










# The Experience of Living with Severe Asthma, Depression and Anxiety: A Qualitative Art-Based Study

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**Purpose:** Severe asthma, depression and anxiety often co-exist and increase disease burden. Currently there are no published studies investigating severe asthma and psychological comorbidity using arts-based methodology. We aimed to (i) illustrate the individual experience of adults living with severe asthma, with and without symptoms of depression and/or anxiety and (ii) to explore common characteristics depicted in artworks between those groups.

**Patients and Methods:** A qualitative arts-based study was conducted. Adults with severe asthma were categorised into two groups according to Hospital Anxiety and Depression Scale scores (<8 on either subscale [SA-D/A] (N=15) or (≥8 on one or both subscales [SA+D/A] (N=15)). Art thematic analysis was undertaken using a hybrid approach. The Common-Sense Model of Self-Regulation was used to examine frequencies in artworks.

**Results:** Participants with severe asthma alone and severe asthma with depression/anxiety were of older age (median 67 and 63 years respectively). There was greater asthma QoL impairment in participants with psychological comorbidity than without ( $4.7 \pm 8.3$  versus  $5.8 \pm 0.85$ ,  $p < 0.01$ ). Analysis of art works identified three themes: (1) “darkness” depicting misery, isolation and sadness; (2) “impacts” describing physical and social consequences; and (3) “resilience” illustrating acceptance and perseverance of living with all three conditions.

**Conclusion:** Art-based research in severe asthma facilitates detailed exploration of intimate and individual experiences. Darkness, impacts and resilience are common themes emerging from artworks. Understanding these experiences may help guide assessment and treatment of psychological comorbidity in the clinic.

**Keywords:** mental health, severe asthma, artworks, anxiety, depression

## Introduction

Severe asthma is a heterogeneous airway disease characterised by clinical phenotypes, biological endotypes, triggers and comorbidities.<sup>1</sup> Globally, severe asthma affects 3–8% of the estimated 334 million people with asthma.<sup>1,2</sup> Despite its lower prevalence, a sizeable burden still exists.<sup>3</sup> The significant health-related quality of life (HRQoL) burden in people with severe asthma results from the excessive symptom profile, high pharmacological treatment requirements and frequent life-threatening acute attacks.<sup>4</sup> Likewise, HRQoL burden is negatively impacted by the presence of comorbidities, particularly psychological comorbidity.<sup>5</sup>

In severe asthma, depression and anxiety are common psychological comorbidities. A multicentre cross-sectional and two-year prospective cohort study reported 38% of participants with severe asthma had anxiety and 25% had depression, compared to 30% and 9%, respectively of a non-severe asthma population.<sup>6</sup> Anxiety and depression also correlate with the level of asthma control<sup>7</sup> and may increase the risk of acute asthma attacks. Ten Brinke et al demonstrated an 11-fold increased risk for two or more acute attacks in people with severe asthma who experience comorbid depression and anxiety compared to those without.<sup>8</sup>

Whilst there are tools to screen for symptoms of depression and anxiety<sup>9</sup> and validated tools to assess illness expectations in asthma,<sup>10</sup> little is known about the experience of living with severe asthma<sup>11</sup> in conjunction with psychological comorbidity. It is recognised that life experiences are multi-sensory, multifaceted, and related in complex ways to time, space, ideologies, and relationships with others;<sup>11</sup> therefore, difficult to capture in an instrumented way. Artwork may be a methodology that can capture the true, unique and personal experience of those with an illness, but its utility has not yet been explored in gauging the experiences of a severe asthma population despite being increasingly used in other conditions including spinal cord injury,<sup>12</sup> myocardial infarction<sup>13</sup> and osteoporosis.<sup>14</sup> Cheung et al have used arts-based methodology to examine patient perceptions in mild-to-moderate asthma populations,<sup>15–17</sup> however no studies use arts-based methodology in a severe asthma population.

Our aim was to conduct a qualitative arts-based study to (i) illustrate and explore the individual experience of living with severe asthma, with/without depression and/or anxiety in an adult population and (ii) explore common characteristics in artworks produced in an adult severe asthma population.

## Materials and Methods

### Study Design

A qualitative arts-based study was conducted. Detailed assessment methods are outlined in the online [Supplementary Material](#). Arts-based research is outlined in [Supplement A1](#), additional data collection methods are outlined in [Supplement A2](#), Patient-Reported Outcome Measures (PROMs) in [Supplement A3](#), drawing/painting materials in [Supplement A4](#), the standardised interview script in [Supplement A5](#), prompting questions in [Supplement A6](#). The Common-Sense

Model of Self-Regulation (CSM) is further detailed in [Supplement A7](#). Participants were invited to complete an art-based activity. Additional data were gathered using PROMs to assess asthma control, quality of life, anxiety and depression and illness perception ([A3 Supplement](#)). Ethical approval was obtained from Hunter New England Health Human Research Ethics Committee Approval No. 2019/ETH12553. Our study was conducted in accordance with the Declaration of Helsinki and conforms to Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria for reporting qualitative research<sup>18</sup> (see COREQ [Supplementary File](#)).

