

Understanding the Treatment Preferences of People Living with Schizophrenia in Australia; A Patient Value Mapping Study

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Purpose: To examine the treatment and long-term outcome preferences for people living with schizophrenia.

Patients and Methods: Sixty-six Australian adults, living with schizophrenia completed a novel online survey with six sections: Demographic characteristics; Disease history; Quality-of-life; Patient support programmes; Discrete Choice Experiment, and Best-Worst Scaling exercise.

Results: Participants indicated that they preferred to be involved in treatment decision with their doctor. A minority of participants reported having been previously involved in a patient support programme (28.8%) and only one in six participants had a National Disability Insurance Scheme (NDIS) package (16.7%) with over a third of participants indicating that they were ineligible (37.9%). Participants' average quality-of-life score was 60%.

Conclusion: Recent hospitalisation influenced the relative importance of treatment attributes, with effectiveness on hearing voices being the most important treatment attribute. The most important long-term goals were having a stable place to live, being independent, and physical health. People with schizophrenia care about their long-term functional recovery outcomes, rating symptom control and independence as their highest priority. They want to be part of the treatment conversation with their doctors. Therefore, psychiatrists are encouraged to use shared decision-making to establish the treatment course that best aligns with individuals' long-term goals.

Keywords: discrete choice experiment, patient preference, patient value mapping, schizophrenia, shared decision-making, treatment goals

Introduction

Schizophrenia is a psychotic disorder associated with problems in social and occupational functioning and self-care.¹ The most recent estimates suggest that Australians aged between 18 and 45 years have a lifetime morbid risk of developing schizophrenia of 2.37 per 1000 people.² The current Australian clinical guidelines recommend that schizophrenia is managed through a multidisciplinary team approach, with comprehensive psychosocial support and appropriate pharmacological treatment.³ Antipsychotic medicines remain the cornerstone of schizophrenia treatment both for acute episodes and ongoing maintenance therapy.³ Antipsychotic medicines effectively treat the symptoms of schizophrenia³ and are available in both oral and long-acting injectable (LAI) forms. LAIs have been found to be superior to oral medication at preventing hospitalisation and reducing relapse in randomised controlled trials as well as real-world use.⁴ However, LAI uptake among people living with schizophrenia is relatively low at 19% to 30%.⁵

Despite advances in the treatment options available, only one in seven individuals meet the criteria for recovery from schizophrenia.⁶ Non-adherence to prescribed drug treatment can be considered the most challenging aspect of treating schizophrenia,⁷ with discontinuation rates for oral antipsychotics ranging from 26% to 44%.⁸ This may be due to a

combination of factors, including the severe side effects (such as extrapyramidal effects, metabolic or cardiac effects),³ as well as the clinical manifestations of the disease itself (which can include poor insight and cognitive dysfunction).^{7,9} Social, economic and health system barriers may also contribute to medication non-adherence.⁹ Non-adherence leads to a high risk of relapse, hospital readmission, and poor long-term outcomes.⁸ Even a small gap, of one to ten days, in treatment compliance increases the risk of hospitalisation (odds ratio = 1.98).¹⁰ These findings have led clinical guidelines to recommend that psychosocial interventions include strategies to encourage adherence to medicines.³

While use of LAI antipsychotics may improve medication adherence, these are often underutilised due to the perceived negative beliefs and attitudes of both people with schizophrenia and their health-care providers.⁸ Psychiatrists often believe that their patients will refuse LAIs, despite positive patient attitudes towards LAIs, which includes feeling more supported due to regular contact with health-care professionals.⁹

Shared decision-making is recognised as a way of increasing collaboration between the person with schizophrenia and the clinician.¹¹ It has been defined as “an approach where clinicians and patients make decisions together using the best available evidence”.¹² Shared decision-making is seen “as the pinnacle of patient centred care”.¹³ Supporting patients to consider their options and express informed preferences towards treatment and management options can improve long-term compliance,¹⁴ increase acceptance of LAIs,¹¹ and improve wellbeing and treatment satisfaction among people living with schizophrenia.¹⁵

To date, few studies have investigated antipsychotic treatment preferences of those living with schizophrenia.^{16,17} However, incorporating the values of people with lived experience into health outcomes is becoming increasingly important and is known as patient value mapping.^{18–20} Patient value mapping, is a term used to capture patient preferences for hypothetical treatment options that can be used to map value back to real treatments.²¹ This methodology has previously been used to assess the preferences of patients living with treatment-resistant depression,²² inflammatory arthritis,²⁰ type-2 diabetes,¹⁸ and multiple myeloma.^{19,21} This study aimed to develop a greater understanding of the treatment preferences and preferred long-term outcomes of people with a lived experience of schizophrenia.

