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Bad things happen and can drive you crazy: The causal beliefs of 701 people

taking antipsychotics.

ABSTRACT

In almost all countries the public prefers psycho-social explanations of 'schizophrenia' to bio-

genetic ones. The causal explanations of people who experience psychosis have been under

researched, and, if they diverge from the dominant bio-genetic paradigm, can be dismissed as

'lack of insight'. Of the 832 people completing a survey about their experiences on antipsychotic,

701, from 30 countries, answered an open question about what had caused the problems for

which they had been prescribed the drugs. On a 'Bio-Social' likert scale, from 1 = 'Purely

Biological' to 5 = 'Purely Social', the mean score was 4.24. Thematic analysis produced seven

themes: Social (75.6%), Psychological (18.4%), Bio-genetic (17.5%), Iatrogenic (17.1%), Drug

and Alcohol (10.1%), Medical Condition (6.8%) and Insomnia (6.0%). Those with a psychosis

diagnosis were even more likely than others to report a Social cause. The causal beliefs of this

sample are consistent with previous studies of people diagnosed with 'schizophrenia' and the

beliefs of the public. They are also aligned with recent research into the social causes of

psychosis. It is argued that rather than dismiss the beliefs as 'lack of insight' it is more respectful

and productive to listen carefully and adjust our understandings and services accordingly.

Keywords: Causal beliefs, Psychosis, Schizophrenia

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1. Introduction

There have always been competing ideas about the causes of madness (Geekie, 2013; Read, 2013). It has even been argued that the concept of 'madness' is, like 'justice' and beauty', an 'essentially contested construct', the true boundaries and causes of which can never be known (Geekie, 2013; Geekie and Read, 2009). In many cultures hearing voices, for example, is considered a normal experience with social, cultural and spiritual meaning (Taitimu et al., 2018). Professionals and researchers in the 'developed' world, however, tend to view such experiences as symptoms of a bio-genetically based illness called 'schizophrenia' (Murray and Dean, 2008; Roberts, 2019) or as reactions to life events (Bentall, 2009; Cooke, 2017; Read and Dillon, 2013). Although thousands of research papers have contributed to this debate, relatively little is known about the causal beliefs of the people who have the experiences, or diagnoses, in question.

We know much about the public's causal beliefs (Angermeyer et al., 2009; 2011; Haslam and Kvaale, 2015; Read et al., 2006). By 2013 there were reports on 84 samples, spanning 25 countries (Read et al., 2013a). The majority (73%) believed more strongly in psycho-social causes than bio-genetic ones, 20% more strongly in bio-genetic factors, and 7% apportioned equal emphasis. In Japan the most frequently cited cause was 'interpersonal relationships' (65%), with 27% citing 'predisposition and genetics' (Tanaka et al., 2005). In South Africa 83% believed that schizophrenia is caused by 'psychosocial stress' and 43% thought it was a 'medical disorder' (Hugo et al., 2003). In a French study, published after the 2013 review, 24% endorsed 'heredity', 45% 'brain disease' and 66% 'negative life events' (Angermeyer et al., 2013). An Australian study found: 'Problems from childhood' 94.5%; 'Chemical imbalance' 92%; 'Day-to-day problems' 91%; 'Death of someone close' 90.5%; 'Traumatic event' 90%; 'Inherited or genetic' 75%; 'Virus or infection' 30% (Reavley & Jorm, 2014). A 2019 Taiwan survey produced: 'Stress situations' - 75%; 'Brain disorder or chemical

imbalance' 54%, 'Childhood problems' - 48%; 'Genes and hereditary factors' - 40% (Lien and Kao, 2019). Nineteen of 26 samples (73%) of family members also preferred psycho-social causes (Read et al., 2013a). There is one exception. In nine of the 20 samples (45%) from the USA bio-genetic beliefs were favoured, compared to eight of the other 64 samples (12.5%).

Bio-genetic beliefs are related to negative attitudes (Angermeyer et al., 2011, Haslam and Kvaale, 2015; Read et al., 2006, 2013b; Yao et al., 2019).

The 2013 review (Read et al, 2013a) found 16 samples of people diagnosed with 'schizophrenia' or other psychotic disorders, spanning nine countries and 50 years (Jones et al., 1963). In all 16, life events were considered more important than genes or neurotransmitters. The causes espoused by German patients were: 'recent psycho-social factors' 88%; 'family' 64%; 'biology' 31% (Holzinger et al., 2002). In London 5% of people diagnosed 'schizophrenic' believed their problems were a result of having a 'mental illness', 13% cited biological causes, and 43% cited social causes such as interpersonal problems and childhood events (McCabe and Priebe, 2004). In an Italian study of people diagnosed with 'schizophrenia', 76% mentioned at least one social cause, with 10% citing a biological cause (Magliano et al., 2009).

A US study found that patients, family members, and the general public endorsed non-biomedical causal factors more frequently than clinicians (van Dorn et al., 2005). The patients were the most likely (66%), and clinicians least likely (18%), to cite 'the way he was raised'. Clinicians endorsed genetics more frequently than the other groups. Patients were less likely than clinicians to endorse chemical imbalance. The largest study is of 311 people who experienced psychosis or were diagnosed with 'schizophrenia' or related diagnoses in England. The findings were: 'personal sensitivity' 64%; 'trauma in adulthood' 60%; 'recent stress' 57%; 'trauma in childhood' 54%; 'chemical imbalance' 46%; and 'hereditary factors' 45% (Carter et al., 2018a).

A recent review, of 13 studies of people who experience psychosis, found 'a clear preference for psychosocial or spiritual interpretations over biological beliefs' (Carter et al., 2017, p. 12).