### Participants and Recruitment

Adults with severe asthma were recruited consecutively from the John Hunter Hospital Department of Respiratory and Sleep Medicine's ambulatory care clinics and research database. Eligibility criteria for severe asthma and study exclusion criteria are outlined in [Table 1](#). Eligible participants were categorised into two groups according to the Hospital Anxiety and Depression Scale (HADS): severe asthma without depression and anxiety [SA-D/A] (<8 on either subscale), and severe asthma with depression and/or anxiety [SA+D/A] (≥8 on one or both subscales). All participants provided written informed consent prior to study commencement. Participants were informed as part of the consent process that any information used in publications would be unidentifiable.

### Materials and Procedure

Between 16 January 2020 until 11 March 2020, and 01 June 2020 until 17 August 2020, a single centre, qualitative arts-based study was conducted at the Hunter Medical Research Institute. Research activity was halted for 11 weeks due to COVID-19 restrictions and recommenced adhering to mandatory mask wearing and physical distancing measures. All participants completed a 2-hour face-to-face, one-on-one arts-based activity. To ensure uniformity, the same researcher (MS) facilitated all arts-based activities. Additionally, MS has no prior relationship with participants.

### Sociodemographic Information

Data regarding gender, age, education, formal mental health diagnosis, age at severe asthma diagnosis, exacerbation history and prescribed medications were gathered.

### Art-Based Activity

Participants were offered a range of drawing/painting materials ([A4 Supplement](#)). Participants received verbal instructions from the researcher following a standardised

**Table 1** Severe Asthma Eligibility Criteria

Severe Asthma Inclusion Criteria	Study Exclusion Criteria
(i) Doctor diagnosed severe asthma <sup>1</sup> (ii) Previous evidence of bronchodilator response $\geq 200$ mL or 12% (post-bronchodilator FEV <sub>1</sub> following administration of 400 $\mu$ g salbutamol); or (iii) Airway hyper-responsiveness in response to any standard challenge agent; or (iv) Peak flow variability (diurnal; variation $\geq 15\%$ or $\geq 50$ mL); and (v) Prescription of high dose ICS $\geq 1000$ mcg with LABA; or (vi) Maintenance prednisone; and  (vii) FEV <sub>1</sub> post bronchodilator: $<80\%$ Predicted; or (viii) FEV <sub>1</sub> /FVC $<70\%$ ; or (ix) ACQ score $\geq 1.5$ ; or (x) Severe exacerbation within the previous 12 months with OCS use	(i) Aged under 18 years (ii) Non-English speaking  (iii) Diagnosed cognitive impairment  (iv) Current diagnosis of acute psychosis (v) Inability to attend study visits (vi) Not willing or able to provide consent

**Abbreviations:** ICS, Inhaled Corticosteroids; LABA, Long-Acting Beta Agonists; FEV<sub>1</sub>, Forced Expiratory Volume in one second; FVC, Forced Volume Capacity; ACQ, Asthma Control Questionnaire; OCS, Oral Corticosteroids.

script ([A5 Supplement](#)). Participants were asked to paint/draw their experience of severe asthma. The researcher clearly articulated to participants that their views were the focus of the arts-based activity, not their artistic ability.

When artworks were completed (verified verbally by the researcher), participants described their work to aid interpretation/analysis. Guiding this discussion was Guillemín's adaptation<sup>19</sup> of Rose's critical visual methodology framework,<sup>20</sup> which explores the process of image production, composition of image, and relationship between image and the audience.<sup>15</sup> This framework guided prompting questions ([A6 Supplement](#)). Participants' descriptions of their artwork were voice recorded and transcribed verbatim.

## Data Analysis

In this study, reliability and validity were obtained via triangulation: rich descriptions of art works produced by participants, supporting quotes, and the use of the CSM model ([A7 Supplement](#)).

Qualitative data analysis was undertaken using a hybrid approach of deductive-inductive content/thematic analysis respectively. Artwork descriptive data transcripts were

coded using NVivo software. The lead researcher (MS) coded transcript data according to categories matching CSM domains. A second researcher (EM) independently coded 50% of transcripts (7 SA-D/A and 7 SA+D/A) with the same approach. Coding comparison (deductive approach) achieved 95% agreement with a Kappa coefficient of over 0.75 indicating excellent agreement across domains. Following this, MS and EM searched for patterns and frequencies were examined within CSM categories. Coded data were inductively analysed to generate themes (inductive approach). Any conflicting elements of data interpretation were discussed with co-authors EM, VC and VM until consensus was reached. Throughout analysis, transcripts were frequently reviewed, and artwork descriptive data were compared for areas of agreement. This was undertaken using coding stripes for visualization and consistency.

