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# Reasons for disengagement in first-episode psychosis – perspectives from service users and their caregivers

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## Abstract

**Background** The efforts of early psychosis intervention programmes can be impeded by difficulties in maintaining the engagement of service users. As disengagement is often an autonomous decision made by service users, the main aim of this study was to gain insight into the reasons for service user disengagement through qualitative interviews with the service users themselves, and caregivers as proxies or secondary informants.

**Methods** Participants recruited for the study were enrolled in the Early Psychosis Intervention Programme in Singapore for at least a year, aged 21 and above, able to communicate in English, and had disengaged for at least three months. The recruitment and interview processes were conducted independently for service user and caregiver participants. Potential participants were invited to a face-to-face semi-structured interview over video call or in-person. Each interview spanned one to two hours, and comprised five phases – icebreaker, exploration of the participant's experience with EPIP before deciding to disengage, discussion of reasons for disengagement, exploration of the post-disengagement experience, and feedback and suggestions for EPIP. Recruitment aimed to conclude after 10–15 participants were interviewed for both service user and caregiver groups, with the expectation that data sufficiency would be reached with no new themes being generated.

**Results** Ultimately, 12 service user and 12 caregiver participants were recruited. There were six pairs of service user and caregiver dyads, where the caregivers interviewed were caring for service users also enrolled in the study. Valuable qualitative insights were gathered, including the type of disengagement, medication compliance during disengagement, the decision-making process behind disengaging, and circumstances surrounding re-engagement. A total of five categories each with subthemes were identified from the reasons for service user disengagement – individual factors, stigma, progression, treatment factors, and external factors.

**Conclusions** There is a need to narrow down urgent areas of attention, aligning the study themes with established risk factors so that feasible solutions can be developed and appropriate care models can be adopted, to minimise adverse outcomes related to disengagement. It is important to keep an open mind to understand what personal recovery means to the individual service user, so that treatment goals can be better harmonised.

**Keywords** Disengagement, Psychosis, Early intervention, Service users, Caregivers, Qualitative

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## Background

While early psychosis intervention programmes aim to reduce the duration of untreated psychosis (DUP) and improve prognosis, such efforts can be impeded by difficulties in maintaining the engagement of service users. The issue of disengagement poses a significant obstacle, often occurring when therapeutic need persists, resulting in adverse outcomes and increased mortality rates [1, 2]. Doyle et al. [3] conducted a seminal systematic review, revealing that approximately 30% of individuals with first-episode psychosis disengage from services; with variables such as DUP, baseline symptom severity, insight, substance abuse and dependence, and the involvement of a family member as consistent predictors of disengagement. A more recent review and meta-analysis by Robson and Greenwood [4] updated the disengagement rate across early intervention services to 15.6%. Reasons for disengagement included disinterest in engagement or a perception that engagement is unnecessary. The review also highlighted conflicts in the literature due to the absence of a common and standardised definition of disengagement, with variations in proxy criteria such as lack of attendance or active participation, and duration (ranging from two weeks to three months). Consequently, reporting rates of disengagement vary substantially across studies [1–6]. Locally, a study conducted in 2013 reported a disengagement rate of 14% [7]. This lower number was explained by the service's exclusion criteria of having a forensic or substance abuse history, which historically have been associated with greater risk of disengagement [7]. Despite these challenges, an encouraging observation emerged from a study of young people in an Australian early intervention service. Although over half of the cohort had disengaged at least once, the majority subsequently re-engaged [8]. This underscores the complexity of disengagement as a phenomenon and emphasises that it is woefully understudied, despite its clinical significance.

In an effort to gain a deeper understanding of this concept, Reynolds and colleagues highlighted the necessity for further qualitative studies directly involving service users to explore their experiences and reasons for disengagement [1, 2]. There has been a limited number of such qualitative studies to date. Tindall et al. [9] conducted a longitudinal study in a sample of young people with first-episode psychosis, utilising multiple interviews at three timepoints to comprehensively examine the engagement or disengagement process within the first year of treatment. The study triangulated perspectives from the service user, their caregiver, and their key clinician, and the findings revealed three key processes contributing to disengagement: service mismatch, lack of shared purpose, and responses to individual processes [9]. Another qualitative study by Smith et al. [10] involved recruiting

service users with severe mental illness who had disengaged from care, along with service providers; and explicitly outlined reasons for disengagement, such as services not meeting needs from the perspective of the service user and the lack of awareness of the illness from the perspective of the service provider. The study underlined the fundamental conflict in reasons cited by service users and providers.

While illness-related factors, including a lack of insight and delusional beliefs, contribute to disengagement, an effective early intervention service should proactively review its care model and adapt to, rather than oppose these factors. Seeking innovative ways to enhance service user engagement could ultimately improve long-term clinical outcomes. Indeed, a literature review by O'Brien et al. [5] suggested that therapeutic alliance, satisfaction with services, and service model are potential predictors of engagement.

Recognising that disengagement is often a personal and autonomous decision made by service users, the authors believe that understanding the reasons behind it is better achieved through the perspectives of the service users themselves. Anticipating potential challenges in accessing disengaged service users willing to share their experiences, caregivers were considered as proxies or secondary informants. In Asian cultures, where values such as respect for elders, close family relationships, collective goals, and family harmony are emphasised, caregiver perspectives hold significant importance, especially in cases where the service user may be unwilling to participate. The study aimed to gain insight into the reasons for service user disengagement, and to highlight gaps experienced by service users in the Early Psychosis Intervention Programme (EPIP), through qualitative investigation. The study results, derived from first-hand experiences of service users and caregivers, will contribute to existing literature and shed light on the decision-making process and outcomes associated with disengagement from the service.

## Methods

### Setting

Singapore is an island city-state located in Southeast Asia with a multiracial and multicultural population of 5.7 million residents, made up of Chinese (74.3%), Malays (13.5%), Indians (9.0%), and other ethnicities (3.2%) [11]. EPIP is a nationwide intensive multidisciplinary first-episode psychosis intervention programme, based in the Institute of Mental Health, the only tertiary psychiatric hospital in Singapore. Service users can be referred into the programme via specialist care (e.g. medical hospitals or private psychiatrists), primary care (e.g. general practitioners or polyclinics), the police, employers or schools, or self (patient or family), and can present as outpatient

appointments or inpatient admissions [12]. Service users accepted into the programme fulfil the following criteria: (a) age between 12 and 40 years inclusive, and (b) first-episode psychosis that is not secondary to a general medical condition or substance use. A phase-specific recovery model, with a strength-based case management approach, is typically provided to all enrolled service users for a minimum duration of three years. As part of the ongoing evaluation of EPIP, service user clinico-demographic data are systematically collected at predetermined intervals and entered into a standing database registered with the Singapore National Healthcare Group (NHG) Domain Specific Review Board (DSRB; Reg. No.: IMH-2004-0001). Variables collected included the Positive and Negative Syndrome Scale [13] and the Global Assessment of Functioning scale [14]. This study had received ethics approval from the NHG DSRB (Ref. No.: 2020/00857).

