mean. Legend: APS, attenuated psychosis syndrome; ARMS, at risk mental state; CPR, change of personal reality; HSD, hints of subjectivity dysregulation; PP, psychosis proneness; UHR, ultra high risk for psychosis.

the one that includes the type of attitude and terms), we found a significant effect of both attitude type (F(3, 2460 = 24.86, $p < 0.001$), and terms (F(5, 2460 = 12.84, $p < 0.001$), and a significant interaction between these factors (F(15, 2460 = 2.72, $p < 0.01$). Planned comparisons revealed that participants gave different scores to each attitude statements (see Fig. 3 for visual inspection; for all planned comparisons, see Table S2). Among the already established terms, participants found ARMS significantly less "frightening or shameful" than both APS (F(1, 2460 = 9.01, $p < 0.01$) ($M_{diff} = -0.41$) and UHR (F(1, 2460 = 9.01, $p < 0.01$) ($M_{diff} = -0.41$). Similarly, they found ARMS significantly less "stigmatizing" than APS (F(1, 2460 = 7.31, p 0.02) ($M_{diff} = -0.37$) and UHR (F(1, 2460 = 7.31, p 0.02) ($M_{diff} = -0.38$).

By examining each attitude separately, we found a significant main effect for the group in the statements that assessed stigmatizing (F(2, 603 = 5.79, $p = 0.03$), unnecessary (F(2, 603 = 7.57, $p < 0.01$, and useless (F(2, 603 = 9.01, $p < 0.01$) attitudes for each term, with relatives generally reporting the higher scores. In contrast, the groups did not differ concerning the scores attributed to frightening or shameful attitudes (see Table S3).

3.4. Preferences on terms

Fig. 4 shows that ARMS was the preferred and least stigmatizing term in clinicians and youth, while CPR was the preferred term in relatives. ARMS was also the most informative and one of the most informative terms in clinicians and youth, respectively. CPR was the term explaining the difficulties of the young person best according to youth and relatives, and one of the least stigmatizing terms in all groups. According to youth and relatives, UHR was the least preferred term, the most stigmatizing term, and the term explaining the young person's difficulties the least. Notably, UHR was considered the most stigmatizing term in all groups (Table S4).

3.5. Opinions on timing, extent, and context of the disclosure of the at-risk concept

The first preference in all groups was that disclosure about the psychosis-risk concept should be provided when the young person has established a relationship of trust with the treating clinician (see Table 1). Notably, that option was reported in only 43 % and 41 % of youth and relatives, respectively, and it was slightly preferred to "as

early as possible" in such groups (36 % of youth and 40 % of relatives). Concerning the extent of the information, all groups agreed on full disclosure (i.e., the term and explanations about the term, and the at-risk concept in general).

Concerning the context of the disclosure, most clinicians thought that the psychiatrist should be present. 56 % and 43 % of clinicians believed that the psychologist/case manager and family members should be present, respectively. Young people reported a slight preference for the presence of the psychiatrist over the presence of the psychologist, while half of the relatives reported a preference for the presence of the family members over the presence of the psychiatrist (which, in turn, was slightly preferred over the presence of the psychologist). Notably, only a few young people (4/46) thought that the family members should be present at the moment of the diagnosis.

4. Discussion

In this study, we generated new terms for labeling the at-risk concept and investigated young people's, relatives', and clinicians' literacy, attitudes, and preferences about already established and newly generated labels.

Regarding mental health literacy on the "psychosis risk" concept, young people and relatives were exposed, and understood at-risk labels significantly less than clinicians. This emphasizes the need for improving mental health literacy in Italy (Altuncu et al., 2023; Fusar-Poli et al., 2020), especially among youth and families already enrolled in early intervention clinics, many of whom have not been effectively informed why they are in treatment. Awareness programs have been implemented by half of Italian early psychosis services, offering initiatives targeting the general public, such as school programs (Cocchi et al., 2018). Future public programs could benefit from involving individuals with lived experience of mental ill-health (World Health Organization, 2022) and several stakeholders, like associations, family doctors, and ethnic organizations (Parabiaghi et al., 2019).