Aims

The current study aims to contribute to our understanding of the causal beliefs of people who experience psychosis and/or who are diagnosed with 'schizophrenia', and people prescribed anti-psychotics for other reasons, by reporting the statements of 701 people. The sample, being more than twice as large as the largest previous study, enables analyses of the relationships of the causal beliefs with demographic and other variables.

2. Methods

Approval was granted by the Human Research Ethics Committee of Swinburne University of Technology, in Melbourne.

2.1 Instrument

Data was gathered using 'The Experiences of Antidepressant and Antipsychotic Medication Survey' (Read and Williams, 2019). This was based on the 'Views on Antidepressants' questionnaire (Read et al., 2014, 2018), to which questions relating to antipsychotics and psychosis were added. This online questionnaire used Qualtrics software. It generated quantitative (yes/no and multiple-choice) and qualitative (open-ended questions) data about: the prescribing experience, positive and negative effects of antidepressants and antipsychotics, causal beliefs, alternative treatments, and experiences of withdrawing from medication. This paper reports the qualitative data about causal beliefs, in the antipsychotics section, from the question:

'There are many theories, and lots of debate, about what causes mental health problems. What do you think caused the experiences for which you received antipsychotic medication?'

2.2 Participants

Of the 2,346 people who responded, 668 were recruited by an Australian research company, and 1,678 people via social media and snowball sampling (Read and Williams, 2019). 1,067 reported that they had taken antipsychotics. However, 104 failed to tick 'Yes' for the item confirming they met three criteria: 'I have been taking or have previously taken antipsychotic medication continuously for at least one month'; 'I am aged 18 or older'; and 'I am not currently compulsorily detained in a psychiatric hospital'. Among the remaining 963 responses, 51 emanated from the same Internet Protocol address as another response, indicating use of the same computer. Of these 51, 23 were deemed a repeat response by the same person (based on identical demographics or similar responses). Of the remaining 938, 27 responded to 'What is the name of your current or most recent antipsychotic medication?' with a drug that is not an antipsychotic. Of the remaining 911, 210 did not provide causes when asked. This left 701 responses.

2.3 Data analysis

The 571 participants who gave one or more bio-genetic causes of 'schizophrenia' (e.g. genetic, biochemical imbalance, brain disorder etc.) and/or one or more social causes (e.g. stress, trauma, loss, poverty etc) were given a 'Bio-Social' score between 1 = 'purely bio-genetic' and 5 = 'purely social' (Table 2). Scores of 2 and 4 represented 'mixed' bio-genetic or social causes, respectively, where the dominant cause was bio-genetic or social but one or more other causes were also mentioned. A score of 2 or 4 was also assigned if either bio-genetic or social causes

were equally weighted with any type of cause other than bio-genetic or social. A score of 3 was assigned if equal weight was given to social and bio-genetic causes.

The responses of all 701 participants were categorised into seven types of causes, developed using thematic analysis (Braun & Clarke, 2006). After the initial categorising, all responses not already coded into each category in turn were entered into a *word* document, and the *find* function was used to scan for key words (e.g. 'genetic', 'biochemical' etc. for the Bio-genetic theme; 'abuse', 'violence' etc. for the Social theme) to check for any data missed in the initial coding exercise. Thirteen items had been missed and were added to the relevant themes.

Bio-Social mean scores, and the presence of each of the seven causal types, were analysed in relation to gender, age, duration of antipsychotic treatment, helpfulness of antipsychotics, symptoms (psychotic or other), diagnosis (psychosis or other), using two-tailed t-tests, Spearman-rank correlations and chi-squares as appropriate. Preliminary scanning of the data indicated a pattern whereby USA participants appeared to score differently from other participants, so that possibility was explored statistically for the Bio-Social score and the seven themes.

3. Results

3.1 *Sample characteristics*

The majority (72.5%) were female. The average age was 43.6 years.

In response to 'What experiences were you having that led you to being prescribed anti-psychotic medication?' 247 ticked 'delusions' and 190 ticked 'hallucinations'. When responses written in the 'other' box were added the numbers became delusions - 261 (37.2%), and hallucinations - 201 (28.7%). A further 14 psychotic symptoms (such as negative symptoms and thought disorder) were found in the 'others' box. So 342 (48.8%) reported one or more symptoms of psychosis. The next most common type of experience was 'mania' (210; 30.0%).

Of the 635 who reported diagnoses, 277 (43.6%) cited a diagnosis in the psychosis spectrum, 160 (25.2%) bipolar disorder (without a psychosis diagnosis) and 198 (31.2%) other diagnoses. Of the psychosis spectrum diagnoses the most common were 'schizophrenia' (117), 'psychotic episode/disorder' (53), 'schizoaffective disorder' (49) and 'paranoid schizophrenia' (34).

The antipsychotics were experienced as 'helpful' ('very' or 'somewhat') by 37.7% and 'unhelpful' by 44.8%. These and other characteristics are summarised in Table 1.

Table 1 Sample characteristics of 701 respondents

Gender	male 27.5%	female 72.5%			
Age	mean = 43.6 (sd 13.1)				
Employment	employed 44.7%	unemployed 20.8%	retired 9.4%	student 8.3%	disabled 6.4%
Ethnicity (self-defined)	'white'/'caucasian' 49.6%	'British' 12.9%	'Australian' 10.6%	'European' 9.4%	'NZ' 4.2%
Country*	USA 26.8%	Australia 22.7%	UK 21.5%	Canada 4.4%	New Zealand 4.1%
	Netherlands 3.4%	Ireland 2.6%	Denmark 2.4%	Germany 2.3%	Norway 1.7%
Diagnoses	Psychosis 43.6%	Bipolar 25.2%	Other 31.2%		
Time on antipsychotics	< 3 months 6.8%	3-12 Months 18.7%	1-2 years 11.3%	2-3 years 7.0%	>3 years 56.2%
Antipsychotics helpful?	Very helpful 14.3%	Somewhat helpful 24.4%	Unsure 16.5%	Somewhat unhelpful 7.8%	Very unhelpful 37.0%

^{*} Less than 1.5%: Austria, Belgium, Croatia, Estonia, Finland, France, Germany, Greece, Iceland, India, Israel, Italy, Lithuania, Portugal, Romania, South Africa, Spain, Sweden, Switzerland, Ukraine.