### Recruitment

Participants recruited for the study were individuals aged 21 and above, enrolled in the EPIP programme for at least a year, and able to communicate in English. Additionally, they had disengaged from EPIP services for at least three months. EPIP case managers (CMs) played a crucial role in the screening and referral process due to their routine interactions with clients and caregivers as part of the service. These CMs referred individuals who intentionally ceased communication or ignored attempts at contact for a minimum of three months, a timeframe deemed adequate to discern intentional disengagement from incidental lapses. Notably, these service users might have been compelled to return for mandatory treatment or autonomously re-established contact with their CMs. Conversely, those who maintained regular appointments but had not actively communicated with their CMs for more than three months were excluded from the study, as their behaviour was not considered as disengagement. Service users and caregivers explicitly instructing the treatment team or any other staff not to contact them were also excluded. Caregivers recruited for the study included informal carers of potential service user participants who had previously disengaged and were able to communicate in English. Given the CMs' dual interaction with service users and their caregivers, potential caregiver participants could be referred by the CMs or the service users they cared for. Purposive sampling was employed to enhance sample diversity in terms of service user age, gender, ethnicity, time with the programme, type of disengagement; and for caregiver participants, the relationship between caregiver and service user.

The recruitment and interview processes were conducted independently for service user and caregiver participants. The service user and caregiver participants may

be informed of each other's participation in the study, depending on the enrolled participant's preferences. Service user-caregiver dyads were not mandatory; service users could participate in the study without an identified or enrolled caregiver, and vice-versa. Clinical team members aided in bridging contact between potential participants and a study team member who was not part of the treatment team. This team member explained the study and conducted the remaining procedures to prevent undue coercion and foster open and transparent discussion about their experiences. Potential participants were invited to a face-to-face semi-structured interview at a location and time convenient for them. Anticipating challenges with recruiting a participant who had autonomously and intentionally disengaged with the clinical team, and the then-prevailing COVID-19 situation, video or voice call options via Zoom were offered as an alternative to in-person interviews and consent-taking procedures. Privacy measures, such as password protection, waiting and locked room functions, and verification of identification documents, were implemented. Written informed consent was obtained from all participants using an electronic version of the informed consent form, either in-person or over a video call to accommodate participants' schedules. Recruitment aimed to conclude after 10–15 participants were interviewed for both service user and caregiver groups, with the expectation that data sufficiency would be reached with no new themes being generated.

### Procedure

Recognising the sensitive and personal nature of each participant's experience with EPIP and the comprehensive data the study aimed to gather, we opted for a semi-structured, in-depth interview format. To guide the conversation and delve into specific areas of interest, an interview guide was developed for use with both service user and caregiver participants. This guide included key questions directing the inquiry and topic probes to extract additional information. Each interview, spanning one to two hours, comprised five phases: (a) Ice-breaker, focused on rapport-building through questions like, "How have you been doing recently?" to set the stage for the main interview; (b) Exploration of the participant's experience with EPIP before deciding to disengage, involving inquiries such as, "What was the experience with EPIP services like?" and "What do you remember about your time in EPIP?"; (c) Discussion of reasons for disengagement, with participants encouraged to list and elaborate on their decision, and caregivers providing insights into the service user's perspective; (d) Exploration of the post-disengagement experience, including whether participants pursued alternative intervention options; (e) Feedback and suggestions for EPIP, probing

participants on their expectations and hypothetical conditions for continued engagement.

Throughout the interview, emphasis was placed on maintaining a safe environment. Open-ended questions and non-judgmental language were employed to encourage participants to express their beliefs, opinions, and experiences freely and honestly. Confidentiality was consistently assured to prevent any feelings of interrogation or accusation regarding non-compliance with the prescribed plan. All interviews were audio-recorded, transcribed verbatim, and coded and analysed using NVivo. This approach ensured a systematic and rigorous examination of the collected data. Quantitative data from EPIP's standing database was also extracted to describe the sociodemographic and clinical characteristics of recruited participants. However, as the database does not contain caregiver data, a separate sociodemographic data collection form was used for caregiver participants.

### Reflexivity

The study team comprised three senior clinical staff members (SV, CT, and KP), each contributing a supervisory role in analysis and discussion. Research staff trained in qualitative methodology conducted the interviewing (YC) and coding (YC and KR). Although the interviewer (YC) was not part of the clinical team and has never been part of the treatment process, collegial relationships with the treatment team could still have resulted in a personal conflict of loyalty. To avoid potential bias on the part of the interviewer, the first four interviews were witnessed by one other study member (with the consent of the participant), and actively reviewed after each session. All interview transcripts were also reviewed by at least one other member not part of the EPIP team (e.g. KR), and regular meet ups between study team members were held to confer and discuss on the progress of the project. Additionally, the interviewer's employment within the organisation could potentially be viewed by participants as a threat to confidentiality; in order to circumvent this, participants were repeatedly reminded that their participation was voluntary and could be withdrawn at any time, that the interviewer would uphold their privacy and not discuss their responses with their treatment team, and that their responses would not compromise the quality of the care they were entitled to receive from EPIP.

### Analysis

The principles of thematic analysis methodology [15] were applied to guide data analysis in the present study. The study team initiated discussions using the first transcripts from service user and caregiver interviews to identify preliminary themes. YC and KR utilised these themes to develop two separate but overlapping codebooks encompassing all relevant themes and their

definitions for subsequent analyses. The two codebooks were analysed and reviewed iteratively through multiple discussions between the study team, and new themes were inductively generated as the interviews proceeded. Insights from initial interviews guided and refined the interview guide for subsequent sessions, to yield richer and more in-depth discussions with the participants. For instance, the addition of a specific inquiry about disengagement details stemmed from a service user's denial of intentionally disengaging with the CM, prompting the team to recognise differing perceptions between service users and providers regarding the act of disengagement. Based on clinical experience, the supervisors also deductively generated additional themes to ensure comprehensive coverage of all inquiry areas and maintain methodological robustness. For one, location accessibility was a common concern already known to the clinical team, as brought up by service users during regular treatment sessions, and this was confirmed as a theme during interviews (see theme: resource conservation, under category: individual factors). A satisfactory inter-rater agreement kappa coefficient (Cohen's kappa=0.70) was established between coders on one test transcript, and the coders reconvened after independent coding to review each other's coded transcripts and address potential disagreements, to ensure that there was agreement or at least resolution between the final codes. This approach ensured reliability and consistency in the coding process.