The term UHR was associated with the highest stigma, corroborating findings from previous investigations (Kim et al., 2017; Polari et al., 2021). In contrast, the word "psychosis" is not included in the term ARMS, which suggests a broad condition of risk that should be monitored (Lee et al., 2013; Sartorius et al., 2014; Sato, 2006), in line with recent transdiagnostic approaches (Tandon, 2024). In our study, ARMS was considered the preferred already established term by youth and
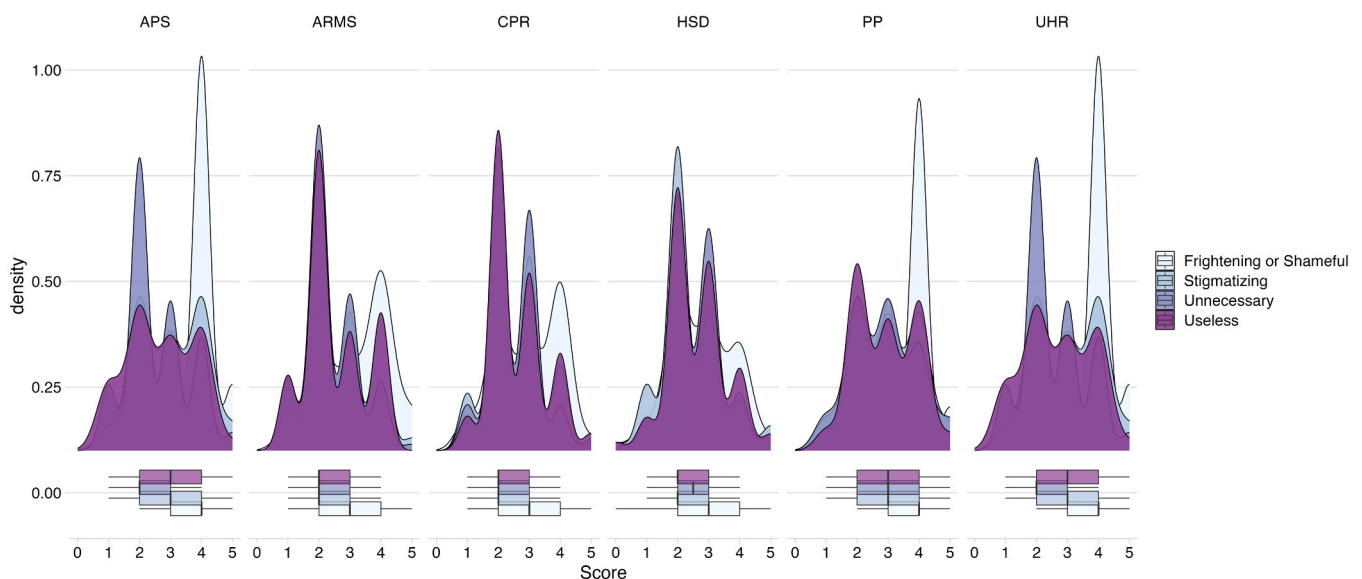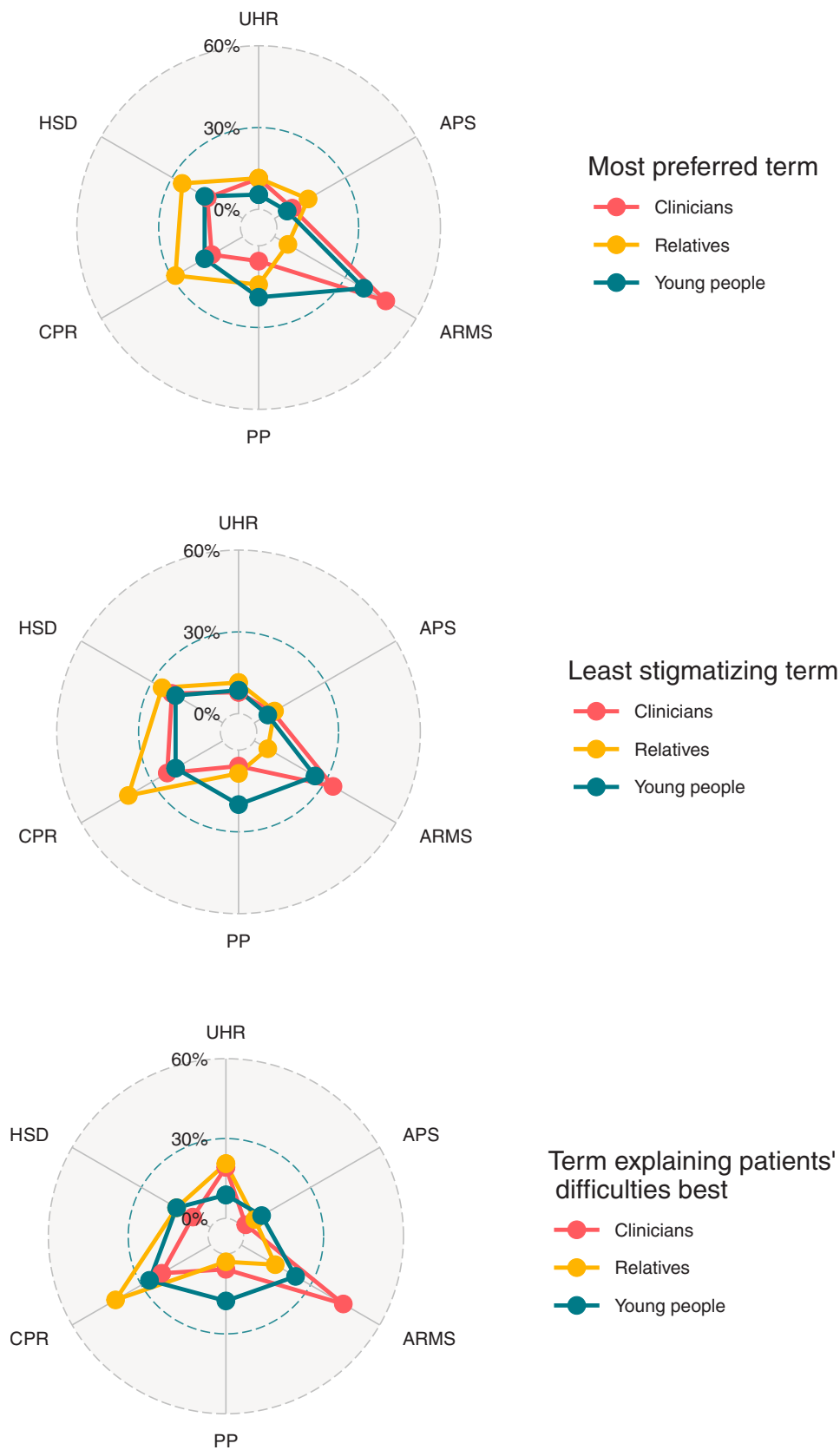