For quantitative data, statistical analysis was performed using STATA v.15 software. Descriptive statistics were used to characterise the population. Reporting of variables was decided based on the normality of the data spread. Parametric variables are reported as means (standard deviation (SD)) and non-parametric as medians (Q1, Q3). Student's *t*-test (parametric) or the Mann Whitney test (non-parametric) were used for group comparisons. A *p*-value of  $<0.05$  was considered statistically significant.

## Sample

In qualitative studies, data saturation is used instead of formal sample size calculations. Data saturation is a term used to indicate that no new information is expected to be added that will enhance or change the findings of a study. Data saturation was achieved after  $N=30$  participants were recruited.

## Results

### Participant Characteristics

Demographic results are detailed in [Table 2](#). There were more females in SA+D/A than SA-D/A [10 (67%) versus 7 (47%)  $p=0.27$ ], although not statistically different. Participants in both groups were of similar age and education level, with similar exacerbation history in the past 12 months, use of biological therapy, maintenance oral corticosteroid use and ICS dose. A higher proportion of the SA+D/A group had a formal mental health diagnosis compared to SA-D/A [8 (53) versus 1 (7),  $p=0.01$ ]. Age at diagnosis of severe asthma was significantly younger in SA+D/A compared to SA-D/A ( $28.3 \pm 17.5$  versus  $42.7 \pm 18.7$ ,  $p=0.04$ ). HADS scores were significantly higher in SA+D/A compared to SA-D/A. The

**Table 2** Participant Demographics and Patient-Reported Outcome Measures

Characteristic	Severe Asthma without Anxiety/Depression (SA-D/A)	Severe Asthma with Depression/Anxiety (SA+D/A)	p-value
N	15	15	-
Sex, F (%)	7 (47)	10 (67)	0.27
Age (y), median (Q1, Q3)	67 (43, 79)	63 (28, 82)	0.21
Education, n (%)			1.00
High school qualification	6 (40)	5 (33)	
Certificate or diploma qualification	5 (33)	5 (33)	
Bachelor or higher degree qualification	4 (27)	5 (33)	
Age at diagnosis of severe asthma (years), mean $\pm$ SD	42.7 $\pm$ 18.7	28.3 $\pm$ 17.5	<b>0.04</b>
Exacerbation past 12 months, median (Q1, Q3)	1.0 (0, 3.5)	2.0 (1.5, 3.5)	0.42
Hospital admission past 12 months, mean $\pm$ SD	2.1 $\pm$ 0.7	2.1 $\pm$ 0.7	0.50
Biological therapy, n (%)	12 (80)	10 (67)	0.64
Use of maintenance oral corticosteroids, n (%)	6 (40)	3 (20)	0.59
ICS dose (beclomethasone equiv. $\mu$ g/day), median	2000 (2000, 2000)	2000 (2000, 2000)	1.00
Formal mental health diagnosis (%)	1 (7)	8 (53)	<b>0.01</b>
HADS (anxiety score), mean $\pm$ SD	3.9 $\pm$ 2.4	11.1 $\pm$ 3.2	<b>&lt;0.0001</b>
HADS (depression score), mean $\pm$ SD	2.3 $\pm$ 1.7	8.2 $\pm$ 3.9	<b>&lt;0.0001</b>
Health-related quality of life and asthma control			
BIPQ score, mean $\pm$ SD	32 $\pm$ 11.7	44.2 $\pm$ 8.8	<b>&lt;0.01</b>
PCAQ score, mean $\pm$ SD	27.4 $\pm$ 3.4	26.4 $\pm$ 3.8	0.45
EQ-5D-5L VAS score, mean $\pm$ SD	81.7 $\pm$ 11.4	67.9 $\pm$ 13.3	<b>0.01</b>
ACQ average score, mean $\pm$ SD	1.3 $\pm$ 1.3	1.9 $\pm$ 1.0	0.17
AQLQ total score, mean $\pm$ SD	5.8 $\pm$ 0.86	4.7 $\pm$ 0.83	<b>&lt;0.01</b>

**Notes:** Parametric variables are reported as means (standard deviation (SD)) and non-parametric as medians (Q1 and Q3). Student's t-test (parametric) or the Mann Whitney test (non-parametric) were used for group comparisons. A p-value of <0.05 was considered statistically significant. Bolding indicates a significant p-value of <0.05. **Abbreviations:** SD, Standard Deviation; HADS, Hospital Anxiety and Depression Scale; BIPQ, Brief Illness Perception Questionnaire; PCAQ, Perceived Control of Asthma Questionnaire; EQ-5D-5L VAS, Visual Analogue Scale; ACQ, Asthma Control Questionnaire; AQLQ, Asthma Quality of Life Questionnaire.

