SURVIVING BUT NOT THRIVING, understanding the association of chronic psychosis with or without substance use on burden of care and quality of life for caregivers

Mmed protocol: DR J A Yerriah

Supervisor :   Dr S Paruk

Co supervisor :   Andrew Tomita

UKZN INSPIRING GREATNESS

Disclosure

- Funding was received from UKZN via Dr Tomita's research fund account, for participants travel expenses (caregivers R100 and patients R50)

Background and Introduction

- Schizophrenia is one of the top ten leading causes of disability in the world

- It affect the way people think, act and behave, and require lifelong treatment

- Inherent to the condition is functional decline and poor insight and judgement

- The responsibility of caring for patients with serious psychotic illness may involve many material, emotional and social challenges for caregivers.

- These challenges are only made worse by co-morbid substance use.

- Caregivers once overwhelmed and unsupported often forfeit this responsibility leading to a large number of admissions into psychiatric units on social grounds rather than clinical need.

Substance abuse and schizophrenia

- Nearly 50% of patients with schizophrenia have lifetime substance use disorders(1)

- Most common substances used are nicotine, alcohol, cocaine and cannabis(2)

- the odds of having a substance use related disorder were found to be 4.6 times higher for subjects with schizophrenia than the general population

- Dual diagnosis patients have worse outcomes in terms of course of illness, engagement in treatment, violence, homelessness, legal problems, life functioning, and physical illnesses

Substance use in Schizophrenia

- Cannabis use ranges from 18-80% in various studies

- Alcohol use varies with some studies citing one third of patients suffering alcohol use disorders and others no difference from general population

- Nicotine use has been reported in up to 90% of patients with schizophrenia

Link between SCZ and substance use

- Multifactorial, genetic, neurobiological, environmental
- two-hit model posits a neurobiological/genetic vulnerability interacting with an environmental stressor that leads to schizophrenia
- related model (the cumulative risk factor hypothesis)
- Self medication model
- "primary addiction hypothesis" or a "reward deficiency syndrome"
- These competing hypotheses are not necessarily mutually exclusive (4)

Effects on caregivers

- Numerous local and international studies attest to the difficulty experienced by caregivers of patients with serious mental illness such as schizophrenia and the effect on their quality of life (5-8)

- My personal experience was that the suffering of the caregiver was often overlooked, until it was too late

Research Question

What is the burden associated with caring for a person with schizophrenia spectrum disorder?

Does comorbid substance use increase burden of care for caregivers of patients with schizophrenia spectrum disorders?

Is there an association between increased burden of care and poorer caregiver quality of life?

Methods

- A caregiver was defined as all persons who support and help a person in need of care regularly for personal and non-professional reasons and was resident with the patient for a minimum of one year.

- Patients aged 18-45 and caregivers over the age of 18 where eligible to participate

- Data was collected from August 2019 and January 2020

Methods

- Ethical approval (BE121/19) to conduct the study was granted by Biomedical Research Ethics Committee of the University of KwaZulu-Natal.

- Further consent to conduct this study was granted by THH, KDH and provincial Department of Health

- We conducted a study of 101 matched-paired samples of family caregivers and adult patients (N=202) seeking care from two tertiary psychiatric hospitals in Kwazulu-Natal South Africa.

- The assessment consisted of an interview by PI with study participant, in English or Zulu and comprised 4 tools :
  - The sociodemographic questionnaire
  - Zarit Burden Interview for caregiver burden
  - WHO- BREF Quality of life scale
  - WHO ASSIST for substance use.

Zarit burden Interview

- developed to measure subjective burden among caregivers of adults with dementia. However, it has since been used in numerous burdens of care studies related to schizophrenia.

- Items were generated based on clinical experience with caregivers and prior studies resulting in a 22-item self-report inventory

- The factors include the caregiver's health, psychological wellbeing, finances, social life, stigma details, and relationship between patient and caregiver.

- The instrument has a possible score of 0 - 88, depending on the caregiver's responses.

- Responses are rated from 0 - 4, based on the level of distress

- Interpretation of Score:

    0 - 21 little or no burden

    21 - 40 mild to moderate burden

    41 - 60 moderate to severe burden

    61 - 88 severe burden

WHO QOL-BREF

- The World Health Organisation Quality of Live (WHOQOL-100) assessment was developed by the WHOQOL Group to provide a cross-culturally sensitive assessment tool (1998).

- It produces scores for four domains related to quality of life namely, physical and psychological health, social relationships and environment.

- The BREF is a shortened version with 26 questions

- Individual domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life).

- The mean score of items within each domain is transformed to a score out of 100 and used to calculate the total score.

WHO Assist

- This screening questionnaire developed by the World Health Organization (WHO) to establish the use of psychoactive substances, in patients.

- The test screens for 10 hazardous, harmful and dependent categories of substances: tobacco, alcohol, cannabis, cocaine, amphetamine-type stimulants, inhalants, sedatives, hallucinogens and opioids.