3.2 Bio-Social scores

The 571 participants whose responses included Bio-genetic and/or Social causes produced a mean Bio-Social score of 4.24 (sd 1.02), where 1 = purely 'bio-genetic' and 5 = purely 'social'.

Just over half reported purely social causes (302; 52.9%), with158 (27.7 %) reporting 'mixed-social' causes. Whereas 22 (3.9%) reported purely bio-genetic causes, and 12 (2.1%) 'mixed-bio' causes. 'Mixed' causes were reported by 77 (13.5%).

Bio-Social scores were negatively correlated with self-reported helpfulness of antipsychotics, such that bio-genetic beliefs correlated with greater helpfulness (rho = .22, p < .001).

Bio-Social scores were not related to gender, age, duration of treatment, or symptoms. Those with a psychosis diagnosis had a higher Bio-Social mean (4.36) than those without a psychosis diagnosis (4.12), i.e. they had a stronger social perspective (t = 2.79, df = 522.7, p = .007). USA participants had a lower mean Bio-Social score than other participants (4.03 vs 4.31), i.e. they had a less social perspective (t = 2.84, df = 569, p = .005).

Table 2 Examples of allocations of 'Bio-Social' scores

1 = purely 'bio- genetic'	Serious mental illness affecting my brain
	chemical imbalance in the brain
(3.9%)	
	born with a disorder
	genetic disorder
2 = mixed 'bio- genetic'	Poor genetics, bad luck, and some compounding socio-economic factors
	I had some difficult life experiences which contributed to triggering my
(2.1%)	illness, but I believe that it is mostly physically based. A 'broken brain'.
	Inappropriate coping skills along with strong family history of mental disorders
3 = equally 'bio-	Both biological/genetic factors, and environmental factors
genetic' and 'social'	
	probably a mixture of genetics and life experiences
(13.5%)	
	Genes childhood scars

	A mixture of genetics and environmental effects e.g. sexual abuse Family conflicts, chemical imbalance
	Strong family hx of mental illness Rape & sexual assault
4 = mixed 'social'	Too much stress combined with grief. Lack of sleep.
(27.7%)	Traumatic childhood, hashis, ancxiety
	violiant assults, and drug and alcohol abuse
	Stress, alcohol, diet, work, family deaths, separation
	Intense grief, complex trauma and also an innate sensitive personality
5 = purely 'social'	Voice hearing caused by trauma
(52.9%)	The dead of my son
	Childhood sexual, physical and emotional abuse
	the passing of both parents in 5 months apart
	unresolved grief and early childhood emotional neglect

Table 3 Seven categories of causes, with sub themes

		Childhood	Adulthood	
SOCIAL	530	207	152	171 unclear
Trauma	214	98	11	105 unclear
Abuse/Neglect	146	112	45	11 both
Sexual	48	38	13	
Emotional	43	27	18	
Physical	29	20	11	
Bullying	17	17	-	
Neglect	22	22	1	
Stress	111			
Loss	46	Death of loved one	Relationship	Loss of parent
		29	11	10
Work	32			
Relationships	17			
Isolation	17			
Childbirth	17			
Poverty	16			
·				

PSYCHOLOGICAL	129			
Dysfunctional coping	25			
mechanisms				
Overwhelmed	21			
Spiritual	21			
Sensitivity	18			
Emotions	18			
Low self-esteem	14			
Dissociation	10			
Faulty thinking	9			
Perfectionism	7			
Existential	7			
Self-analysis	6			
Guilt/shame	6			
Attachment problems	4			
BIO-GENETIC	123	Genetics	Brain	Chemical
		93	dysfunction 21	imbalance 9
IATROGENIC	120			
Medication	67	Anti-depressants	Anti-psychotics	Benzodiazepines
		34	10	7
Professionals	67	Denying adversity	Misdiagnosis	Coercion
		20	17	12
DDUG LALCOWOL	=1			
DRUG and ALCOHOL	71			
Alcohol	16			
Marijuana	14			
LSD	5			
Ecstasy	3			
MEDICAL	48			
CONDITION	70			
Hormonal	10			
Brain injury	5			
Intestinal	5			
mesunar	3			
INSOMNIA	42			

3.3 Social causes

The themes emerging from the data were, by frequency: 'Social', 'Psychological', 'Iatrogenic', 'Bio-genetic', 'Drug and Alcohol', 'Medical Condition' and 'Insomnia' (Table 3).

Most participants (530, 75.6%) gave one or more responses that were categorised in the 'Social' theme, because they identified one or more adverse events or circumstances (excluding 'alcohol and drugs', 'iatrogenic' causes, 'insomnia' and' medical conditions'). Slightly more reported childhood events (207, 39.1% of the 530) than adult events (152, 28.7%) as causes, with the remaining 171 (32.3%) not reporting a time frame.

Women were more likely to report one or more social causes (78.4%) than men (70.2%) ($X^2 = 5.01$, p = .025). People with a psychosis diagnosis (81.9%) were more likely to report social causes than those with other diagnoses (73.2%) ($X^2 = 6.78$, p = .009). People in the USA were significantly *less* likely to report social causes (68.6% vs 78.2%; $X^2 = 6.80$, p = .009). Citing social causes was unrelated to age, symptoms, duration of treatment or helpfulness of the antipsychotics.