Fig. 3. : This figure represents density plots for each attitude. Boxplots illustrates the mean of each attitude. Legend: APS, attenuated psychosis syndrome; ARMS, at risk mental state; CPR, change of personal reality; HSD, hints of subjectivity dysregulation; PP, psychosis proneness; UHR, ultra high risk for psychosis.

Fig. 4. This graph represent radar plots for each preferences, expressed in percentage. Legend: APS, attenuated psychosis syndrome; ARMS, at risk mental state; CPR, change of personal reality; HSD, hints of subjectivity dysregulation; PP, psychosis proneness; UHR, ultra high risk for psychosis.

Table 1
Best timing, extent and context of information about the at-risk for psychosis state disclosure.

	Overall, N = 168[1]	Group			p-value[2]
		Clinicians (n=61)	Young people (n=47)	Relatives (n=60)	
When					0.007
As early as possible	52 (33 %)	14 (24 %)	15 (36 %)	23 (40 %)	
The young person feels better	14 (8.8 %)	1 (1.7 %)	5 (12 %)	8 (14 %)	
The young person has established a relationship of trust with the treating clinician	83 (52 %)	41 (69 %)	18 (43 %)	24 (41 %)	
Only before the discharge from service	4 (2.5 %)	2 (3.4 %)	2 (4.8 %)	0 (0 %)	
Never, I don't think any of the suggested terms are useful or appropriate	4 (2.5 %)	1 (1.7 %)	2 (4.8 %)	1 (1.7 %)	
Other	2 (1.3 %)	0 (0 %)	0 (0 %)	2 (3.4 %)	
Missing observation	9	2	5	2	
How much information					0.14
Full disclosure (term and explanations)	126 (79 %)	47 (81 %)	32 (73 %)	47 (81 %)	
Only the term at the beginning of the treatment, its explanation afterward	5 (3.1 %)	1 (1.7 %)	2 (4.5 %)	2 (3.4 %)	
Only the term	5 (3.1 %)	0 (0 %)	2 (4.5 %)	3 (5.2 %)	
Only the explanation	18 (11 %)	9 (16 %)	5 (11 %)	4 (6.9 %)	
Neither the term nor the explanation	3 (1.9 %)	0 (0 %)	3 (6.8 %)	0 (0 %)	
Other	2 (1.3 %)	1 (1.7 %)	0 (0 %)	2 (3.4 %)	
Missing observation	8	3	3	2	
Comunication context*					
With the psychologist/case manager	82 (49 %)	34 (56 %)	23 (49 %)	25 (42 %)	0.30
With the psychiatrist	93 (55 %)	40 (66 %)	24 (51 %)	29 (48 %)	0.13
In the presence of the relatives	60 (36 %)	26 (43 %)	4 (8.5 %)	30 (50 %)	<0.001
Other	6 (3.6 %)	3 (4.9 %)	1 (2.1 %)	2 (3.3 %)	0.88