## Results

### Quantitative sample characteristics

Forty potential service user participants and 24 potential caregiver participants were initially identified through referrals from CMs. Ten potential service user participants were deemed ineligible, including three who reportedly exhibited hostility towards past contact attempts. Additionally, three were unresponsive, and eight rejected participation. In parallel, one potential caregiver participant was ineligible, one was unresponsive, and seven rejected participation, with two citing fear of the service user's reaction if they discovered their involvement. Ultimately, 12 service user and 12 caregiver participants were recruited. Among the caregiver participants, ten were parents, one was a spouse, and one was a sibling. There were six pairs of service user and caregiver dyads, where the caregivers interviewed were caring for service users also enrolled in the study. Data sufficiency was reached around the tenth interview for both service user and caregiver group participants, where no new themes were identified from new interviews. The quantitative sociodemographic and baseline characteristics of all participants are detailed in Table 1. Among the service user participants, the inability to sustain engagement presented diagnostic challenges; one participant was

**Table 1** Sociodemographic and clinical characteristics of participants

	Service users (n = 12)	Care-givers (n = 12)
Age – years, mean (SD)	29.4 (6.5)	54.8 (10.0)
Gender – no. (%)		
- Male	8 (66.7)	6 (50.0)
- Female	4 (33.3)	6 (50.0)
Ethnicity – no. (%)		
- Chinese	6 (50.0)	9 (75.0)
- Malay	2 (16.7)	1 (8.3)
- Indian	2 (16.7)	1 (8.3)
- Others	2 (16.7)	1 (8.3)
Religion – no. (%)		
- Christianity	3 (25.0)	4 (33.3)
- Buddhism/Taoism	2 (16.7)	3 (25.0)
- Islam	4 (33.3)	2 (16.7)
- Hinduism	1 (8.3)	1 (8.3)
- Free thinker	2 (16.7)	2 (16.7)
Highest education level – no. (%)		
- Primary	1 (8.3)	0 (0.0)
- Secondary	0 (0.0)	3 (25.0)
- Tertiary	11 (91.7)	8 (75.0)
Vocational status – no. (%)		
- Meaningfully occupied	8 (66.7)	11 (91.7)
- Unemployed	4 (33.3)	1 (8.3)
Duration with EPIP – months, mean (SD)	32.0 (6.3)	30.3 (7.9)
DSM-IV diagnosis – no. (%)		
- Schizophrenia	7 (58.3)	-
- Schizophreniform disorder	3 (25.0)	-
- Bipolar disorder with psychotic features	1 (8.3)	-
- Adjustment disorder	1 (8.3)	-
DUP – months, mean (SD)	16.6 (33.7)	-
No. of inpatient admissions in total – no. (%)		
- No admissions	4 (33.3)	-
- One admission	3 (25.0)	-
- Two admissions	3 (25.0)	-
- Three admissions	2 (16.7)	-
PANSS scores at baseline – mean (SD)		
- Total	89.3 (28.0)	-
- Positive	22.4 (7.7)	-
- Negative	19.8 (9.4)	-
- General psychopathology	47.1 (14.3)	-
GAF disability score at baseline – mean (SD)	40.9 (12.9)	-

EPIP: Early Psychosis Intervention Programme; DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, fourth edition; DUP: duration of untreated psychosis; PANSS: Positive and Negative Syndrome Scale; GAF: Global Assessment of Functioning

originally accepted into the programme in lieu of their presenting psychotic symptoms, but their diagnosis was eventually revised to adjustment disorder as treatment progressed.

### Qualitative information surrounding disengagement

Through the interviews, valuable qualitative insights were gathered regarding various aspects of disengagement for the current sample of recruited participants, including type of disengagement (and frequency of contact), medication compliance during disengagement, the decision-making process behind disengaging, and circumstances surrounding re-engagement.

Among service user participants, seven individuals had severed contact with their CM intentionally. Some expressed their disengagement bluntly, with statements like, “*I already block the CM, what else can you do, you email me I also not gonna open.*” [SU12] Two of these service users even changed their phone numbers to avoid any attempts at contact. Conversely, three service user participants denied deliberately avoiding their CM (“*I’m not sure whether I have ignored [CM’s] messages before, but if I do it’s not intentionally*” [SU05]) but acknowledged a decline in the frequency of contact, stating, “*every time he text me or anything I would still reply back... But, I would say the frequency got lesser and lesser*” [SU01]. All but one service user participant reported non-attendance at outpatient appointments or activities. Among caregiver participants, nine reported that their service users actively refused contact with the CM, citing reasons such as being too busy (“*doesn’t want to meet [CM], so he gave a different kind of reason that he’s busy*” [CG12]). Two caregivers mentioned their service users expressing displeasure whenever the CM and caregiver communicated, noting, “*he was very very angry that she calls him, whenever I talk to her, then she will call him then he will get really upset*” [CG02]. All 12 caregiver participants concurred that their service users were not participating in any outpatient appointments or activities.

Regarding medication compliance, all service user participants confirmed complete discontinuation of medications, with two only taking them when deemed necessary (“*I was a bit anxious... I needed to go to work, so I think I better take, so I can sleep*” [SU07]) or when they felt like it (“*I just choose to eat when I feel like taking*” [SU02]). Among caregivers, nine reported that their service users had stopped taking medications altogether; one mentioned a lower dosage adjustment, and three disclosed covertly medicating their service users (“*the medication melts in water, so sometimes I will put in the drink and give it to her*” [CG10]).

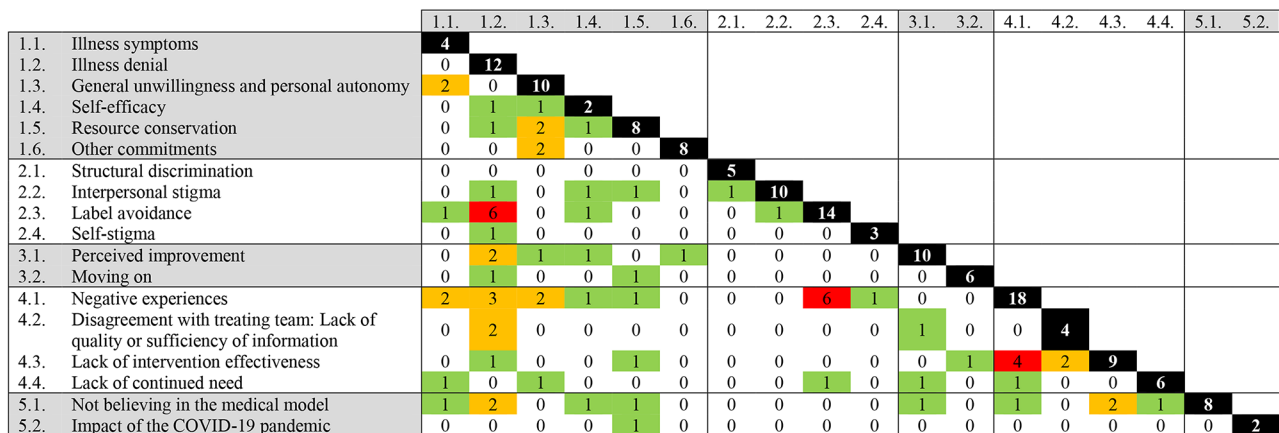
Exploring the decision-making process for disengagement, eight service user participants mentioned involving their families (“*Actually it’s one of my cousins who asked me to, if I’m okay already then just stop taking the medicine*” [SU02]), while four made the decision independently (“*it was purely my own decision*” [SU12]). Timings for disengagement varied, with five participants deciding when they felt better, and two deciding from the