Materials and Methods

Sample

Australian adults with a lived experience of schizophrenia were recruited through consumer organisations (SANE Australia, One Door Mental Health, Neami National, Lived Experience Australia, and Mental Illness Fellowship of Australia (MIFA)); Healthcare professionals’ networks (mental health practitioners, psychiatrists, etc.) and online market research companies (Dynata and Stable Research).

Participants that completed the online survey were offered AU\$40 as a bank transfer (or equivalent panel points, for those recruited through market research companies) or a donation of this amount to a consumer organisation involved in recruiting for the study.

The study was approved by the Bellberry Limited Human Research Ethics Committee (Application no. 2019–12-1161-A-1), as no author was affiliated with a research institution at the time of seeking ethics approval. The study complied with the Declaration of Helsinki.²³ Informed consent was obtained by asking participants to read an information sheet about the benefits and risks of the study and then confirming their consent to take part by clicking a checkbox in the online survey. All information and consent forms were delivered online at the beginning of the online survey. Participants were able to withdraw from the study at any time.

Design

Participants who met the eligibility criteria completed an online survey ([Supplementary Table 1](#)), which took approximately 20 to 30 minutes. The survey instrument was designed based on a review of the academic literature and in consultation with two external advisers – a clinician and a person with lived experience of schizophrenia. The final survey had six sections which covered the following areas: 1. Demographic characteristics; 2. Disease history; 3. Quality-of-life (QoL); 4. Patient support programmes; 5. A Discrete Choice Experiment (DCE) to evaluate the relative

importance of treatment attributes, and 6. A Best-Worst Scaling exercise (BWS) to determine the importance of long-term outcomes. Consumer groups advised on the DCE attributes.

Demographic Information and Disease Background

Information was collected about the participants' demographic characteristics and their disease history. This included time since diagnosis, comorbid conditions, recent hospitalisations, experience with antipsychotic medications, attitudes towards LAIs, and involvement in treatment decisions (therapeutic alliance, time with therapist, discussion around LAIs).

Quality-of-Life

QoL was measured by the Quality-of-Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF). The Q-LES-Q-SF contains 16 items which represents the “general activities” subscale of the long-form Q-LES-Q.^{24,25} Q-LES-Q has been used widely to measure life satisfaction in patients during pre- and post-treatment phases of therapy.

Patient Support

The authors developed questions relating to patient support, the National Disability Insurance Scheme (NDIS – an Australian government scheme that fund the costs associated with disability) and the impact of COVID-19.

The Discrete Choice Experiment

The DCE was used to evaluate the importance of treatment features of oral versus LAI medication. DCEs are a methodological approach to studying choice behaviour, with a theoretical background in psychology and economics.^{26–28} DCEs are used by many fields to understand and model the preferences and trade-offs revealed by the choices people make.²⁹

DCEs present participants with a number of scenarios and ask them to choose the alternative that they prefer based on their own value framework ([Supplementary Figure 1](#)). It is an assumption of the underlying theory that participants choose the alternative that maximises their utility (ie, satisfaction, or utility maximisers). In this instance, the DCE asked participants to choose between two hypothetical treatment alternatives ([Supplementary Methods](#)). Each treatment had various attributes, including method of administration. The treatment alternatives were described by the various attributes and levels shown in [Table 1](#). The attributes and their levels were derived from existing market research, the literature, and expert opinion. Participants had three response options. Participants could choose either of the hypothetical medications or the opt out which represented “continue to do what you are doing now”.

In DCEs, sample size calculations require knowledge of the expected parameter estimates, and therefore these calculations are typically not performed a priori.²² During the experimental design process, the minimum required sample size is approximated based on the utility function being estimated (which is a function of the number of parameters). This study utilised a Bayesian efficient design approach, where knowledge of attributes, such as size and direction, is used to optimise the design given sample constraints.³⁰ The experimental design follows good practice guidelines.^{31,32}

The econometric software, Nlogit version 6 (Econometric Software, Inc.), was used to model the DCE data. Preference data were assessed using a mixed multinomial logit (MMNL) model, which allowed for preference heterogeneity (variation) between participants.^{32,33} The model was used to quantify the overall value of treatments and the relative importance to participants of each of the defining attributes. Additional details of the model specifications and utility functions can be found in the [Supplementary Methods](#).