Responses were further categorised in nine sub-themes (see Table 2 and below).

3.3.1 Trauma

The words 'trauma' or 'traumatic' were used to describe causes by 214 people. Nearly half of these (98; 45.8%) located the trauma in childhood, 11 (5.1%) in adulthood and the rest did not state the time of life. The cause or type of the trauma was usually unspecified. The most common type of traumatic event specified, abuse, was cited by 46 (21.5% of the 214).

3.3.2 Abuse and Neglect

Abuse or neglect were reported by 146 people (20.8% of the 701). Of these, 112 occurred in childhood (76.7% of the 146), 45 in adulthood (30.8%), and 11 in both (7.5%). The frequencies

of the different types of abuse are recorded in Table 1. The perpetrator was usually not identified. Examples of childhood abuse/neglect include:

I believe being raised in a house with a dad with anger issues led me to live in constant fear as a child. But I didn't understand that fear so instead it changed to paranoid thinking like monsters or demons were coming to kill me. Then I developed protective delusions (such as me being a werewolf or God)

I suffered abuse as a child which I think caused abnormalities in my beliefs, self image, perception of the world, and my emotional responses

molestation by my grade 4 primary school teacher over period of a year

Trauma, stress, burnout, death of a parent while still a child, abusive and neglectful parenting, social isolation, bullying

Psychological abuse stemming from my own mom's abuse

Child Abuse, Teen Mum, Domestic violence, Physical Illness, Severe Depression, Hyper vigilance

Childhood abuse/neglect, professional and interpersonal stress, and life events leading to a temporary psychotic state

Extreme ongoing child sexual assault and being the victim of a paedophile network and not being believed and supported

prolonged trauma for 9 months when I was 12, this trauma included physical and emotional abuse and neglect. This was compounded by me telling adults about the abuse and they let the abuse continue

significant trauma throughout my childhood (sexual abuse, witness to domestic violence, emotional abuse), which caused me to become very fearful and withdrawn. I started hearing voices when I was a child

child and adult abuse - my world at that time was crashing and I broke, segmenting myself into pieces. My psychosis was a screaming message to others but mostly to myself

sexually abused by my father. I was so scared, confused etc. I began to hear his voice, although I knew he wasn't there

bullying at English public school for being physically and socially awkward

Incest over many years

My psychosis was a natural transition from the physical and mental abuse experienced as a child/teenager.... As a child if you don't have at least one adult that you know you can depend on to be there for you then what do you have? Paranoia, seclusion and hallucinations are a natural consequence of this abuse.

Was raped in the home for years beginning at the age six or before.

Examples of abuse in adulthood:

Adult Rape (re-triggered child sexual & physical & emotional abuse)

I was in an abusive relationship and had unresolved childhood trauma.

Young adult trauma. Rape. Oppressive depressed marriage. Divorce. Abusive relationships

Labeled bipolar after being raped. Was told i wasnt acting normal

Putting up with too many bullies Harassment at home Harassment in the workplace

3.3.3 Stress

'Stress' was cited as a cause by 111 people (15.8%), often with little or no elaboration about cause, type or age. Where the cause of the stress is identified the response is also included in another sub-theme, e.g. Abuse and Neglect; Poverty, etc..

3.3.4 Loss

A range of types of loss was reported by 46 people (6.6%), most commonly death of a loved one (29, including 10 loss of parent as a child and three loss of child as a parent), and relationship break-ups (11). Some examples include:

Trauma (sexual abuse) and my mum abandon me when i was 2

My son being taken off me and long time use of drugs

I have autism and my brother died. I couldn't manage the change and I ended up in a psychiatric hospital and then they started drugging me to calm me down as I didn't want to be there. That's how it all started.

Divorce and loss of children

Marriage breakdown with a young child

My moms murder years ago

Past trauma and environment, isolation, father's suicide, holocaust 1st generation German Jew, seeing my mom pass away from a heart attack

Life events around loss and threat of loss that led to severe depression with over valued beliefs/psychotic symptoms.

The dead of my son

The passing of both parents in 5 months apart

Best friend took his own life

Issues in the year prior to my psychotic episode. I had one grandparent pass away, and one who had to be moved into a care facility due to a rapid decline mentaly and physically due to dementia. I was very close to both of my grandparents and was heavily involved in their care during their declines. I also experienced a relationship breakdown with my long term boyfriend

3.3.5 Work

Problems relating to work was a cause for 32 people (4.6%). For example:

Workplace bullying

Working 12 hours a day, six days a week.

Empty life and boring work

3.3.6 Relationships

Relationship problems were mentioned as causes by 17 people (2.4%).

Issues in my relationships with friends, what they thought of me

Abusive marriage

divorce after 25 years of marriage

3.3.7 Childbirth

Problems during or soon after having a baby were reported by 16 women (3.2% of the women) and one man.

I had a baby and was totally unprepared for the huge changes this brought about to my life. I became isolated and withdrawn from family and friends

Psychological and physical abuse in my relationship, birth of my child/giving it up for adoption

I had three under three years and was living in another country and had almost no support

Childhood trauma, post natal psychosis

Struggling with becoming a dad and what to do with my life. It all became like pressure

3.3.8 Poverty

Financial hardship was cited by 16 (2.3 %):

Very little money and large debts

A lot of stress and living in poor quality housing

3.3.9 Isolation

Isolation or loneliness was cited by 16 people (2.3%):

Stress from poor living conditions and isolation

Traumatic brain injury, loss of identity, displacement from supportive peer group. These factors led to increased isolation and substance use

Traumatic childhood. Ostracized by peers

3.4 Psychological

129 respondents (18.4%) reported psychological or intrapersonal experiences, processes or characteristics as causes of their psychosis or other mental health problems. These were often, but not always, reactions to adverse events. Reporting a psychological cause was not related to any of the other variables investigated.