**Table 2** Reasons for service user disengagement, reported by service users and their caregivers

Category	Theme	Exemplar from SU	Exemplar from CG
1	Individual factors		
	Illness symptoms	-	suspicious of the whole centre
	Illness denial	not that I'm crazy	"I am not sick"
	General unwillingness and personal autonomy	better for me to decide	very stubborn
	Self-efficacy	-	"I can cure myself"
	Resource conservation	very far	quite thrifty
2	Stigma		
	Other commitments	too busy	cannot get leave
	Structural discrimination	reflected in record	affect his future
	Interpersonal stigma	friends may shun me	people scared of you
3	Label avoidance	I'm not one of those	"I don't belong here"
	Self-stigma	feel inferior	"I'm not that bad"
	Perceived improvement	I got better	he's more confident
4	Progression		
	Moving on	move on with life	put this behind
	Treatment factors		
	Negative experiences	feel like a dog inside	side effects
5	Disagreement with treating team: Lack of quality or sufficiency of information	not sure if I'm diagnosed properly	-
	Lack of intervention effectiveness	felt no difference	medicine won't work
	Lack of continued need	no point in contact	he only went along
	External factors		
	Not believing in the medical model	religious method	alternative methods
	Impact of the COVID-19 pandemic	we couldn't meet	team cannot visit

SU: service user; CG: caregiver



**Fig. 1** Matrix of coding overlap among elicited themes for reasons for service user disengagement

outset after their initial discharge from the ward. Contrastingly, most caregiver participants (all but one) were not involved in their service user’s decision to disengage, citing the inability to force them to participate (“*he still don’t want to go, I can’t force him*” [CG07]), with five service users deciding to disengage early in their treatment with EPIP.

Following disengagement, four service user participants had to return to treatment, with one facing legal charges (“*they actually sent me to IMH, for the remand*” [SU04]), and three others experiencing worsening symptoms or a relapse (“*there’s just some anxieties, and some minor panic attacks, so I just contacted my CM*” [SU12]). Nine caregiver participants reported their service users

re-engaging with EPIP due to worsening symptoms or a relapse, with resultant inpatient admission in five cases.

**Reasons for service user disengagement – service users’ and caregivers’ perspectives**

A total of five categories each with subthemes were generated from the reasons for service user disengagement obtained from both service user and caregiver interviews. Table 2 presents the themes with the respective exemplars. Despite the numerous themes identified, Fig. 1 illustrates that overlaps in coding the accumulated content were uncommon, regardless of participant type, highlighting that the themes developed are suitably distinct.

Each cell denotes the count of transcripts which had content that were double-coded in both row and column themes. Each count is accompanied by a colour, ranging from green (low counts) to red (high counts). Numbers in the top row correspond to the theme numbers in the first column on the left.

### Individual factors

Within this category, six distinct themes were generated, shedding light on individual traits and illness-related factors specific to the service user.

**Illness symptoms** Caregivers emphasised the relevance of illness symptoms and their severity in influencing service user disengagement. For example, suspicions about the organisation and mistrust in healthcare professionals stemming from the symptoms were cited as contributing factors. In contrast, this theme was not brought up by any service user.

*“He is very suspicious of the whole organisation and event. That’s for sure. And he did mention that don’t ask the CM to call him at all. He will be very angry, he will shout at him, he’ll scold him... straight after he was discharged. Since day one, I think he has suspicious of the whole centre, the whole area. The doctor is not a doctor, the nurse is not a nurse.” [CG11].*

*“She doesn’t want to go to IMH... [EPIP doctor] told us it’s because of the sickness, sometimes she doesn’t want to take medicine... she even issued a letter from her lawyer... this is one of the sickness thing.” [CG13].*

### Illness denial

Service users expressed a belief that their symptoms were not severe, considering them normal or manageable. This theme is distinct from the previous theme where the service user’s refusal to continue with treatment was perceived by caregivers as a direct manifestation of existing symptoms, instead denoting a misalignment between the service user’s perception of their mental health and the expectations of others regarding continued treatment. For example, one service user felt that they were able to sustain employment and thus need not attend appointments; another thought that they were simply “in a bad mood” [SU08] and that their admission was unwarranted.

*“... my relapse I can’t stop talking. Don’t know why. That’s just about it. It’s not really that bad for me to have to take the medicine... I can still go to work... my everyday life is very very normal. What I feel right, my second relapse, is actually because of the*

*medicine... I just don’t think I have mental illness.” [SU02].*

*“Then after that, I tried the medicine, the voice is still there. So I honestly believe that this voice is real, not that I’m crazy, it’s not that my brain wire got something wrong, there’s nothing wrong with my brain you see. It’s just what it is, yeah.” [SU04].*

*“When he tells me about his symptoms, he just treat it like one of those physical symptoms, caused by the weather, caused by the Singapore culture, caused by the Singapore environment. So it’s that to him... So, I don’t know, what kind of a environment or situation it will get for him to actually accept.” [CG02].*

### General unwillingness and personal autonomy

Service users displayed a general unwillingness to adhere to prescribed treatments or engage with healthcare institutions. Exercising personal autonomy, service users expressed preferences such as deciding when to take medication (“better for me to decide when I want to take the medicine” [SU02]) and avoiding hospital interactions (“don’t want to go through anything with the doctors” [SU10]). Caregivers reported that service users were “stubborn” [CG06, CG11] and wilfully refused appointments despite the caregivers’ offers to accompany them.

### Self-efficacy

This was the only other theme that was generated from caregiver and not service user interviews. Caregivers described instances where service users were confident in their ability to self-treat through willpower and self-research, without external intervention.