- The ASSIST generates a score for each substance or risk factor, with a stratification into low, moderate, or high risk based on respondent's pattern of use

Inclusion criteria	Exclusion criteria
The patient had received medication for a minimum of two years and was able to provide consent.	intellectual disability
Formal diagnosis was confirmed using DSM 5 criteria for schizophrenia spectrum and other psychotic disorders by clinical interview and chart review	comorbid neurocognitive disorders
	patient or caregiver refused to participate the pair were excluded from the study.

Results- Demographics

- The caregivers were predominantly female n= 83 (82.2%) and in their mid-50's (M=54.1, SD=13), with 60% being the patients parent

- The patients with schizophrenia spectrum disorders were predominantly male n=65 (64.4%) with the mean age of 31 years (SD=9,4).

Results Caregiver Burden and QOL

- The majority of caregivers (n=81; 80.2%) reported either high or severe caregiver burden, with mean scores on the ZBI being 56.1 (SD 17.6.)

- None of the four quality of life domains surpassed the 60% mark, where the observed score (out of 100) for physical and psychological health, social relationships and environment were 56.2 (SD = 16.2), 55.3 (SD = 17.6), 47.1 (SD = 19.3), and 53.5 (SD = 16.3) respectively.

Results

- In terms of the effect of caregiver burden on their quality of life, we found correlation between the QoL domains, with greater burden was associated with lower physical ($r = -.53$, $p < .001$), psychological ($r = -.54$, $p < .001$), social ($r = -.41$, $p < .001$) and environmental domains ($r = -.55$, $p < .001$)

Correlation matrix between caregiver burden and quality of life using Pearson's correlation coefficients

	Caregiver age	Burden	QoL - Domain 1 Physical	QoL - Domain 2 Psychological	QoL - Domain 3 Social	QoL - Domain 4 Environmental
Caregiver age	1					
Burden	0.17	1				
QoL - Domain 1 Physical	-0.40*	-0.53*	1			
QoL - Domain 2 Psychological	-0.16	-0.54*	0.72*	1		
QoL - Domain 3 Social	-0.29*	-0.41*	0.47*	0.58*	1	
QoL - Domain 4 Environmental	-0.22*	-0.54*	0.66*	0.6*	0.62*	1

*$p<0.05$. As the age and role of older caregivers are a major finding/implication in our study, we include aged in the correlation analysis.

Results- substances and caregiver burden

- High risk patient alcohol (β = 20.70, p = 0.04) and cannabis use (β = 15.41, p =0.02) were significantly associated with caregiver burden, but not in any of QoL domains.

Patient factors of caregiver burden and quality of life domains with alcohol use

Variable	Reference category		Burden			QoL - Domain 1 Physical			QoL - Domain 2 Psychological			QoL - Domain 3 Social			QoL - Domain 4 Environmental		
			adj β	SE	p	adj β	SE	p	adj β	SE	p	adj β	SE	p	adj β	SE	p
Age:			0.28	0.23	0.22	-0.29	0.18	0.11	-0.32	0.23	0.16	-0.33	0.25	0.20	-0.03	0.20	0.89
Gender:	[Male]	Female	-4.81	4.45	0.28	6.36	3.22	0.05	5.73	4.00	0.16	3.28	4.48	0.46	0.67	3.66	0.86
Income category:	[<R2501]	R2501-5000	-6.28	4.06	0.13	-1.85	3.78	0.63	-0.13	4.48	0.98	1.46	4.86	0.76	5.07	3.72	0.18
		>R5001	-6.86	4.16	0.10	10.63	3.62	<0.01	2.64	4.31	0.54	12.68	4.7	0.01	16.14	3.75	<0.01
Education attainment:	[Some college or higher]	High school and below	6.00	5.45	0.27	-4.91	4.00	0.22	-4.57	4.76	0.34	1.45	4.61	0.75	-6.42	3.94	0.11
Area:	[Urban]	Rural	1.34	5.36	0.80	-7.81	4.81	0.11	-5.31	5.89	0.37	-3.49	6.01	0.56	-3.43	4.18	0.41
Comorbidity:	[None]	Present	4.38	4.74	0.36	-10.93	4.42	0.02	-6.94	4.69	0.14	-4.26	5.05	0.40	-3.37	4.18	0.41
Alcohol risk:	[Med]	Low	17.7	8.78	0.05	-6.42	6.63	0.34	5.55	9.26	0.55	-5.42	8.5	0.53	7.17	8.28	0.39
		High	20.7	9.74	0.04	2.19	6.95	0.75	14.62	9.30	0.12	-6.41	9.56	0.50	4.51	8.39	0.59

Red highlight p<0.05

Patient factors of caregiver burden and quality of life domains with cannabis risk