Best – Worst Scaling (BWS) Exercise

The BWS exercise was used to determine the importance of long-term treatment outcomes and built upon previous work in this area.¹⁶ BWS tasks avoid many of the scaling problems associated with Likert ratings. Participants are shown different combinations of sets and asked to select the best and worst option in each comparison.³⁴ The BWS exercise included a total of 15 items which described possible outcomes from receiving treatment for schizophrenia. Participants were shown several subsets of seven items and asked to choose the most important and the least important aspect in each set ([Supplementary Figure 2](#)). The full list of items included in the BWS were:

Table 1 DCE Attributes and Levels

Attributes		Description	Option A	Option B
			Oral Medication (Administered at Home)	Injectable Medication (Administered at a Community Mental Health Facility/GP)
Frequency of administration		How often the treatment is administered	Twice a day	
			Once a day	
				Once every 14 days
				Once a month
				Once every 2 months
				Once every 3 months
				Once every 6 months
Risk of hospital admission*		Risk of being admitted to hospital if symptoms return		None
			Decrease (x times in 2 years)	Decrease (x times in 2 years)
			Same (x times in 2 years)	Same (x times in 2 years)
			Increase (x times in 2 year)	
Injection site reaction/pain		Whether there is any swelling, redness or pain around the skin where the treatment was administered		Moderate
				Mild
				None
Effectiveness of medication	Hearing voices/illusions	Whether the medication is effective in improving symptoms such as hearing voices, seeing things that are not real	Not hearing voices or not bothered by voices, feeling well	Not hearing voices, and feeling well
			Occasionally hearing voices, feeling unwell every once in a while	Occasionally hearing voices and feeling unwell every once in a while
			Hearing voices frequently, not feeling well, unable to trust people	Hearing voices frequently, not feeling well, unable to trust people
	Lack of emotions/ability to communicate	Whether the medication is effective in improving symptoms such as lack of emotions, inability to communicate, preference for being alone and no interest in work or study	Able to and desire to communicate with friends and/or support network	Able to and desire to communicate with friends and/or support network
			Some difficulty communicating with friends and/or support network	Some difficulty communicating with friends and/or support network
			Great difficulty communicating with friends and/or support network	Great difficulty communicating with friends and/or support network

(Continued)

Table I (Continued).

Attributes		Description	Option A	Option B
			Oral Medication (Administered at Home)	Injectable Medication (Administered at a Community Mental Health Facility/GP)
	Ability to connect with friends and/ or support network	Whether the medication is effective in improving the ability to connect with friends and/or support network	No difficulty maintaining a relationship with friends and/ or support network, desire to socialise	No difficulty maintaining a relationship with friends and/ or support network, desire to socialise
			Some difficulty maintaining a relationship with friends and/ or support network, some desire to socialise	Some difficulty maintaining a relationship with friends and/ or support network, some desire to socialise
			Great difficulty maintaining a relationship with friends and/ or support network, no desire to socialise	Great difficulty maintaining a relationship with friends and/ or support network, no desire to socialise
Side effects of medication	Weight gain	Side effects that may or may not interfere with daily activities	Occasionally feeling hungry and some weight gain at start of treatment (2–5 kg)	Occasionally feeling hungry and some weight gain at start of treatment (2–5 kg)
			Often feeling hungry and considerable weight gain at start of treatment (5–10 kg)	Often feeling hungry and considerable weight gain at start of treatment (5–10 kg)
			Feeling hungry all the time and a high amount of weight gain at the start of treatment (15 kg or more)	Feeling hungry all the time and a high amount of weight gain at the start of treatment (15 kg or more)
	Akathisia/ restlessness		No problems with pacing/ being able to sit still	No problems with pacing/ being able to sit still
			Some problems with pacing/ being able to sit still	Some problems with pacing/ being able to sit still
			Constant crossing/uncrossing of legs, rapid alteration between standing and sitting, jitteriness	Constant crossing/uncrossing of legs, rapid alteration between standing and sitting, jitteriness
			No change in amount of energy	No change in amount of energy
	Not feeling slowed/fatigued		Feels slowed down, like a “zombie”	Feels slowed down, like a “zombie”
			Sexual problems	No problems with erections/ no breast enlargement (men), normal periods (women)
	Problems getting and maintaining erections/breast enlargement (men), irregular periods (women)			Problems getting and maintaining erections/breast enlargement (men), irregular periods (women)

Notes: *Please see [Supplementary Methods](#) for detail on how Risk of Hospital Admission levels were presented to participants.

1. Having an income and/or work
2. Having personal relationships with family
3. Having personal relationships friends/partner
4. Pursuing hobbies and interests
5. Being independent/autonomous
6. Having a stable place to live
7. Being physically healthy
8. Staying out of hospital
9. Not feeling the stigma of having the disease
10. Not having side effects from treatment
11. Not feeling controlled by the doctor or health-care system
12. Not being embarrassed by the side effects of treatment
13. Being able to stop medication
14. Having a medical team that is sympathetic to my needs
15. Not feeling lonely

Data from the BWS exercise were computed into scores by calculating the difference between the number of times it was chosen as most important and least important, and then dividing it by the total number of times it appeared throughout the exercise. The BWS scores are a number between one and minus one and represent the relative ranking of the 15 items in terms of their importance.