degree to which illness is perceived by participants as threatening was worse in SA+D/A compared to SA-D/A (44.2  $\pm$  8.8 versus 32.0  $\pm$  11.7,  $p$  < 0.01) as indicated by Brief Illness Perception Questionnaire scores (Table 2). Self-rated health indicated by EQ-5D-5L Visual Analogue Scale (VAS) scores were lower in SA+D/A compared to SA-D/A (67.9  $\pm$  13.3 versus 81.7  $\pm$  11.4,  $p$  = 0.01) indicating poor QoL in participants with symptoms of depression and/or anxiety (Table 2). Furthermore, HRQoL impairment was higher in SA+D/A compared to SA-D/A as indicated by Asthma Quality of Life (4.7  $\pm$  0.83 versus 5.8  $\pm$  0.85,  $p$  < 0.01) scores (Table 2).

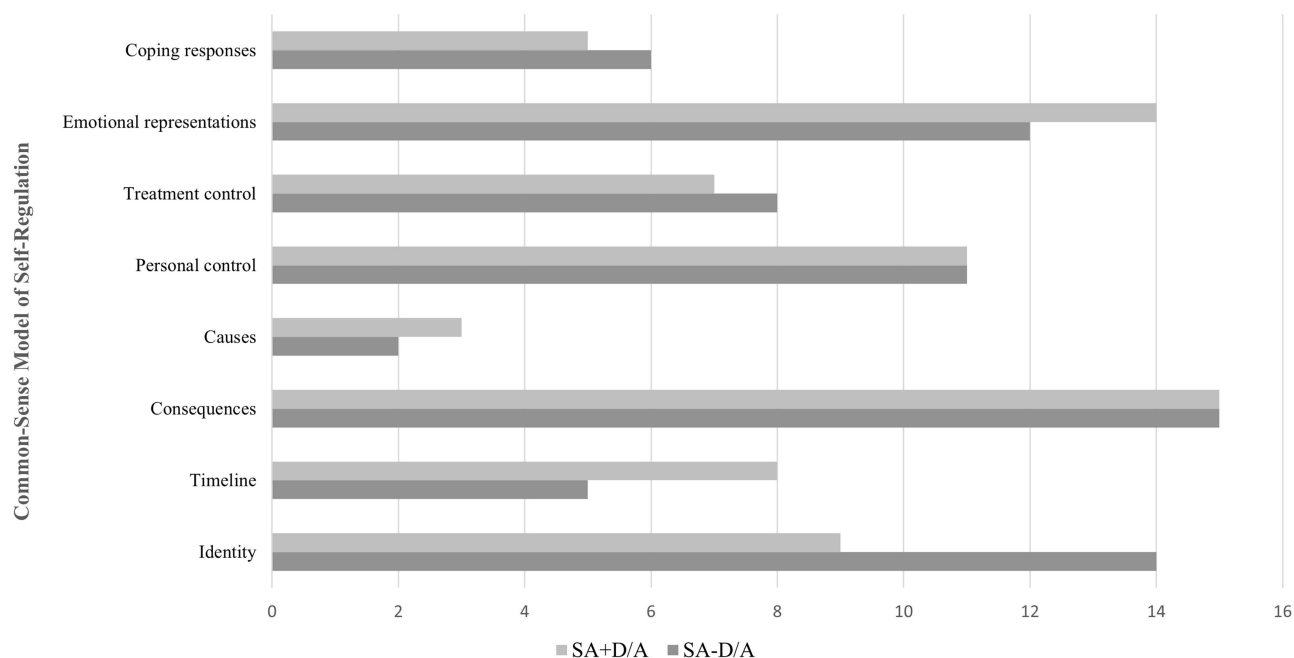
## Common-Sense Model Coding of Artworks

CSM domains were represented in artworks (Figure 1). Consistent with emerging themes, participants illustrated and/or described consequences of living with severe asthma with/without symptoms of depression and/or

anxiety which included physical, social and mental impacts. A number of artworks illustrated emotional representations of the CSM including darkness, misery and helplessness. Personal control was depicted in artworks and expressed as resilience with main features of acceptance and perseverance.

## Themes from Participants' Artworks

Artworks produced by participants were diverse. Content of artworks varied from being unembellished to entirely abstract. Some artworks included symbolic representations with deliberate lack of colour. Participants chose assorted combinations of art materials and used techniques conveying their emotions, thoughts, and complex history. These results include not only direct content of artworks, but participants' stories and sentiments. Three themes emerged from inductive analysis: (i) darkness, (ii) impacts and (iii) resilience. Illustrative quotations supporting each theme are presented in Table 3.



**Figure 1** Coding of artwork according to the CSM.

**Abbreviation:** SA+D/A, severe asthma without depression and/or anxiety; SA-D/A, severe asthma with depression and/or anxiety.