*“So [service user] did try to participate in some activities. But, after one or two sessions she just keep telling herself, ‘I’m normal,’ and ‘I don’t need medication.’ ‘I can cure myself,’ which is not true... ‘I can cure myself, by willpower I can cure myself.’” [CG06].*

*“And he feel he himself can face it. And [service user] is quite educated, so he get a lot of information online... He got self-confident can recover.” [CG08].*

### Resource conservation

Both service users and caregivers reported considerations of medical expenses, travel costs, and disruptions to daily routines as factors influencing disengagement. The perception of wasting time and the impact on lifestyle habits contributed to the decision to disengage.

*"The payment is because I got money in my bank, that's why I cannot apply for the assistance. So maybe for the very needy... maybe they can use their MediFund or something. Yeah, I cannot, because I got cash in my bank. Yeah. That's the problem." [SU04].*

*"Yeah, go there still waste time. Because I can do many other things, than going to the hospital." [SU10].*

*"He cultivated this habit. Not to travel further than [location]. So all his part-time work, all in [location]... The main reason, he's sleeping... he's not a rude person. So he will tell you, he's not in a tidy manner. Decent manner... So at least he need to wash up, to smell nice, look decent." [CG07].*

### Other commitments

Service users and caregivers mentioned the service user's other commitments, such as work-related responsibilities, as obstacles to continued engagement. Instances of being busy with activities like gym sessions, driving lessons, or overseas postings were cited as reasons for reduced participation. One service user also commented that during their busy periods, they inadvertently replied lesser in frequency and lower in quality.

*"I got busy with going to the gym. Then, my driving lessons also... That period also I didn't really stay in contact. 'Cause I was quite busy." [SU01].*

*"Then the appointment given to me... I was posted [overseas], I need to oversee a new building project... It's very difficult for me to adjust the time... It's just the appointment. It doesn't fit my time." [SU11].*

### Stigma

This category described different types of anticipated or experienced discrimination which prevented service users from continuing with treatment. Perceived or self-inflicted stigma was identified as a key factor leading to disengagement. Notably, instances where the service user had inflicted stigma on other service users were described.

### Structural discrimination

Service users expressed concerns about the long-term impact of the episode on their medical records, worrying about the potential negative influence on employment opportunities and future prospects. The fear of discrimination based on mental health history during job interviews were cited.

*"But when it's reflected in your health record, let's say your next employer, then they have a right to pay you less. Because of your condition. Yeah. I think it's just a tool to save on the salary... when you go for an interview you need to fill in those particulars whether you've been any mental issue and so on? If let's say you have depression or something, even mild issues you have to declare... Then they can skim on promotion they can skim on anything. I felt that's the true agenda." [SU08].*

*"He was also concerned about going in to IMH itself is because, he was worried that he will have a record in his medical history. And, he was also very worried that this will affect his employment, in future. That's something that, he did mention. 'Why you all did this to me? Why y'all bring me in? I'm okay. This is gonna affect me for life.'" [CG11].*

### Interpersonal stigma

Both service users and caregivers highlighted concerns about prejudice and rejection during social interactions. The impact of mental health stigma on social life and relationships was a common concern, and instances of experiencing changes in demeanour from others, hiding identities, and being apprehensive about public awareness were described.

*"In the past, I also had a bit of anxiety... So I took Fluoxetine... So I mentioned this to my dentist, and then he had a very change in demeanour, so I guess people do have a very adverse reaction to it." [SU05].*

*"When the first time I came here, I was with my cap and sunglasses. Back then no mask right, I wear a cap and a sunglasses. Then while walking, I even tell my wife, 'Yeah I hope I don't bump into people I know.'" [SU11].*



*“To me, if happen to me, also the same. I also get same feeling. I don’t like to people know I go to IMH. Because public awareness, a lot of people think IMH is for crazy people. It’s like, the remark is no good, the record is no good. ‘People cannot accept us’.. Then, the friend also avoid. When they know you go and you have this problem, they avoid you. Your social life, people scared of you... Some of the friend is scared, then they block the WhatsApp group to him. They blocked him.” [CG08].*

### **Label avoidance (Anticipated stigma)**

This theme is distinct from interpersonal stigma, in that participants were anticipating but not yet experiencing discrimination from being involved with mental health services. Service users perceived a misfit between themselves and other service users they encountered during treatment, expressing fear or disgust at the latter’s actions. They disengaged to avoid being associated with the perceived negative image of mental health patients. Fear and discomfort with the taboo image associated with mental health services were evident, with some participants even avoiding the mention of “IMH” (referring to the Institute of Mental Health, Singapore) or “EPIP” during the interview.

*“Cause there’s always taboo you see. It’s a taboo kind of image, so you don’t want to be any associated with the thing. So the best is not to go, not to even be seen around the place.” [SU08].*

*“... just going to the facility itself—just going to the grounds of, uh, you know, itself, uh... The healthcare centre itself where he got his injections, just being there, at the—I don’t want to say it out loud—you know which one I’m referring to, uh, where you guys are. Just saying that, he says, ‘Mum I don’t belong here. You know what? Let me go out for a smoke, when it’s ready just text me. And I can just go straight into the room.’” [CG02].*

### **Self-stigma (Internalised stigma)**

Service users internalised negative conceptions and felt inferior due to their diagnosis or need for treatment. Negative self-evaluations, feelings of demoralisation, and a sense of not belonging to the working society were expressed. The impact of internalised stigma on self-esteem and future prospects was evident.

*“It makes me feel down about myself. Like why I also have issue, why do I need to go and visit doctor over there... I feel my future is very demoralising at that time. Like why I cannot go back to the working society as a graduate... I try to generalise my surrounding with myself. But I am also part of something that isn’t alright.” [SU06].*

*“When we enter IMH... I remember that there’s one lady laughing, keep on laughing loudly, and another man trying to, out of a sudden, sit next to me... And when [service user] saw that, he told me that he’s not that bad, like don’t know what he’s doing. So I said, ‘Yeah. I know, you are different, everybody is different.’” [CG12].*

### **Progression**

Service users expressed improvements in their mental health and a desire to move beyond their current episode with EPIP. This involved the decision to discontinue treatment and move forward from the services provided.

### **Perceived improvement**

Service users expressed improvements in their mental health during the interview or discussions with their caregivers. This involved the resolution of symptoms or a general sense of feeling “better now” after undergoing treatment. Two service users highlighted that the reduction in contact with their CM was a natural process as their symptoms lessened over time, signalling a sense of recovery. Improved confidence, academic success, and a perception of stability were cited as reasons for discontinuing treatment.