Data Cleaning

Prior to data cleaning, 89 participants had completed the survey. Participants who finished the survey too quickly (<11 mins), gave nonsensical answers or were suspected duplicates were removed during the data cleaning process (n = 13). Additionally, participants who admitted to a poor understanding of the DCE (a rating of less than six on a scale from 0 [Did not understand at all] to 10 [Understood perfectly]) were excluded from the analysis (n = 10) leaving a total sample of 66 participants. Data for additional survey questions not reported in the results section are provided in the [Supplementary Methods](#). A thorough description of the data analysis process is provided in the [Supplementary Methods](#).

Results

Participant Characteristics

The majority of participants were Australian (50; 75.76%) and lived in a city (54; 81.82%). Full participant demographics can be found in [Table 2](#). Most participants (44; 66.7%) had been diagnosed with schizophrenia more than ten years ago, had not been admitted to hospital in the past two years (37; 56.06%), and had been seeing their current psychiatrist for over a year (36; 54.55%). Half of the participants reported having a diagnosis of depression (33; 50%) and a substantial proportion also reported having an anxiety disorder (27; 40.91%).

Disease Background and Treatment History

Most participants (58/66; 88%) were taking antipsychotic medication, with 44 reporting being on monotherapy and 14 taking more than one antipsychotic. Most participants were taking an oral medication (49/58; 84%). Twenty-nine participants (44%) had taken an LAI prior to their current medication, with nine participants using an LAI at the time of the survey (14%). From this, 30 participants (45%) were categorised as having current or previous experience with LAIs. Thirty-six participants (55%) had no experience of LAIs and of those who had not previously taken an LAI only four had ever been offered LAI medication.

Table 2 Demographic Characteristics of Participants

Demographic Characteristic (n = 66)		n	%
Gender	Male	36	54.55%
	Female	30	45.45%
Age	18–30	5	7.58%
	31–40	15	22.73%
	41–50	22	33.33%
	51–60	13	19.70%
	61–70	11	16.67%
Highest level of education attained	Year 11 or below	11	16.67%
	Year 12	5	7.58%
	Certificate III/IV	21	31.82%
	Bachelor's Degree	14	21.21%
	Postgraduate qualification	15	22.73%
Occupational status	Not employed	29	43.94%
	Employed full time	12	18.18%
	Employed part time/casual	11	16.67%
	Other	14	21.23%
Living arrangements	Single person	28	42.42%
	Couple family with children	10	15.15%
	Couple with no children	9	13.64%
	Group household (ie shared)	7	10.61%
	One parent family	5	7.58%
	Other	7	10.61%
Type of accommodation	Rented house/flat	36	54.55%
	Own house/flat	16	24.24%
	Parents'/family house	9	13.64%
	Other	5	7.59%
Household income before tax	\$1-\$25,999 (ie \$1-\$499 a week)	22	33.34%
	\$26,000-\$51,999 (ie \$500-\$999 a week)	21	31.82%
	\$52,000-\$72,799 (ie \$1000-\$1399 a week)	6	9.10%
	\$72,800-\$103,999 (ie \$1400-\$1999 a week)	3	4.55%
	≥\$104,000 (≥ \$2000 a week)	8	12.13%
	Prefer not to answer	6	9.09%

Involvement in Treatment Decisions and Therapeutic Alliance

Participants were asked to rank their most to least preferred involvement in treatment decisions. According to first- and second-order preferences, participants preferred that their doctor share responsibility with them, or at least seriously considers their opinion in treatment decisions ([Supplementary Table 2](#)). The least preferred option was to leave treatment decisions entirely to their doctor (n = 34 [51.52%] [Supplementary Table 2](#)).

Participants were asked to rank their top three support options for transitioning to GP care. Finding a GP who understands mental health and education around treatment options were ranked most important ([Supplementary Table 3](#)). Participants were also asked to rank barriers to maintaining treatment. The most important barriers were side effects of treatment and finding a health-care practitioner who understands them ([Supplementary Table 3](#)).

Quality-of-Life and Patient Support

Participants in the current study scored an average Q-LES-Q-SF of 60%. The most useful patient supports were digital appointment reminders (36; 54.5%), access to support workers (36; 54.5%), and exercise programmes (31; 47.0%). A minority of participants reported having been previously involved in a patient support programme (19; 28.8%).