## Theme 1: Darkness

Emotional burden depicted by features of darkness was predominant in SA+D/A. Several artworks depicted misery, helplessness and detachment. A participant shared “I was in a dark spot and I didn’t really see a way out of it. I just felt like I was surrounded by darkness - male, 29 years.” The view that severe asthma diminishes QoL is represented in [Figure 2A](#) where the participant described components of her artwork: “the top layer is where I destroyed the painting, and that’s what asthma does, it destroys your life - female, 59 years.” The initial use of colour highlighted the perception of vibrant aspects to a healthy life including growth and happiness. The subsequent destruction of the painting mirrors the perception of the impacts of severe asthma on her life.

The outcome of living with severe asthma and symptoms of depression/anxiety is depicted as a dark, unhappy place. This burden was likened to a black hole of misery: “It just sucks the life out of you, and you end up in a big black hole of misery - male, 71 years.” ([Figure 2B](#)). Artworks illustrated the perception of living a chaotic life with mental health issues resulting in gloomy emotional representations. Colours including dark blue, grey and black were used as symbolic representations of hardships endured living with severe asthma and symptoms of depression and anxiety: “The black is when it gets on top of me, and it does a bit -

female, 71 years.” The same despondent emotion was described by a participant who sketched a black car on a clifftop, surrounded by dark grey clouds and an unruly navy-blue ocean at the bottom of the cliff: “It’s just dark. It’s unhappy. It’s just a bad, bad, place to be - female, 49 years.” ([Figure 2C](#)).

## Theme 2: Impacts

Physical and social consequences of living with severe asthma with or without symptoms of depression and anxiety were common issues in artworks. Participants created artworks demonstrating or symbolising exclusion and restriction. One participant shared the meaning behind this sentiment ([Figure 3A](#)):

There are a lot of things you have to say no to. If there’s a bus trip and your lungs are tight you say no. I want to get up and go but it’s like a ball and chain holding you back – female, 80 years.

Another participant shared: “The feeling of frustration when I can’t participate or play my activities as I normally would – male 68 years.” ([Figure 3B](#)). Whilst some participants were frustrated due to impaired activity capabilities, others expressed the extent to which severe asthma interfered with life. A female participant aged 59 years expressed: “When I’m unhealthy it overtakes everything, every aspect it interferes with.” This is illustrated by