*“Or even [CM] when she text me I would reply back also. But I would say the frequency got lesser and lesser. But to be honest, it was because I was getting better also... ‘Cause I was back to normal already.” [SU01].*

*“He more confident that time is he taking his final paper... he pass all the first of the semester. Then after that he got the bit more confident, he don’t want to go already. He think he okay already.” [CG08].*

*"Because he changed, he better. Then when he decided, he told me that he don't need to go. He can control himself, he don't need to take any medication, to him, yeah. That's when he said he's already stable, he feels that he's okay, he don't need any more help. So that's when he decided to stop and give all that kind of reason not to go... He really think that he's not sick anymore. From the way he talk, but actually he's not, I think he still need those help." [CG12].*

### **Moving on**

Service users actively sought to move on from their experience with EPIP, indicating a desire to close that chapter of their lives. Unlike the previous theme of perceived improvement, their time with EPIP was often viewed negatively or even as traumatic. Service users expressed eagerness to disengage from EPIP, not wanting to be associated with it any longer, and choosing to move forward without dwelling on the past. This theme reflects a readiness to embrace life beyond the constraints of hospitalisation and treatment.

*"I felt very ready to move on with life and also because I felt like as a 24-year-old, I'm not going to waste time in the hospital right, about my health." [SU07].*

*"No ill feelings, just don't want to relate you in their lives, something like that. Want to put this episode behind his life. Sometimes people like that. He may not realise that he need to open up." [CG07].*

### **Treatment factors**

Within the category of treatment-related factors influencing service user disengagement, four distinct themes were identified, reflecting the direct connection between the treatment experience with EPIP and the decision to disengage.

**Negative experiences.** Negative experience with the service was one of the most frequently reported contributory factors for disengagement. Seven service users and eleven caregivers highlighted specific adverse events that negatively impacted service users, resulting in them opting to avoid future unfavourable experiences and consequently discontinuing treatment with EPIP. Examples included medication side effects, traumatic inpatient admissions, dissatisfaction with the hospital environment, and discomfort with changes in the CM.

*"Honestly, I just don't want to go back in. And given the chance, I will migrate overseas. Don't want to come back already. That's what I'm planning right now. So bad, I don't like it. I feel like a dog inside... I didn't harm anyone, I didn't steal or I didn't take drugs or something. So I didn't commit against the law, that's why I find it inhumane to stay inside... need to pay money and be insulted by them I feel very bad." [SU04].*

*"I wanted to tell you that the very strongest reason for not following up is the side effects. Because it gives him akathisia, you know the thing that makes his restless legs? And he feels that his joints are very itchy he's got to keep moving? And also, he's got this thing he calls it chemical castration? And this was with Invega. So it kind of like scared him off." [CG02].*

*"I know she was quite close with [CM 1]. But then when there's a change, [service user] sometime don't like it... I know she don't like too many changes... She was three four years with [CM 1] so suddenly change... she's not used to that so it will take her a longer time to so-called 'click' with [CM 2]." [CG06].*

### **Disagreement with treating team: Lack of quality or sufficiency of information**

Service user (but not caregiver) participants expressed disagreement with the treating team, particularly in terms of the quality and sufficiency of information provided. Communication about the diagnosis and symptoms was perceived as incongruent with service users' needs. Dissatisfaction with the information regarding medication use and a desire for more clarity on when to discontinue medication were common concerns.

*"Because I know my own body also. Like when I eat the medicine right, sometimes I feel like very, not so good... I trust them, but I need to know when can I eventually really stop... Like I can't keep on going back to, appointment and appointment and appointment, until when?" [SU02].*

*"I don't know what's the threshold for going off the medication completely 'cause, sometimes I feel I don't need it, but I'm still on it, and I feel that the doctors don't... can't provide a good enough reason, in my opinion, to stay on the medication." [SU05].*

### Lack of intervention effectiveness

Most service users and caregivers expressed dissatisfaction with the perceived lack of effectiveness in the prescribed medication in symptom resolution. Two service users also felt that psychosocial interventions were not providing tangible benefits in their attempts to reintegrate into the working environment or society.

*"I was hoping that I can gain in more skills. Like working-related skills... Maybe it will work for some people. But because it's not relevant to the skills that I needed to go into the working environment, so I didn't stay. This is really the main reason." [SU06].*

### Lack of continued need

Some service users, particularly those initially involuntarily admitted, expressed a lack of perceived need for continued engagement with the treatment. Participants felt that the treatment did not add value to their lives, and they engaged in the process primarily to reassure family members. The perception of not benefiting from continued treatment and the notion of fulfilling expectations rather than genuine engagement influenced the decision to disengage.

*"Like, honestly there was nothing. There was nothing that they could add value to me. Or I could add value to them. Other than asking me to do this interview. So there was nothing from them for me. So there's no point in contacting me also." [SU01].*

*"Because in the first place I felt it wasn't necessary, it was just to assure my parents you see. So because [parents] kept asking me, 'Did you take your medicine?' And so on. So it's just to assure them then after that I stopped taking... I think they were quite worried. So it was just a show for [parents]." [SU08].*

*"Since his discharge of course he say that, for example, 'We can go there.' But remember, listen to us must go back take medication, go for review every three months—' He'll tell me 'yes yes yes.' But I think deep in his thoughts he is like, 'I just want to satisfy you all. But I'm not going to go back.'" [CG11].*

### External factors

These included circumstances or belief systems beyond the direct influence of the service. Although they reflect factors external to the service, they were still pertinent in understanding service user disengagement.

### Not believing in the medical model

Two service users, along with their caregivers, chose not to believe in the conventional medical model and pursued the religious/spiritual route instead. They found that to be more helpful through direct and indirect ways, and shared that focusing on studying religious scriptures and socialising with similar like-minded peers prevented a recurrence of their positive symptoms. Medication side effects, coupled with the persistence of symptoms, led one service user and their caregiver to attribute their problems to Islamic mythological creatures like *jinns* and bad spirits. Another service user experienced a reduction in auditory hallucinations while engaging in religious study and decided to explore this avenue further, discontinuing involvement with EPIP. Another service user expressed scepticism about therapy and drugs, advocating for alternative methods, a sentiment echoed by their caregiver.

*"I especially don't believe in this kind of therapy working for people... They need two things okay. They need new environments, and they need new things to do... you got to move to somewhere else, and if your old job still makes you crazy, then you just got to get a new one... They just wanna find a new way to deal with what they already have. Because new is always better... It will always work." [SU09].*

*"Around one week after I go the first appointment, I need to go to [country].... then after I come back, the whisper gone already then I stopped going... I go there for studying religion. Then I make friends, suddenly the voice start disappear." [SU10].*

### Impact of the COVID-19 pandemic

The pandemic played a minor role in service user disengagement by affecting the operations of the service. Difficulty in maintaining contact between the service user and CM was cited as a challenge due to pandemic-related restrictions. Disruptions caused by COVID-19, such as limited physical visits, increased intervals between appointments, and challenges in communication, contributed to the decision to disengage.