Only one in six participants had an NDIS package (11; 16.7%). This was primarily used to provide support to participate in community activities such as recreation, education, training and employment (9/11; 81.8%); and assistance to build capacity to live independently and achieve goals, such as building social relationships, financial management and tenancy management skills (8/11; 72.7%). More than 10% of participants had been rejected for an NDIS package (8; 12.1%). Nearly one-in-five (12; 18.18%) had not been told about an NDIS package and what it offers, and over a third of participants thought that they would not be eligible for an NDIS package (25; 37.9%).

Covid-19

The impact of the COVID-19 outbreak on participants' mental health was assessed in the survey. Two-thirds of the sample (43; 65.15%) were able to access psychosocial support as normal and most (53; 80.30%) did not require additional support during the outbreak. Participants were asked to rate the impact of the outbreak on their mental health on a scale (0 = no impact to 10 = major impact) with a median result of seven.

The DCE

The DCE measured the relative importance of each attribute by estimating associated parameters for each level (Table 3). These parameters represent the magnitude of influence of each level on patient utility (satisfaction). Only some treatment attributes significantly predicted choice in the DCE model. These were risk of hospital admission (oral treatment only), effectiveness on hearing voices, effectiveness on inability to communicate with friends/support network, impact on restlessness and impact on sexual health. Treatment attributes which did not significantly predict choice were: frequency of administration; injection site reaction/pain; effectiveness on inability to connect/maintain relationships with friends/support network; impact on appetite and weight; and impact on energy levels and fatigue. This is not to say that these treatment features are not important in decision-making but that they did not have a significant influence on decision-making, relative to the other attributes, in this experiment.

Preference for the Status Quo

Some individual characteristics were found to influence participants' preference to remain with their current treatment (status quo). Younger participants (≤ 40 years) and those who were diagnosed with schizophrenia more than 10 years ago were more likely to prefer their current treatment. Participants with a higher QoL, who had been hospitalised in the last two years were also more likely to prefer the status quo. Participant characteristics did not directly affect choice of the oral or injectable treatments (these remained proportional as uptake for the status quo increased or decreased).

See https://cappre.shinyapps.io/Janssen_SCHZ/ for a visual representation of the model results and to simulate the effect of different treatment scenarios on participants' choices.

Recent hospitalisation influenced the relative importance of treatment attributes, therefore the DCE model was segmented into two groups: 1. Those who have had at least one hospitalisation in the past two years; and 2. Those who have not been hospitalised in the past two years.

Recently Hospitalised

For those recently hospitalised, the most important treatment attributes were effectiveness on hearing voices, impact on sexual health and effectiveness on inability to communicate (Figure 1). When taking into account the unique effect of the treatment type in the hypothetical scenario (holding all other treatment attributes constant), both treatment alternatives were preferred to the status quo (reference category), and preference for oral administration ($\beta = 2.340$, T-ratio = 3.220) was stronger than preference for injectable administration ($\beta = 1.809$, T-ratio = 2.490). Decreased risk of hospital

Table 3 DCE Parameter Estimate

Random Parameters		Recent Hospitalisation				No Recent Hospitalisation				Explanation
		Coefficient	SE	T-ratio	P value	Coefficient	SE	T-ratio	P value	
Effectiveness on hearing voices	Not hearing voices	0.370	0.080	4.590	<0.001	0.370	0.080	4.590	<0.001	Not hearing voices preferred over occasionally/frequently hearing voices
	(RC: Occasionally/frequently hearing voices)									
Effectiveness on inability to communicate with friends/support network	No difficulty	0.174	0.069	2.540	0.011	0.174	0.069	2.540	0.011	No difficulty communicating with friends/support network preferred over some/great difficulty
	(RC: Some/great difficulty)									
Impact on sexual health	No problems	0.188	0.070	2.690	0.007	0.188	0.070	2.690	0.007	No problems with sexual health preferred over problems with erections/breast enlargement for men or irregular periods for women
	(RC: Problems with erections/breast enlargement (M); irregular periods (F))									
Impact on restlessness	No problems	0.146	0.074	1.970	0.049	0.146	0.074	1.970	0.049	No problems with restlessness preferred over some/constant problems with pacing and being able to sit still
	(RC: Some/constant problems with pacing and being able to sit still)									
Non-random parameters		Coefficient	SE	T-ratio	P value	Coefficient	SE	T-ratio	P value	
Alternative-specific constants	Oral	2.340	0.726	3.220	0.001	-0.311	0.191	-1.630	0.103	Holding all else equal: Oral most preferred for recent hospitalisation, SQ most preferred for no recent hospitalisation
	Injection	1.809	0.727	2.490	0.013	-0.870	0.199	-4.360	<0.001	
	(RC: Status quo)									
Risk of hospital admission (oral only)	Increased risk	-0.232	0.186	-1.250	0.212	0	-	-		Decreased risk in hospital admission preferred over same or increased risk for oral treatments in recent hospitalisation group
	Decreased risk	0.340	0.187	1.820	0.069	0	-	-		
	(RC: Same risk)									

(Continued)

Table 3 (Continued).