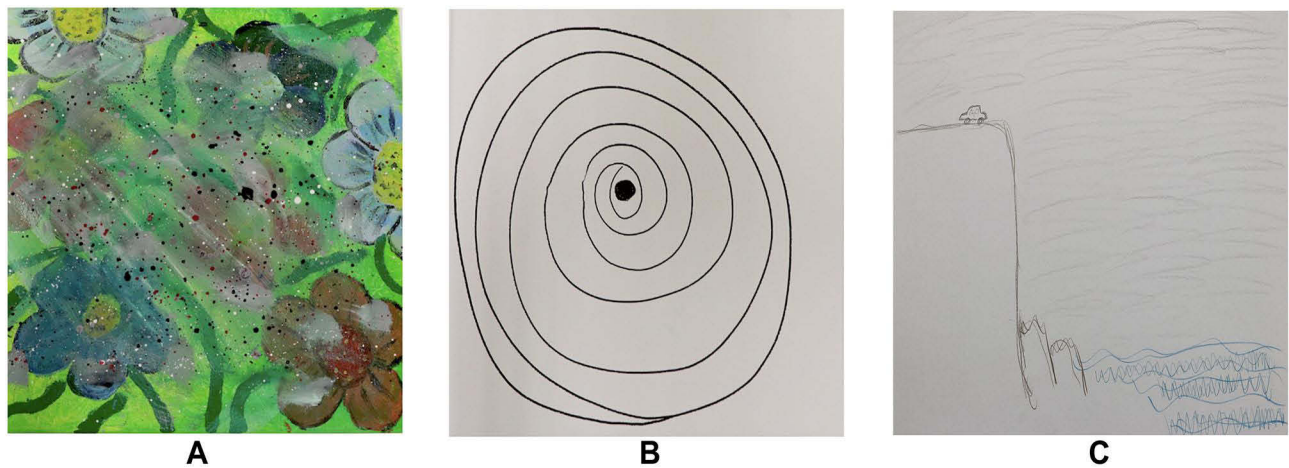


**Table 3** Themes and Illustrative Quotations

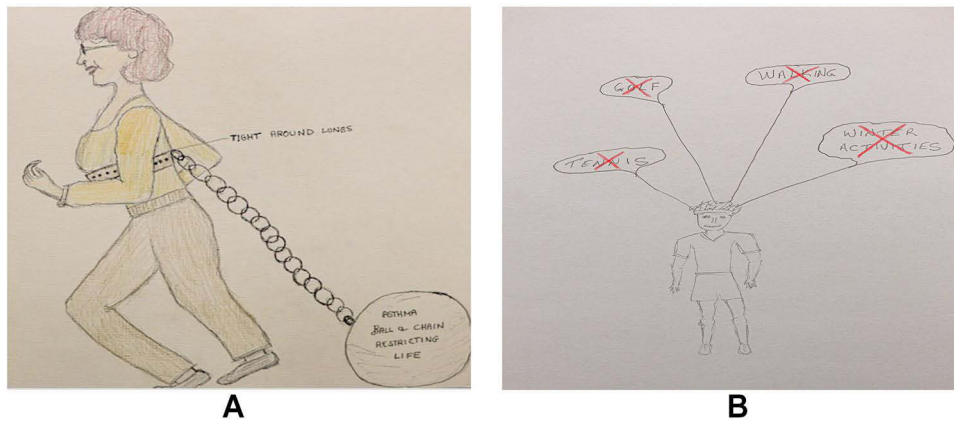
Theme	Severe Asthma without Anxiety/Depression (SA-D/A)	Severe Asthma with Depression/Anxiety (SA+D/A)
Darkness	<p>1.a.i I just feel stress, uncomfortable, worried and depressed (female, 64 years)</p> <p>1.a.ii Severe asthma is just suffering (male, 80 years)</p> <p>1.a.iii The sun's bright because that's the way it should be, and the other ones are dark because that's a dark feeling if you do not control that, bringing you down (female, 73 years)</p>	<p>1.b.i It's how I feel about asthma, depression and anxiety. That they all control me and keep me within the brick walls. They keep me from seeing the sunshine (female, 56 years)</p> <p>1.b.ii When you have severe asthma it's just like any chronic illness, a myriad of different complaints. It just dark and depressing (male, 71 years)</p> <p>1.b.iii I have only used darker colours because there was certainly no happiness. It was completely devoid of any real colour (female, 49 years)</p> <p>1.b.iv Severe asthma is just a dark cloud. To me it's just a cloud over you, and it hovers over you all the time (male, 75 years)</p> <p>1.b.v The first thought was going from dark into lightness. But as I kept going, it did not go that way (female, 62 years).</p>
Impacts	<p>2.a.i Just the feeling of frustration when I cannot participate or play my activities as I normally would (male, 68 years) A24)</p> <p>2.a.ii Once I got severe asthma life was reduced to just getting dressed in a day, sometimes not even getting dressed in a day. You lose so much (female, 59 years)</p>	<p>2.b.i I used to sit outside and look at how nice everything looked, but I would never feel well enough to go out there (male, 29 years)</p> <p>2.b.ii As I said, it put an end to my cricket career I had planned (male, 76 years)</p> <p>2.b.iii I am not able to do everything that I could do back down there. I think every aspect of my life has gone downhill (male, 69 years)</p> <p>2.b.iv A lot of things do not happen anymore in life (male, 60 years)</p> <p>2.b.v The deterioration of my life, I suppose, and my world (male, 57 years)</p>
Resilience	<p>3.a.i This gives a representation of me and my disease and my approach to my disease and managing it the best I can with my respiratory teams and keeping a positive outlook on life (male 67 years)</p> <p>3.a.ii I just hope the majority of the time this is me, not this poor sad things down here that's woe is me. Woe is me gets you nowhere. You have got to be I can do this. You know you are sick and that your illness is there, but do not let it rule you (female, 73 years)</p> <p>3.a.iii You are trying to remember that you will get help there and you will feel better (female, 73 years)</p> <p>3.a.iv It's an expression and representation of how I feel, the struggle I have with breathing, the fact that the sun rises and that there's something to look forward to always, as indicated by the happy faces (male 76 years)</p>	<p>3.b.i I need to focus on the good things in my life instead of what's happening that's bad (male, 29 years)</p> <p>3.b.ii Just never give up (male, 71 years)</p> <p>3.b.iii I think there is a lot of positive about it too, because I have been able to grow through it. You learn your life and you grow through it (female, 71 years)</p>

a pair of trees, one with healthy deep green leaves, its trunk surrounded by verdant grass and a vibrant blue sky. The second tree is coloured charcoal grey and black with a dreary skyline and dull, dry soil (Figure 4A). This artwork juxtaposes healthy and unhealthy. The concept of healthy and unhealthy is also connected to loss of self as

expressed by a female participant aged 42 years: “Life should be growing and constantly changing, but for the last 7 years, I lost most of my life.” Furthermore, artworks presented the concept of deterioration and isolation (Figure 4B). A participant (female 63 years) verbalised these concepts:



**Figure 2** (A) Female, 59 years, ACQ6 average score: 4, (SA-D/A). (B) Male, 71 years, ACQ6 average score: 2, (SA+D/A). (C) Female, 49 years, ACQ6 average score: 3, (SA+D/A).