*“But because of the COVID situation then [CM] couldn’t come as freely as she want to. So now the doctor appointments, which were usually accompanied with a talk with her, became just medical appointments alone. So that could be maybe months, before she would get back to me. Just to catch up with me. So the interval went from maybe a couple months to several months gap.” [SU05].*

*“Or, if it’s not because of COVID, I think [CM] would’ve come down and visit him... It’s important, and I know y’all would do it... you should add into your report. [CM] cannot visit us.” [CG07].*

## Discussion

In this comprehensive study, profound insights were gathered through in-depth interviews with both service users with psychosis and caregivers, providing detailed descriptions of the factors contributing to service user disengagement. The findings were grouped into five categories: individual factors, stigma, progression, treatment factors, and external factors. Each category was dissected into distinctive thematic concepts, allowing for targeted interventions if needed. Beyond the primary objective of understanding the reasons for disengagement from an early psychosis intervention programme, the study delved into additional aspects such as types of disengagement, treatment adherence, decision-making processes, and circumstances of re-engagement.

Within the individual factors category, six themes highlighted the importance of acknowledging the unique traits and autonomy of service users. Conflicting findings from previous quantitative studies on symptom severity predicting disengagement [3, 16] were addressed by a proposed bimodal relationship – for patients with higher symptom severity, poor insight into their illness or symptom interference could mediate the relationship with nonadherence to treatment; for those with lower symptom severity, the need to continue treatment may not be as keenly felt by the patients and/or caregivers, leading to a poorer compliance to the treatment routine [17]. This was exemplified in the present study, where only caregivers but not service users reported service user disengagement due to illness symptoms and severity; while many service users considered their symptoms mild, normal, or manageable without conventional treatment. Service users expressed a strong desire for greater autonomy in decision-making, emphasising the need for shared decision-making practices which can potentially enhance patient empowerment and promote user involvement, satisfaction and retention [18, 19]. A Norwegian study

revealed that many participants felt excluded from participating in treatment decisions [20], even though they believed they were capable of doing so [21]. Caregivers in the study reported observing high levels of self-efficacy in their service users too, who were confident of their ability to self-manage their diagnosis, with the aid of information they gathered online while researching on their symptoms. As self-efficacy has been associated with health-related quality of life [22] and health literacy [23], this may be considered a desirable outcome; however, it warrants further investigation into whether this sense of confidence is a constructive recovery tool, or simply illness-related denial and lack of insight, which can lead to poor health outcomes. Resource conservation was identified as a theme, with service users wanting to save time and effort by avoiding outpatient appointments. This suggests a need to explore ways to increase service accessibility and better value alignment with patients. Additionally, commitments such as school or work were identified as barriers to treatment adherence, prompting the need for measures to accommodate service users’ real-life responsibilities. While online interventions show promise, further research is necessary to tailor them to service user needs and ensure that similar challenges of sustaining engagement does not carry over onto virtual platforms [24].

Stigma was identified as the second category, encompassing structured discrimination, interpersonal stigma, label avoidance, and self-stigma. Structured discrimination has been discussed in previous studies, where disclosing a mental illness diagnosis was seen as disadvantageous as it may create unfair performance expectations [25], or result in unequal remuneration and reduced chances for advancement [26]. This has important implications, especially since functioning level and employment status is an important measure of social impairment and outcome of treatment [27]. The remaining three stigma themes were congruent with the Mental Illness Stigma Framework (MISF) conceptualised by Fox and colleagues [28] and reflect pervasive and prevalent obstacles service users encounter while navigating society, which affect their engagement rates with intervention services. Stigma-reduction efforts should thus target a range of factors at different levels to be effective – for example, employing anti-discrimination policies in workplaces (structural discrimination), targeting harmful beliefs, attitudes, and actions through community dialogues (interpersonal stigma), providing effective psychoeducation to promote acceptability of mental conditions (label avoidance), and facilitating and strengthening sources of social support (self-stigma) [29, 30]. Further research is to understand the intersection of various stigma forms and their impact on service users; as reflected in Fox and colleagues’ findings, there is

substantial heterogeneity in how people experience and respond to being stigmatised [28, 31].

The third category, progression, introduced themes of perceived improvement and moving on. Two users expressed some surprise or disagreement when their disengagement was brought up, responding that the reduction in contact with the service as they progressed was natural and aligned with their expectations of returning to school or work. This is consistent with Tindall and colleagues' reactive disengagement concept, where positive life changes make continued engagement less prioritised against other commitments [9]. Contrary to the view that disengagement is exclusively negative, perceived improvement suggests it could be a positive outcome, albeit potentially uninformed. Users feel their initial treatment needs are met, and further engagement is redundant. Caution is needed to ensure this well-being improvement is genuine and not a denial of symptoms. Meanwhile, participants who express a desire to "move on" report discontinuing help-seeking after traumatic events related to symptoms or service experiences. Understandably, the onset of psychosis is described to be distressing, potentially leading to secondary symptoms resembling posttraumatic stress disorder [32]. Involuntary hospitalisation and restraint contribute to intense feelings of shame and helplessness, resulting in formidable barriers to continued engagement [33]. Service providers play a crucial role during treatment, helping users navigate hospitalisations, understand and manage their illness with minimal traumatic complications, and prevent hazardous premature disengagement. Care models like shared decision-making and trauma-informed care can support this [34].

Treatment factors constituted the fourth category, revealing negative experiences with medications, treatment teams, hospital environments, and appointment mechanisms. Medication side effects and unpleasant interactions with staff were highlighted. The integration of comprehensive monitoring tools [35] and management strategies [36] into pharmacological strategies during clinical consultations may improve medication adherence [37]. Other negative treatment experiences included unpleasant interactions with the treatment team or hospital staff where users felt disrespected, and frightening memories of being in the hospital. Witnessing floridly disorganised or aggressive behaviours exhibited by other patients was reported as traumatising. The hospital environment was viewed as scary or too clinical, hindering recovery. These highlight the need for urgent and systematic improvements to inpatient mental health settings, as well as regular client satisfaction surveys and interventions to address poor therapeutic alliance before disengagement occurs. Even though the usage of patient reported outcome measures are on the rise, these