Non-random parameters		Coefficient	SE	T-ratio	P value	Coefficient	SE	T-ratio	P value	
Time since diagnosis	Diagnosed within the last 10 years	-2.008	0.367	-5.470	<0.001	-1.001	0.310	-3.220	0.001	Patients diagnosed over 10 years ago more likely to choose SQ than those diagnosed within last 10 years
	(RC: Diagnosed more than 10 years ago)									
Current age	41+ years	1.364	0.376	3.630	<0.001	-0.905	0.236	-3.830	<0.001	Patients aged over 40 years more likely to choose SQ than those aged 18-40 years for recent hospitalisation, while opposite true for no recent hospitalisation
	(RC: 18-40 years)									
Quality-of-life	Q-LES-Q-SF score	2.246	0.920	2.440	0.015	0	-	-		Patients with higher QoL more likely to choose SQ than those with lower QoL for recent hospitalisation

admission ($\beta = 0.340$, T-ratio = 1.820) was preferred over the same risk (reference category) or increased risk ($\beta = -0.232$, T-ratio = -1.250) for oral treatments.

No Recent Hospitalisation

For those not recently hospitalised, the most important attributes to affect treatment choice were effectiveness on hearing voices, impact on sexual health, effectiveness on inability to communicate and impact on restlessness (Figure 1). When holding other attributes constant (ie, no effect of other treatment attributes), the treatment status quo was preferred over injectable treatments ($\beta = -0.870$, T-ratio = -4.360) and to a lesser extent, the oral treatments ($\beta = -0.311$, T-ratio = -1.630). Between the two treatment modes, preference was greater for the oral over the injectable administration mode. However, if the injectable medication was more efficacious in managing hearing voices compared to the oral treatment, then some participants would switch treatments (see dashboard URL for more treatment scenario simulations).

BWS

The most valued long-term outcomes were having stable accommodation, being independent/autonomous and having good physical health (Figure 2). The least important outcomes included reducing the stigma associated with schizophrenia, reducing embarrassment due to the side effects of treatment, and being able to stop taking medication (Figure 2).