The most common sub-themes were Unsuccessful Coping Mechanisms (25), Feeling Overwhelmed (21), Spiritual Experiences (21), Sensitivity (18) and Difficulties with Emotions (18). Examples of these four, and eight others mentioned by four or more respondents follow.

3.4.1 Unsuccessful coping mechanisms

Twenty-five respondents reported ineffective mechanisms for coping, typically with adverse events or the feelings evoked thereby:

Difficult childhood experiences that led to unhelpful patterns of coping, a lack of emotional development and as a consequence emotional regulation difficulties

Trauma, not learning effective coping strategies in childhood due to father modelling anxiety & mother modelling depression

Living in an abusive household for the first eighteen years of my life, and used negative coping mechanisms as a result

developed, unknowingly, coping strategies to help me survive. Unfortunately I carried these same strategies into adult life where they did not serve me so well

3.4.2. Feeling Overwhelmed

A sense of being overwhelmed by events or feelings was reported to be a cause by 21 people:

An inability to match resources (psychological and emotional support, financial support, communication skills, living skills etc.) to the life event or set of circumstances that I had encountered. Feelings of being overwhelmed

Trans-generational experiences of overwhelming pain and powerlessness

I was in an abusive relationship then suffered a bereavement and just got overwhelmed by it all

3.4.3 Spiritual Experiences

Twenty-one people reported spiritual experiences as causes or explanations. Six wrote of a spiritual 'emergence' or 'awakening':

I had spiritual experiences which I couldn't share with people. This made me feel very lonely and strange

I had lost every member of my family over the course of 5 years . . . after 911 I was inundated with the dead spirits (which I can sense and sometimes see) in distress, I went into an extreme state

For me psychosis is always a deeply spiritual and religious experience

A spiritual emergence but at the time no one took me seriously and so I was force drugged

Psychological / spiritual / existential leading to unusual experiences, beliefs and behaviour

3.4.4. Sensitivity

Being very or too sensitive to events or emotions was cited as a cause by 18 people. The cause of the sensitivity ranged from genetics to trauma, but was often unstated:

I think that I was born more emotionally sensitive than others. This may have predisposed me to not being able to cope very well with emotional pain

Intense grief, complex trauma and also an innate sensitive personality

Trauma, extra sensitivity...NOT biological defect

I suppose it's been a combination of genes, sensitivity, life-events

3.4.5 Difficulties with Emotions

Problems tolerating or expressing emotions were cited by 18 people:

I had a complicated and heavy youth in which I suppressed my feelings

I have had trouble learning to regulate my own emotions and distress

Emotional expression wasn't modelled or encouraged in my family so I always tried to make myself seem happy and strong. I think many of my delusions, paranoia, and other symptoms were a response to fear, shame, guilt, and other emotions I couldn't easily access

3.4.6 Low Self-esteem

A negative view of oneself was considered a cause by 14 people

Low self esteem even though very confident on the outside

Low self esteem most of my life and focused on negative thoughts and negative past experiences

Belittled by my mother and ignored by my father. Did not like myself. I think the voices are a reaction to that

3.4.7. Dissociation

Ten people mentioned dissociation as a cause:

Processing the trauma of rape. Dissociating from the experience for years

Childhood abuse/trauma...disossaciation

3.4.8. Problematic thinking

Negative or problematic thinking was a cause for nine people:

Focused on negative thoughts and negative past experiences

Distorted core beliefs and thinking patterns

Lunesta [sedative] made me like a horse bolting out of the race gate, thinking all crazy thoughts mixed up

3.4.9. Perfectionism

For seven people perfectionism contributed to their psychosis or other problems:

I put quite a lot of pressure on myself to be perfect and work hard which is why I was so stressed

I also think that if you add trauma or shyness or perfectionism to the mix it can cause problems

3.4.10 Existential issues

Seven people mentioned existential issues as part of the problem:

Existential questions: wanting to change things in the world, but not knowing how

It's existential pain and emotional hardship and normal psychological reactions to trauma.

3.4.11 Self Analysis

Six people wrote about how efforts to understand themselves contributed to their psychosis and other problems:

I think the 'psychotic symptoms' I was medicated for were my attempts at understanding and making sense of things within me and in my environment that I was struggling to integrate.

I think the psychoanalytic therapy I had been receiving actually made my symptoms worse.

3.4.12 Shame and guilt

Six people cited shame or guilt as causes:

Locking the trauma, pain and hurt away and feeling isolated, damaged, ashamed and embarrassed

Influence of Catholicism which instilled a fear of 'hell', sin and ultimately guilt.

An abortion that I did not want but I couldn't see any way forward; misery and inability to forgive myself

3.4.13 Attachment

Four mentioned attachment problems:

Poor attachment with mother (and father) leading to distorted sense of self and fluctuating patterns of mood.

Childhood trauma, attachment disruptions, misattunement in childhood

3.5 Bio-genetic causes

One or more bio-genetic causes of the kind espoused by biological psychiatry, were reported by 123 participants (17.5%). Those reporting a bio-genetic cause were, on average, younger than other participants (41.2 vs 44.1 years) (t = 2.26, df = 694, p = .024). They were far more likely to find the antipsychotics helpful ($X^2 = 67.83$, p < .001). Participants with a psychosis diagnosis were less likely than those without such a diagnosis to cite a bio-genetic cause (14.1% vs 21.5%; $X^2 = 5.77$, p = .016). Bio-genetic causal explanations were unrelated to symptoms, treatment duration, or country.