methods of measuring patient satisfaction and feedback are conventionally quantitative in nature and prone to clustering or ceiling effects, which could restrict the discriminative ability of results to detect potential sources of service user discontentment [38]. As such, the use of mixed methods approaches may be better suited to elicit meaningful descriptions of service gaps that may be easily overlooked or neglected by service providers [39]. Another theme revealed under treatment factors was a perceived lack of quality or sufficient information provided by the treatment team, which led to dissonance or a perceived breach of trust, culminating into eventual disengagement. Service users complained of not fully understanding their diagnoses and treatment implications. Tiered, curated, and personalised educational materials [40], patient empowerment through shared decision-making approaches [41], and the provision of alternative communication platforms are potential solutions. Some service users also questioned the effectiveness of interventions and felt that their symptoms were not addressed. These participants were motivated to get better but were frustrated by the lack of progress or improvement. Understanding patients' goals, providing tailored psychoeducation and treatment, and managing expectations are critical in addressing this issue. Finally, some users received treatment only when coerced by their family or mandated by the law, ceasing engagement immediately upon discharge. For involuntarily admitted or coerced patients, maintaining a working (and perhaps even transactional) relationship and equipping them or their caregivers with information and tools for symptom and crisis management is crucial. It may be necessary at the initial stages to state explicitly the conditions leading to involuntary treatment so that the patient understands the legalities, and a common goal of preventing a recurrence of involuntary admission can be established. When opportunities arise for reparation of therapeutic alliance, it is important for the treatment team to acknowledge the patient's anger with autonomy violation, so that honest conversations can ensue, and foundations can be built for improved engagement with the aim of building intrinsic motivation for recovery.

In the last category, external factors, two key elements were identified: the adoption of non-medical approaches and the impact of the COVID-19 pandemic. Some users found symptom relief through religious or alternative methods, and some with the support of their caregivers. Previous studies have illustrated that turning to religion or alternative methods have also been shown to be common coping strategies in service users and their families [42, 43], emphasising the need to recognise, respect, and harmonise pre-existing spiritual needs in psychosocial care [44]. The pandemic disrupted clinical operations, limiting face-to-face interactions and reducing

engagement between the EPIP clinical team and users. The resulting panic and paranoia had widespread consequences on mental health and contributed to the development of new psychiatric symptoms or exacerbation of existing ones [45, 46], necessitating the development of future contingency plans to address critical user needs during global crises [47].

Overall, negative experiences emerged as the primary reason for disengagement, among both service users and caregivers. Lack of treatment effectiveness, perceived improvement, and other commitments were reported frequently among service users, while label avoidance, illness denial, and general unwillingness and personal autonomy were endorsed more often by caregivers. Interestingly, comparison between service user and caregiver dyads revealed varying agreement on reported themes. While some pairs aligned on themes like other commitments, interpersonal stigma, label avoidance, and non-medical model, others presented divergent perspectives. Due to the exploratory nature of this study, microscopic themes were developed while the categories were kept broad and open for future interpretation and application. It is not the goal of the present study to recommend addressing all themes concurrently to minimise disengagement; in fact, the aim of discussing and inspecting these findings is to highlight and bring awareness to the complex and multi-faceted nature of the engagement process. More work is required in order to narrow down or efficiently and feasibly elicit urgent areas of attention, such as cross-examining the resulting themes from this study together with risk factors already established in the literature and the economic or individual burden of disengagement.

### Limitations

The cross-sectional nature of data collection, which was captured sometime after disengagement has occurred, makes it prone to recall and hindsight bias. A prospective design capturing real-time events could enhance accuracy [9]. Secondly, the exclusion criteria may have limited perspectives, especially from those with florid symptoms or explicit hostility, potentially missing certain viewpoints. As noted by Doyle [3], true engagers who refused any sort of contact with the service would not be captured and their opinions would remain out of reach. To mitigate this, attempts were made to include those who had disengaged but returned and involve caregivers to present a more comprehensive view. As this was the first study (to the best of the authors' knowledge) to discuss disengagement with service users explicitly, the topics covered were broad. The semi-structured nature of interviews allowed organic content generation, limiting time for prompting and verification of themes outside

of those self-generated by participants. Both groups of participants had vague and loose definitions of disengagement, which while representative of the emic perspective, resulted in the study team having to sometimes infer when and how the intention to disengage arose. Future studies should include focus group discussions to firm up this definition, which is a sentiment echoed in previous studies. These focus group discussions can then also examine and assess the current model of care provided to service users and caregivers, to introduce a more user-centric approach in designing these early interventions. These sessions would also be a suitable platform to discuss the acceptability and validation of the themes elicited from this study, by adding in cognitive interview techniques.

Another limitation was the intentional choice of a single interviewer to ensure standardisation of the content and format of each interview session. However, during the interviews, participants sought reassurance that confidentiality would be ensured and that they were free to share their opinions without repercussions, before delving into sensitive topics. This, together with the honest and negative feedback collected from the participants suggested that undue influence on the participants' responses was successfully minimised. Lastly, while previous literature has explored substance abuse as a significant predictor of disengagement, this was not elicited or explored in the present study due to the stringent anti-drug laws in Singapore [48].

### Conclusions

The extent of themes that emerged from the study underscores the complex nature of the engagement process and provided valuable insights from an understudied and hard-to-reach population. There is a need for further work to narrow down urgent areas of attention, aligning the study themes with established risk factors so that feasible solutions, such as shared decision-making, can be developed and appropriate care models, such as trauma-informed care, can be adopted to minimise adverse outcomes related to disengagement. Notably, some service users disengaged due to positive life changes, challenging the notion that disengagement is exclusively negative. This highlighted the importance of keeping an open mind to better understand what personal recovery means to the individual so that treatment goals can be better harmonised. The study results, derived from first-hand experiences of service users and caregivers, provided a comprehensive and thorough review of the factors leading to disengagement.



## Abbreviations

CG	Caregiver
CM	Case manager
COVID-19	Coronavirus disease 2019
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, fourth edition
DSRB	Domain Specific Review Board
DUP	Duration of untreated psychosis
EPIP	Early Psychosis Intervention Programme
GAF	Global Assessment of Functioning
IMH	Institute of Mental Health
NHG	National Healthcare Group
PANSS	Positive and Negative Syndrome Scale
SU	Service user

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## Author contributions

YC: conceptualisation, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, visualisation, writing – original draft preparation. KR: data curation, formal analysis, supervision, visualisation, writing – review and editing. KP: supervision, validation, writing – review and editing. SV: conceptualisation, methodology, supervision, writing – review and editing. CT: conceptualisation, funding acquisition, methodology, supervision, validation, visualisation, writing – review and editing. All authors read and approved the final manuscript.

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## Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

This study was approved by the National Health Group's (NHG) Domain Specific Review Board (DSRB Ref. No.: 2020–00857). Written informed consent was obtained from all participants prior to enrolment in the study. All procedures were conducted in accordance with the Declaration of Helsinki.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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