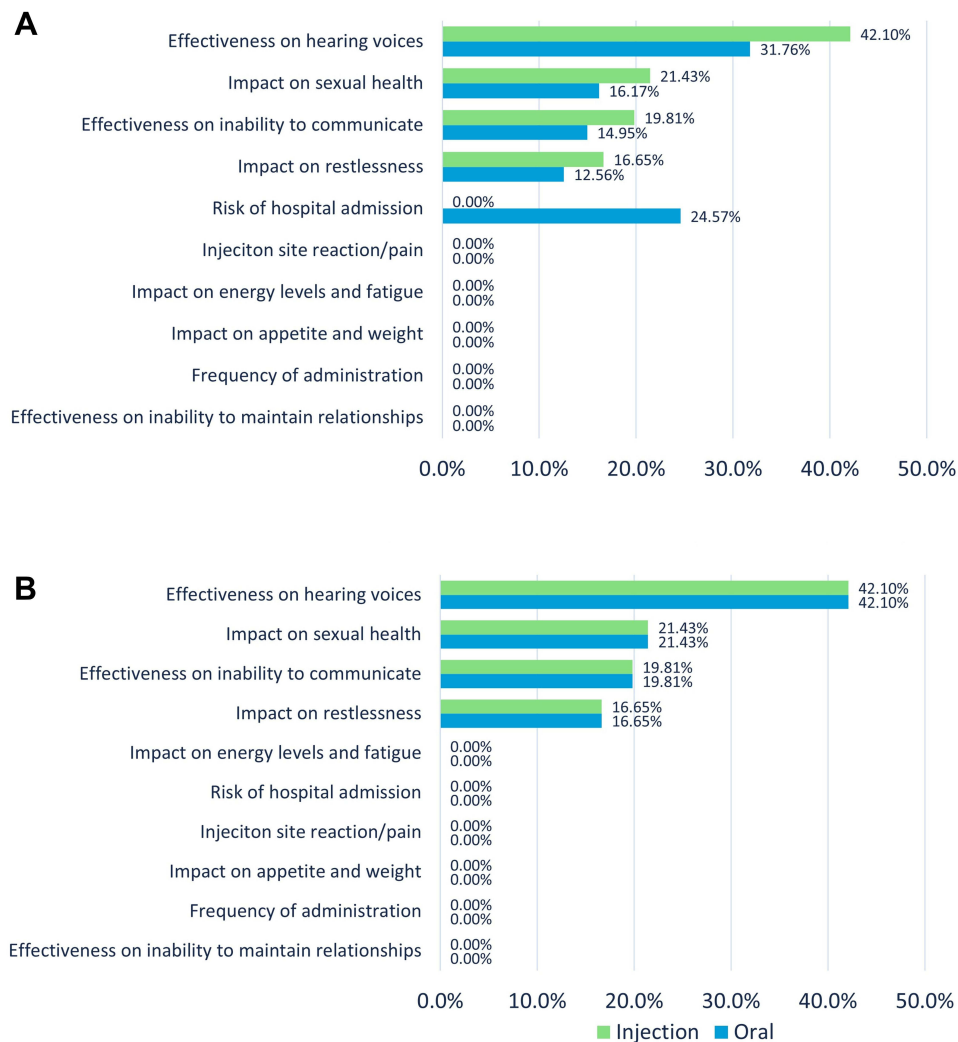


Figure 1 (A) Attribute importance for those hospitalised in the past two year. (B) Attribute importance for those not hospitalised in the past 2 years.

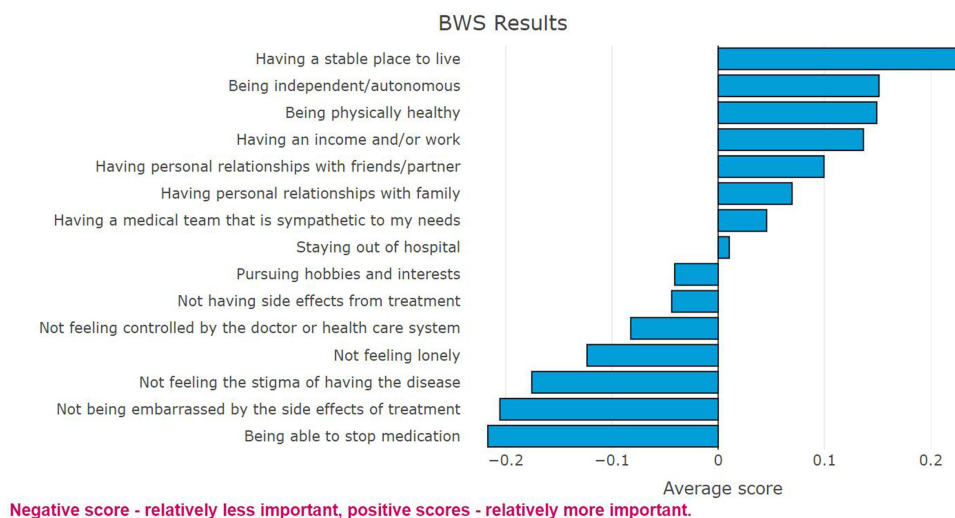


Figure 2 Best-Worst Scaling scores for long-term treatment outcomes.

Discussion

The results from this study provide us with a better understanding of what aspects of treatment planning and outcomes are important to people with schizophrenia. A range of tools were used to obtain insights from this cohort, to uncover the value that people with schizophrenia place on their long-term outcomes. This research was undertaken within the context of assessing the importance of treatment attributes, treatment planning processes, and support programmes that these individuals need on their journey to recovery.

Despite adherence to antipsychotic medications remaining low among people living with schizophrenia^{7,9} and practice guidelines recommending that LAIs be offered to patients early in the clinical course of schizophrenia,³ most participants in the current study reported using oral antipsychotics (80.3%), and a general preference for oral administration modes. However, more than half of participants reported no experience with LAIs (54.5%) and only four people in this group had ever been offered LAIs by their treating clinicians. These low experience rates with LAIs and preference for oral modalities may be due to the perception that LAIs are more stigmatising and result in a loss of autonomy.³⁵ Particularly as this cohort highly valued being independent/autonomous as a long-term treatment outcome. These beliefs are at odds with people who have used LAIs, who reported positive experiences, including better support and fewer relapses.^{8,36}

This study provides an insight into the QoL of people living with schizophrenia in Australia. Compared to other published studies, participants reported a considerably lower QoL (60%) than those experiencing any mental illness (72.7%), those not mentally ill but who have experienced mental illness in the past (78.4%) and those who have never experienced mental illness (81.8%).²⁵

Previous research has shown the importance of support services being tailored to the specific needs of people living with schizophrenia.³⁷ However, we found that the use of patient support programmes was low (28.8%). Even more concerning was the large proportion of participants who did not know about or did not think that they would be eligible for NDIS support (56.7%). In Australia, an NDIS package enables access to patient support programmes and funding for ongoing day-to-day psychosocial, vocational and other support. The desire for patient support programmes, and barriers to understanding and accessing the NDIS should be considered in the context of current mental health reforms.