The most frequently reported bio-genetic cause was 'genetics' (93; 13.3 % of the 701), followed by brain/neurological dysfunction (21; 2.9%) and chemical imbalance' (9; 1.3%).

3.5.1 Genetics

Of the 93 citing genetics, the majority (63) made a brief general statement like 'genetics' 'heredity' or 'biological predisposition' or wrote 'I was born this way'; 12 referred to genetic predisposition to a specific 'illness' or diagnosis, six reported 'family history' (which was assumed to imply genetic rather than social inheritance) and three wrote about being born more emotionally sensitive than others. For example:

I may have certain genes which predisposed me to react to trauma and illicit drug use with psychosis. But without the trauma and illicit drug use I don't think I would have experienced psychosis

There is a lot of mental illness in various branches of my family tree. I just happen to have one of the more dramatic versions and faulty/overactive brain processes are the result

3.5.2. Brain dysfunction

Of the 21 citing brain dysfunctions, eight made brief general comments about 'brain stuff', 'brain issues' or a 'broken brain', four wrote about having a 'neurological deficit' or being 'neurologically different'. Three had more specific theories:

Overstimulation of the brain, lack of filter to weed out useless stimuli.

My brain has difficulty metabolizing micronutrients, my gut gets easily off balance and I cannot get the nutrition I need to feed my brain from my diet.

Trauma or the use of substances can affect brain development and have more of an impact if they occur during childhood or adolescence.

3.6. *Iatrogenic*

120 people (17.1%) reported that the difficulties for which they were being medicated were caused or exacerbated by the medical treatment they received, i.e. either by psychiatric medications or by psychiatrists. People reporting iatrogenic causes were significantly older, on average, than other participants (47.6 vs 42.7 years; t = 3.75, df = 694; p > .001). Those with a psychosis diagnosis were less likely (12.3%) to cite iatrogenic causes than those without (21.7%) ($X^2 = 11.02$, p = .001). Citing iatrogenic causes was strongly related to finding the antipsychotics less helpful ($X^2 = 60.98$, p < .001). USA participants were more likely (30.3%) to report iatrogenic causes than other people (12.3%) ($X^2 = 31.55$, p < .001).

3.6.1. Medication

Sixty-seven people (9.6 % of the 701) mentioned prescribed drugs. Twelve stated that the drugs had made their problems worse.

Antidepressants made everything worse and ended up losing touch with reality.

Iatrogenic damage from antipsychotics causing rebound psychosis

The many types of medication I have been prescribed created other problems psychologically and physically.

The other 55 (7.8 %) stated that the prescription drugs had helped cause their problems:

Psychosis caused by the medication

The mood swings had been induced by Benzodizepines and their dose changes and reductions

Bad withdrawal reaction to Effexor XR spirals into polydrugging, suicidal thoughts, bipolar label

Anti-depressant induced mania

I believe the antipsychotic was prescribed as a direct result of symptoms caused by the abrupt withdrawal from antidepressant and antianxiety medication

I did not have psychotic symptoms until i tried to withdraw off Lithium.

Withdrawing from certain antidepressants caused severe psychotic episodes where I would hear, smell, see, feel and even taste things that I knew couldn't be real.

Withdrawal from antidepressants resulted in mania and psychosis

I took a benzodiazepine for caregiver stress and insomnia - after my mother died I cold-turkeyed off the benzo - i started shaking - I was diagnosed with agitated depression and medicated to insanity

It was while coming off effexor I started to get paranoid....psychiatrists told me there was no connection...but I'm not so sure.

By far the most frequently cited drug type was antidepressants (34), followed by antipsychotics (10) and benzodiazepines (7). Withdrawal effects were cited in ten antidepressant cases and four benzodiazepine cases. There were four cases of mania, and three of suicidality, induced by antidepressants, all leading to the use of antipsychotics.

3.6.2 Professionals

Sixty-seven people (9.6%) reported actions by mental health professionals, mostly psychiatrists, which caused or accentuated their problems, or both. The most common assertions were that psychiatrists had ignored or dismissed the traumas, adversities or drug withdrawals that had caused the psychosis (20), sometimes leading to misdiagnosis (17).

Was sent to psychiatrist and got schizophrenia diagnosis as had history of the same mother's diagnosis and my complaint of unfaithfulness of husband was dismissed as a symptom

Long history of severe abuse in family of origin which was ignored or not believed by those in the mental "health" profession. The trauma lead to homelessness, unemployment and labels galore.

Trauma as a child that surfaced following a mild head injury as an adult - psychiatrist diagnosed "factitious" disorder - said I was making it up - following several years as inpatient made everything worse

My father's repeated physical abuse, the neglect and lack of love in our family for so many years; being bullied by other children, and being falsely told that my terror and rage as a teenager represented an incurable brain disease

Was taken by exasperated parents to a psychiatrist in 10th grad. There received my (BOGUS) "diagnosis", and was put on drugs....Mellaril, Stellazine, Thorazine, etc.,.... Basically, I was an out-of-control teenager, in a drugged America

Hallucinations due to severe and prolongued sleep deprivation incorrectly diagnosed as psychosis.

True statements about life experiences labelled as 'delusions of grandeur' because they didn't believe me.

Twelve people talked about the use of coercion which made their problems worse, or without which they would not have been medicated.

Trauma was the actual cause, but I was coerced into treatment because of a wrongfully given bipolar diagnosis.

Forced into ECT and Risperidal and have been surrounded by Pro Psychiatry family and friends who demand my forcible commitment on a regular basis

I also tried to suppress my childhood but it kept popping up and I had nothing to understand it. As my behaviour escalated I was considered psychotic and locked up in a mental hospital and given antipsychotic medication.