**Figure 3** (A) Female, 80 years, ACQ6 average score: 2, (SA-D/A). (B) Male, 68 years, ACQ6 average score: 1, (SA-D/A).

I go away with a group of girls every year. They'd go hiking up the mountain, I couldn't go. They'd go for a walk along the beach, I couldn't go. I was left just sitting on the beach watching.

### Theme 3: Resilience

Characteristics of coping were portrayed in artworks regardless of the presence/absence of psychological comorbidity. Artworks highlighted acceptance and



**Figure 4** (A) Female, 59 years, ACQ6 average score: 0, (SA-D/A). (B) Female, 42 years, ACQ6 average score: 2, (SA+D/A).

perseverance being key attributes in coping with severe asthma. A female participant aged 80 years shared: “You have to keep your mojo healthy because that’s the thing inside of you that keeps your spirits up.” Whilst thematic similarities were evident in artworks, there were differences in language used between groups. Participants in SA-D/A used the word “positive” indicating hope for the future. A participant demonstrated this with artwork primarily using yellow, symbolising sunshine, hope and happiness. The participant gave further insight into their drawing (Figure 5A): “Try and be positive about everything that you can that’s in your control. Just get along with life the best you can with what you’ve got – female 73 years.”

Whilst participants in SA+D/A also depicted attributes of acceptance and perseverance, narratives alongside artworks included words that described struggle. A female participant aged 35 years shared (Figure 5B): “It was tough, but I got through it, I’m still here, I’m still chugging forward, it hasn’t beaten me.” The participant described/illustrated the struggle of living through the bushfire season due to her severe asthma and psychological comorbidity. Depicting a grey smoke ridden sky, with fire engulfing a house, the participant describes a decline in mental health resulting from the isolation of having to remain indoors. The use of the colour red was intentional according to the participant and was a metaphor for danger.

## Discussion

This study aimed to illustrate/explore the experience of living with severe asthma, in the presence/absence of symptoms of depression and/or anxiety using artwork as a means of expression. This study is novel as it is the first to use an arts-

based method to (i) illustrate the individual experience of adults living with severe asthma, with and without symptoms of depression and/or anxiety and (ii) to explore common characteristics depicted in artworks between those groups. This study utilises both drawing and painting as a tool to investigate symptoms of depression and anxiety in people with severe asthma. Within our sample, three themes emerged. “Darkness” was most prominent in SA+D/A with artworks and descriptions highlighting unhappiness, misery and destruction of life. “Impacts” were described by participants regardless of psychological comorbidity. Physical/social consequences were portrayed with a focus on levels of interference on daily life and reduced QoL. “Resilience” was the last emergent theme. Features of resilience included acceptance/perseverance with differences found in language used between groups.

Content of artworks reflected unique accounts of living with severe asthma alone and with symptoms of depression/anxiety. Artworks were a non-verbal catalyst for participants to communicate rich meanings of their experience. Since artworks are subjective by nature, adjoining verbal descriptions allowed for deeper insight into the participants’ experience. At times, verbal descriptions were equally as compelling as artworks. Heterogeneity of participant experiences was showcased via techniques of juxtaposition, symbolism and metaphors. Heterogeneity was also aided by various art materials including paints, pencils and canvas chosen (A4, Online Supplement). Interestingly, similar to our findings in severe asthma, the use of colour, descriptive metaphors and language is reported in a study conducted by Cheung et al who explored the use of drawing in a mild to moderate asthma population.<sup>15</sup>



**Figure 5** (A) Female, 73 years, ACQ6 average score: 0, (SA-D/A). (B) Female, 35 years, ACQ6 average score: 2, (SA+D/A).



Artworks of participants in SA+D/A reflected downcast attitudes aligning with the emotional representation CSM domain (Figure 1). Participants described dark holes, misery and isolation with some artworks completely lacking colour or using shades of grey and dark blue. Artworks depicting a lone car on a cliff top, a small crying female alone on a large white canvas, and a small room with dark grey clouds hovering over an empty bed symbolise the experience of low mood and isolation. Participants created artworks portraying life to be void of enjoyment aligning with BIPQ scores indicating the degree to which illness is perceived as threatening, is worse in SA+D/A compared to SA-D/A. Studies investigating the choice of colour in depressed/anxious individuals report that patients viewed life as “monochromatic”<sup>21</sup> or having “lost its colour”<sup>22</sup> and support the choice of grey, dark blue and black in artworks of our study. This aligns 5Q-5D-5L VAS findings, with SA+D/A participants’ self-rated health score lower compared to SA-D/A scores. From a biological standpoint, the lack of colour in artworks may be attributed to decreased retinal response.<sup>23</sup> A significant decrease in retinal sensitivity is reported in depressed and anxious people.<sup>23</sup> Low mood and psychological comorbidity foster a viewpoint that the world is a drab, colourless environment, perpetuating emotions of loneliness and sadness.<sup>24</sup> This highlights the importance of timely and routine assessment of mental health in severe asthma populations in an attempt to improve QoL.