When looking at the treatment attributes that impact a person's choice of treatment, the most important attribute was symptom control (hearing voices) and effectiveness on inability to communicate. Participants weighed up these benefits against the potential side effects, particularly their impact on sexual health, impact on restlessness and increased risk of hospitalisation (for those who have been recently hospitalised only). The treatment attributes that did not seem to affect the preferences of people with lived experience of schizophrenia included: frequency of administration, injection site pain, impact on appetite and weight and impact on energy levels and fatigue. This contrasts with the perceptions of

clinicians that these are important.^{9,36} It should be noted that these results do not mean that non-significant DCE attributes were not important to participants. However, when faced with competing treatment attributes, these became significantly less important relative to the other attributes, when deciding between treatments.

The importance of long-term goals was assessed using the Best-Worst Scaling exercise and has provided further rationale for preferred treatment attributes that provide symptom stability. The most important long-term goal was to maintain autonomy, through which symptom control provides the foundations (eg, effectiveness on hearing voices attribute). Side effects and limitations of medications were found to be the least important long-term treatment outcomes. Although this may suggest that people with schizophrenia may be willing to trade-off treatment side effects in order to obtain symptom stability, it is still critically important to address the side effects associated with treatment. Not addressing these side effects can ultimately affect treatment adherence.³ However, these findings do add to a growing body of evidence indicating that people with schizophrenia are comfortable trading disadvantages associated with LAIs, particularly those related to injection pain and location of injection, in order to benefit from effective symptom reduction and long-term stability.^{5,16} As such, conversations about LAIs should be considered, as part of the treatment planning process.

There was a clear preference among this cohort to participate in the treatment decision process with their clinicians. This finding is consistent with prior research on shared decision-making among a cohort of people living with schizophrenia spectrum disorders in Australia.¹⁵ These findings suggest that shared decision-making should be utilised across all support services, including psychiatry, psychology, nursing, and general practice. Previously identified barriers to such an approach include extended consultation times and require the integration of inter-professional collaboration.³⁸ This current study highlighted the importance of knowing and incorporating an individual's long-term goals within a shared decision-making framework. The treatment planning process should also include the discussion and management of treatment side effects. Future studies could explore when patients want to be involved in shared decision-making themselves and when they would prefer for their family to have a role in the process.

Limitations

Due to the nature of the study design, the findings from this study may be limited in their representativeness of Australian adults living with schizophrenia. It is possible that participants able to access and complete an online survey may represent a higher functioning sample of people living with schizophrenia. However, the investigators acted on recommendations from consumer groups in order to reach as wide a sample as possible during recruitment. Additionally, data were collected through self-reported responses at one point in time. Furthermore, while all attributes were explained to participants, we cannot be certain that the participants properly understood the treatment options presented. It is also possible that despite our best efforts, all relevant attributes were not tested in our model. The relatively small sample size should also be considered when discussing the applicability of these results to everyday practice. It is for this reason that it is most important that people living with schizophrenia are consulted on their individual treatment preferences, as the aggregate data from this small sample may not adequately reflect the views of all.

While the study was sponsored by a pharmaceutical company, this was clearly disclosed at all stages of the research. Further, the study was run and administered by a third party, CaPPRe. Any possible biases in the study design, execution and reporting were also balanced by the inclusion of an independent clinician on the study team.

Conclusion

To date, there has been a lack of research around the treatment preferences of people living with schizophrenia treatment, particularly in the Australian setting, and the results from this study begin to fill this gap. Our findings show that people with schizophrenia would prefer to be included in the treatment conversations with their clinicians. It also highlights the importance of uncovering long-term goals of each individual and discussing all available treatment options that may facilitate this goal attainment, while managing personally relevant side effects and maintaining physical health. Participants cared most about long-term stability and effective symptom reduction, and these should be part of any treatment conversations.

Ethics Statement

The study was approved by the Bellberry Limited Human Research Ethics Committee (Application no. 2019-12-1161-A-1), as no author was affiliated with a research institution at the time of seeking ethics approval. The study complied with the Declaration of Helsinki.

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Disclosure

S Fifer and B Keen are employed by CaPPRe. CaPPRe has consulted to AbbVie, Amgen, AstraZeneca, Celgene, CSL Behring, Edwards, GSK, Ipsen, Janssen, Novo Nordisk, Roche, Sanofi, Shire and UCB, outside of the submitted work. A Puig and M McGeachie are employees of Janssen-Cilag Australia Pty Ltd. The authors report no other conflicts of interest in this work.

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