Lots of past trauma and life stress related issues. My concerns were not addressed within the psychiatric hospital I was then attacked then held against my will and forced into medication.

Three people talked about 'incompetence' and 'poor training'. Two mentioned being medicated 'immediately' or after 'one or two minutes'. Two bemoaned not being offered any alternatives to drugs. One reported 'sexual and fysical abuse in psychiatry by the psychiatrist'.

Three of the sixty-seven complaints concerned professionals other than psychiatrists:

I think the psychoanalytic therapy I had been receiving actually made my symptoms worse.

They sent me to therapy, but I never felt listened to there

I was making no progress in therapy whatsoever, wasn't receiving any coping tools to deal with the intense, difficult emotions that I was experiencing.

3.7 Drugs and Alcohol

Seventy-one people cited drugs or alcohol (10.1% of 701). Men were three times more likely to report drugs and alcohol as a cause than women (19.7% vs 6.3%) ($X^2 = 27.39$, p < .001). Drugs and alcohol were reported more often by those with a psychosis diagnosis (133.4% vs 6.1%) ($X^2 = 9.64$; p = .002) and those with psychotic symptoms (14.6 vs 5.8%) ($X^2 = 14.80$; p < .001).

Nearly half (32/71)) used the generic terms 'drugs' and 'substances'. Specific substances cited by more than one person were: alcohol (16), marijuana (14), LSD (5), and ecstasy (3). Some explained the reasons and/or the effects:

I started drinking heavy & then self medicated with street drugs between 37 - 47 yrs old.

I took hallucinogenic drugs which blew open my mind...I interpreted it as a spiritual emergence but at the time no one took me seriously and so I was force drugged.

I was sexualy abused when I was 13, and started taking drugs and got into prostitution by the time I was 15. I think this also contributed to things because I hadn't received proper support around those things at the time.

3.8 Medical Conditions

Of the 48 reporting medical conditions as causes, six used general terms like 'chronic illness' or 'physical health issues. Thirty-two cited specific conditions, most commonly hormonal (10 -

all women, two in relation to childbirth and one relating to menopause), brain injury (5), intestinal problems (5), pain (4) and viral infections (4). Four cited surgery as a cause. Two reported injuries from car crashes. None of the other variables were significantly related.

3.9 Insomnia

Forty-two people (6.0%) reported that difficulty sleeping helped cause their problems. None of the other variables investigated were significantly related. Fifteen of the 42 identified the cause of their insomnia, most commonly stress (8) and withdrawal from psychiatric drugs (3):

I was suffering terribly from insomnia. Stress seems to really affect my sleep and I couldn't escape stress while in school.

I think work stress led to anxiety/insomnia

I believe the antipsychotic was prescribed as a direct result of symptoms caused by the abrupt withdrawal from antidepressant and antianxiety medication. I was not told that was the reason for my insomnia, anxiety and agitation.

Three described *how* the sleeplessness led to their problems, including:

Getting less and less sleep, leading to increasing feelings of euphoria, feeling powerful, which led to grandiose thoughts, convictions.

Hallucinations due to severe and prolongued sleep deprivation incorrectly diagnosed as psychosis.

4. Discussion

Before discussing specific findings, it is important to note that this study confirms that, when asked, most people with psychosis (and others taking anti-psychotics), can articulate the causes of the psychosis and/or other problems (Geekie, 2013; Carter et al., 2017, 2018). Of the 832 people who had taken antipsychotics, 701 (84.3%) provided clear answers to the question, many of

which were multifaceted. Of the 571 whose responses included Bio-genetic or Social causes, nearly half (43.3%) cited more than one of the seven types of causes identified in the thematic analysis (see Table 2). And some of those describing neither Bio-genetic nor Social causes cited more than one type of cause. For example, of those citing Psychological causes 10.4% also cited Medical Condition, 11.6% Insomnia, and 13.2% Iatrogenic.

Secondly, the finding that so many participants had been prescribed antipsychotics without a psychosis diagnosis (56.4%), or any psychotic symptoms (51.4%), is consistent with the increasing levels of 'off-label' prescribing (Carlton et al., 2015; Kales et al., 2017).

4.1 Social vs Bio-genetic

More than four times as many people (4.3: 1) cited Social causes (530) than did Bio-genetic ones (123). If Psychological causes (129) are included, to create a broader, psycho-social, set of causes (Read and Dillon, 2013), the ratio becomes 5.4 to one. This study therefore confirms the previous, smaller, studies (discussed earlier) demonstrating that people who experience psychosis are more likely to explain their psychosis in terms of life events and circumstances rather than genetic, neurological and biochemical factors. Social causes were equally endorsed by those with and without psychotic symptoms, and even more so by those with a psychosis diagnosis (82%) compared to those without (73%). Similarly, those with a psychosis diagnosis were less likely to cite Bio-genetic causes, and produced a higher mean Bio-Social score.

Although the focus of this study is causal beliefs, not causes, it is noteworthy that the participants' focus on social causes, especially abuse and trauma, is consistent with recent research findings (Read, 2019; Scott et al., 2019; Varese et al. 2012), as is their identification of a range of intrapsychic, psychological processes (Bentall, 2009; 2013). Their preference for social

over bio-genetic explanations is consistent with recent findings that the evidence for the latter has been exaggerated (Bentall, 2009; Joseph, 2013; Read and Dillon, 2013).

The findings that women, and older people are more likely to endorse social causes than biogenetic ones is consistent with most, but not all, previous studies of the public (Holzinger et al., 2012; Reavley and Jorm, 2014). (Most studies in this field fail to analyse by demographics.)