[1] Median (IQR) or Frequency (%)
[2] Fisher's exact test

* Answers to this question are not mutually exclusive

clinicians (but not by relatives) and less frightening or shameful and stigmatizing than APS and UHR by all participants. Interestingly, converging evidence on the best acceptability of ARMS came from replications of our study in the Australian (Polari et al., 2021) and in the Japanese (Takahashi et al., 2024) cultural contexts. Among newly generated terms, all groups considered CPR as non-stigmatizing and informative.

Beyond preventive psychiatry, new terms have been generated for renaming the label "schizophrenia;" however, despite several stakeholders considering it as a stigmatizing term, there is no agreement on a universally informative, acceptable alternative label (Mesholam-Gately et al., 2021) to refer to this heterogenous mental health condition (Tandon et al., 2023).

Notably, differences in term preferences across groups suggest that while selecting appropriate terminology is important, it is not sufficient (Uttinger et al., 2018). However, there is no international consensus in clinical guidelines regarding the appropriate timing and manner for disclosing the term (Poletti et al., 2024). Our participants agreed that the diagnosis must not be limited to the disclosure of the term and should be complemented by its explanation and general information about the concept of risk, supporting strategies to inform youth and families about what is happening to them (Woods et al., 2021).

Unlike the study of Polari, who found a preference for immediate disclosure, Italian participants in our study prefer waiting until a trustful clinician-patient relationship is established. This contrast may be due to the differences between Australian and Italian mental health systems. In Australia, the enhanced primary care program *Headspace* offers early access to mental health care (McGorry et al., 2022; Rickwood et al., 2019). In Italy, where a minority of early intervention services rely on primary care (Fusar-Poli et al., 2021), our findings suggest the importance of trust-building before presenting the concept of being "at-risk."

Finally, while around half of the relatives indicated that family members should be present at the time of disclosure, their presence is not necessary according to most youth. We hypothesize that this may reflect a need of youth for privacy and agency during the delivery of the term while suggesting that most relatives wish to be informed about the clinical condition of the young person for whom they care. Our results suggest adopting a collaborative shared decision-making approach with the young person (Simmons et al., 2021), weighing risks and benefits of

involving relatives at the time of disclosure.

This study has several limitations. First, we adopted a cross-sectional study design. Second, as this research used quantitative methods, we did not perform qualitative investigations to explore opinions of the participants. Third, as this was a two-center study, it was conducted only in clinics located in Rome and Milan. Nevertheless, these centers serve as critical hubs for psychosis prevention across two distinct regions of Italy.

This study supports ARMS as a clinically useful term with young people and suggests to decrease use of UHR to prevent stigma. In Italian early intervention services, the disclosure of the at-risk term should be complemented by full explanation about its meaning in the context of a trustful clinical relationship.

Role of funding source

CRediT authorship contribution statement

Tommaso Boldrini: Methodology, Funding acquisition, Project administration, Investigation, Writing – original draft, Writing – review & editing, Supervision. **Gabriele Lo Buglio:** Methodology, Data curation, Writing – original draft, Writing – review & editing. **Arianna Schiano Lomoriello:** Formal analysis, Visualization, Writing – review & editing. **Alice Barsanti:** Validation, Writing – review & editing. **Elena Cordova:** Data curation, Investigation, Writing – review & editing. **Francesca De Salve:** Investigation, Writing – review & editing. **Alessandro Gennaro:** Validation, Writing – review & editing. **Paolo Girardi:** Formal analysis, Visualization, Writing – review & editing. **Renan Göksal:** Validation, Visualization, Writing – review & editing. **Naoyuki Katagiri:** Validation, Writing – review & editing. **Sung-Wan Kim:** Validation, Writing – review & editing. **Suzie Lavoie:** Validation, Writing – review & editing. **Vittorio Lingiardi:** Project administration, Validation, Writing – review & editing. **Lara Malvini:** Investigation,

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Declaration of Competing Interest

I have nothing to declare.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ajp.2024.104254.

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