Red highlight p<0.05

Variable	Reference category		Burden			QoL - Domain 1 Physical			QoL - Domain 2 Psychological			QoL - Domain 3 Social			QoL - Domain 4 Environmental		
			adj β	SE	p	adj β	SE	p	adj β	SE	p	adj β	SE	p	adj β	SE	p
Age:			0.20	0.24	0.40	-0.27	0.18	0.14	-0.35	0.24	0.15	-0.33	0.26	0.21	-0.02	0.21	0.91
Gender:	[Male]	Female	-4.69	4.54	0.30	6.11	3.26	0.06	4.62	4.18	0.27	3.15	4.7	0.50	0.87	3.76	0.82
Income category:	[<R2501]	R2501-5000	-5.6	4.18	0.18	-1.77	3.93	0.65	-0.50	4.5	0.91	1.52	4.9	0.76	4.83	3.75	0.20
		>R5001	-5.13	4.26	0.23	9.66	4.21	0.02	2.10	4.7	0.66	13.29	4.85	0.01	15.47	3.9	<0.01
Education attainment:	[Some college or higher]	High school and below	4.11	5.54	0.46	-5.72	4.01	0.16	-5.84	4.88	0.23	1.57	4.68	0.74	-5.95	4.29	0.17
Area:	[Urban]	Rural	0.84	5.05	0.87	-6.41	4.83	0.19	-4.11	5.81	0.48	-3.50	5.75	0.54	-3.91	4.01	0.33
Comorbidity:	[None]	Present	3.3	4.28	0.44	-9.84	4.2	0.02	-5.56	4.54	0.22	-4.00	4.83	0.41	-3.95	3.96	0.32
Cannabis risk:	[Med]	Low	8.28	5.86	0.16	-5.73	5.25	0.28	-0.55	7.38	0.94	1.37	6.01	0.82	-0.57	5.92	0.92
		High	15.41	6.71	0.02	-1.82	6.7	0.79	-1.66	8.56	0.85	1.93	6.91	0.78	-4.34	6.6	0.51

Limitations

- Cross sectional design, urban setting
- Relatively small sample size
- Psychological coping styles, religious affiliation, support, stigma, a sense of meaning and purpose in life
- Qualitative component will add value

Conclusion

The key finding of this study was the alarmingly high level of caregiver burden which had a negative effect on caregivers QOL

Most of the caregivers in this study were female, the mothers of the patient, and over the age of 55

Patient's modifiable factors that contributed significantly to higher burden scores were high alcohol and cannabis risk scores

Discussion

Interventions are needed that target substance abuse

Support is needed for caregivers especially female and elderly caregivers

Psychoeducation about substances of abuse and their implications for psychotic illnesses should be included at out- and in-patient settings early in the course of illness and on an ongoing basis

Managing dual diagnosis effectively is a key area in alleviating some of the caregiving burden experienced by caregivers of this vulnerable population

References

1. Volkow ND. Substance Use Disorders in Schizophrenia—Clinical Implications of Comorbidity. *Schizophrenia Bulletin* 2009;35(3):469-472.

2. Manseau, M. and M. Bogenschutz, *Substance Use Disorders and Schizophrenia.* Focus (Am Psychiatr Publ), 2016. **14**(3): p. 333-342

3. Winklbaur, B., et al., *Substance abuse in patients with schizophrenia.* Dialogues in Clinical Neuroscience006. **8**(1): p. 37-43

4. Khokhar JY, Dwiel LL, Henricks AM, Doucette WT, Green AI. The link between schizophrenia and substance use disorder: A unifying hypothesis. Schizophr Res. 2018 Apr;194:78-85. doi: 10.1016/j.schres.2017.04.016. Epub 2017 Apr 14. PMID: 28416205; PMCID: PMC6094954.

5. ADEOSUN, I. I. 2013. Correlates of Caregiver Burden among Family Members of Patients with Schizophrenia in Lagos, Nigeria. Schizophrenia Research and Treatment, 2013, 7.

6. AHLEM, H., ZGUEB, Y., OUALI, U., LAAJILI, Y., ALAYA, S. B., JOMLI, R. & NACEF, F. 2017. Family burden in caregivers of schizophrenia patients. European Psychiatry, 41, S799-S800.

7. CAQUEO-URÍZAR, A., ALESSANDRINI, M., URZÚA, A., ZENDJIDJIAN, X., BOYER, L. & WILLIAMS, D. R. 2017. Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. Health and Quality of Life Outcomes, 15, 76-76.

8. CAQUEO-URIZAR, A. & GUTIERREZ-MALDONADO, J. 2006. Burden of care in families of patients with schizophrenia. Qual Life Res, 15, 719-24.

9. CAQUEO-URÍZAR, A., GUTIÉRREZ-MALDONADO, J. & MIRANDA-CASTILLO, C. 2009. Quality of life in caregivers of patients with schizophrenia: A literature review. Health and Quality of Life Outcomes, 7, 84.

Thank you