Unsurprisingly, those reporting bio-genetic causes were far more likely to have found the antipsychotics helpful, as were those scoring low on the Bio-Social scale (although endorsing a
Social cause was, unrelated). A recent British study of 311 people with experience of psychosis,
however, did not find any relationship between causal beliefs and self-reported responses to
medication, or to CBT or family therapy (Carter et al., 2017). In the current study it is not
possible to know whether the relationship was causal, or to determine the direction of causality. If
we assume that causal beliefs are in place before experience with antipsychotics it seems more
likely that the former influenced the latter. However, a reciprocal relationship between biogenetic causal beliefs and experiencing a medical intervention to be helpful is also possible.

4.2 Iatrogenic

Although there are anecdotal accounts of aspects of psychiatric treatment that have that made things worse for people (e.g. Dillon, 2010; Lampshire, 2012; Longden, 2010; Daya, 2015), there has been little research focus on iatrogenic causes of psychosis.

The most common iatrogenic cause was antidepressant medication, particularly withdrawal. This is consistent with a recent review finding that about half (56%) of people withdrawing from antidepressants will experience withdrawal effects and that for about half (46%) of those, the effects are severe (Davies and Read, 2019). Some of these effects, such as agitation and sleeplessness, can lead indirectly to psychosis, and, less often, psychosis can be a direct effect.

In terms of other iatrogenic causes, beyond psychiatric drugs, coercion was mentioned by some people as cause or exacerbator of their psychosis, sometimes because forced treatment triggers previous traumas. The most common non-medication iatrogenic causes, however, were denial of abuse and other adversities, with or without a subsequent misdiagnosis. This is consistent with recent reviews finding that psychiatric services still seldom ask about abuse and neglect (Read et al., 2018a), or respond therapeutically to disclosures thereof (Read et al., 2018b).

4.3 Lack of 'Insight'?

One response to these findings is to ignore them. Another is to discredit the beliefs as meaningless. The World Health Organization's study of nine international sites determined that 96% (780/811) of people diagnosed 'schizophrenic' exhibited 'lack of insight'. This was the most common of 27 symptoms (W.H.O., 1973, p.182). This notion that 'lack of insight' is a symptom of the illness has been frequently reiterated ever since; for example, in the British textbook 'Essential Psychiatry', which confirmed, 35 years later, that 'lack of insight' is 'the commonest symptom' of schizophrenia (Murray and Dean, 2008, p. 285). 'Lack of insight' has three components: recognition of one's symptoms as pathological, causal attribution of symptoms to having an 'illness', and acceptance of treatment (Amador and Kronengold, 2004; Buckley et al., 2007). So making causal attributions that involve your life experiences or circumstances is a clear sign of 'lack of insight', which, in turn, is a clear symptom of an 'illness' with a bio-genetic etiology, which your psychiatrist says you have got but which you are not so sure about. Some have gone so far as to assert that choosing not to believe in biological psychiatry's illness model and/or not accepting their treatments is not only a symptom of 'schizophrenia' but is a specific 'neurological deficit' called 'anosognosia' (Amador & Kronengold, 2004, p. 26). The Diagnostic and Statistical Manual concurs (A.P.A., 2013, p. 101). Believing that your psychosis is a

meaningful reaction to life events has always been proof that you are 'schizophrenic', ever since the invention of the construct over 100 years ago:

An often discussed criterion of cure is that of the patients' insight into the nature of illness. People who speak of their delusions and their weird behaviour during the attack as being pathological phenomena are not without reason easily considered as cured; whereas the opposite is thought of as being a rather certain sign of continuing disease. ... They realise, for example, the poor state of their nerves, the senselessness of their behaviour, but they insist that both are quite understandable reactions to stimuli and irritations of their environment. (Bleuler [1911] 1950, p. 257)

This is, ironically, reminiscent of the 'double bind' theory developed in the 1950s and 1960s as an explanation for how some people are driven crazy (Haley, 1959). The lay term is 'mindfucking' (McGinn, 2008).

4.4 Responding respectfully

A more respectful approach would be to give at least as much credence to the person's explanations as to our own. A UK government report recommended that people be supported to reflect on their own causal explanations, as part of a partnership care model (Schizophrenia Commission, 2012) enhancing therapeutic relationships and outcomes (Caret et al., 2017; McCabe and Priebe, 2004).

Respectful recognition of both the full range of causal explanations, and of the preponderance of social causes in the lives of people experiencing psychosis should, in conjunction with the confirmatory research mentioned earlier, lead to a more balanced, genuinely integrated approach to assessment and treatment, but one that places appropriate emphasis on the sorts of causes identified by those who know best about what has gone on in their lives (Cooke, 2017; Johnstone

& Boyle, 2018; Read and Dillon, 2013). This will require the development of 'trauma-informed-care' (Read et al., 2018a, 2018b; Sweeney et al., 2016).

4.5 Limitations

The sample was a convenience, rather than a randomised, sample. Generalisability is therefore limited, especially to members of ethnic minorities, who were underrepresented. It is, nevertheless, the largest study to date.

Online surveys might disproportionately attract people dissatisfied with the thing being surveyed. Bio-genetic causal beliefs were related to satisfaction with anti-psychotics; so it is possible that the preference for social over biogenetic causes was partially because the sample included a disproportionate number of people with bad experiences with antipsychotics.

Nevertheless, 37% found the drugs helpful, a proportion similar to antipsychotic trials (Hutton et al., 2013; Leucht et al., 2009).

Thematic analysis inevitably involves subjectivity when creating the themes and sub-themes generated. A smaller, more in-depth, study of the same topic produced three, rather than seven, themes ('Social/Interpersonal', 'Psychological', and 'Biological') plus 10 major sub-themes and 12 minor sub-themes (Geekie, 2013). Subjectivity is also involved in the allocation of statements to themes and subthemes. The potential for errors, however, was mitigated by using the *find* function in MSWord.

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