Social restrictions that impact life are portrayed in artworks regardless of psychological comorbidity. Artworks and verbal descriptions highlight impairment resulting from the inability to attend social outings with friends/family. As these aspects directly relate to HRQoL burden, we should not underestimate the impact of this in people with severe asthma.<sup>25</sup> When participation in social activities is decreased, feelings of isolation and loss are experienced. This fosters feelings of exclusion, and a loss of connection/detachment results that may lead to symptoms of depression and/or anxiety. A study by Foster et al<sup>26</sup> support this where one participant describes the burden of severe asthma: “I have lost every facet of my life ...” This quote reinforces findings of our study where a female participant aged 42 years describes: “I actually lost most of my life.”

Physical restrictions that impair/interfere with and impact life are common in artworks in both groups and align with the cognitive facet (consequences domain) of the CSM, confirming our pictorial results and adjoining

verbal descriptions. A severe asthma study by Dockrell et al found 70% of participants reported restrictions in physical activity.<sup>27</sup> Limits in leisure/lifestyle (78%) are also reported by Nelson et al in people with severe asthma.<sup>28</sup> These limitations lead to people with severe asthma feeling isolated or “alone with asthma”.<sup>26,29</sup> Importantly, Clark et al sought to determine outcomes of importance to people with severe asthma, with participation in activities rated among the most important priorities.<sup>30</sup> This gives insight into how greatly patients’ lives are affected and suggests precision assessment of severe asthma including mental health should occur in severe asthma clinics.<sup>31</sup>

Although people with severe asthma have increased psychological stress and difficulty coping with disease (emotionally/behaviourally),<sup>32</sup> artworks highlighted acceptance and perseverance as key attributes of coping. Our results are similar to results of a drawing study in asthma,<sup>15</sup> where aspects/perceptions of strength and empowerment were depicted. These artistic representations align with the value people with severe asthma place on improving overall QoL, as reported in a study by Clark et al.<sup>30</sup> Overall improvements in QoL may be dependent on coping strategies employed by people with severe asthma.<sup>25</sup> The use of negative language or language that indicates struggle (as observed in SA+D/A, Table 3) may be seen as an indication of their circumstance and sizeable disease burden. Furthermore, as language is fundamental in the expression of emotions,<sup>33</sup> language used by people with severe asthma alone and with symptoms of depression and/or anxiety should not be ignored. Words spoken, or thought, will either help increase resilience or actively work against it, resulting in poorer perceptions of their health. Cognitive behaviour therapy builds a set of skills that enables individuals to be aware of thoughts and emotions,<sup>34</sup> and could play an important role in the treatment and management of people with severe asthma.

This study has implications for clinicians in identifying how people with severe asthma, both with/without symptoms of depression and/or anxiety, view and cope with their disease. Early recognition of symptoms of depression and/or anxiety by clinicians can be used to facilitate assessment and referral to psychological services. Art-based activities could be incorporated into asthma management programmes where they may help guide clinicians to identify the patients’ overall experience of living with severe asthma both with and without symptoms of depression and anxiety. Additionally, having the clinician

hear and appreciate the language used to describe the created artworks may also enable them to gain a deeper understanding of the patient's coping and disease burden levels, which may enhance person centred care.

The potential "value-add" in understanding the experience of living with severe asthma and psychological comorbidities gained through facilitating creative expressions (such as artwork) as an adjunct to traditional methods of medical interviewing/history taking is demonstrated in the current study and bodes well for future patient-centred models of care.

We note some limitations. The study population was of older age, hence study findings across age groups are unclear. This study excluded non-English speaking individuals, though artwork could be used in individuals with verbal communication difficulties resulting from functional or language barriers.<sup>15</sup> Data surrounding coexisting comorbidities were not collected in this study. Future research looking at these is warranted. We acknowledge the COVID-19 pandemic may have increased levels of depression and anxiety within our study cohort, however COVID-19 was not specifically reflected in any artwork or their descriptions of such. Furthermore, whilst the aim of our study was to illustrate and explore the individual experience of living with severe asthma, with/without depression and/or anxiety in an adult population and (ii) explore common characteristics in artworks produced in an adult severe asthma population, future studies could include a comparison group of people with non-severe asthma.

Our study findings demonstrate that using arts-based methodology in research is valuable in increasing levels of understanding of the human experience.

## Conclusion

In conclusion, data from this study indicate that people with severe asthma with/without symptoms of depression and/or anxiety experience darkness and impacts from reduced participation in physical and social activities. Despite negative impacts they also demonstrate resilience. Arts-based research in severe asthma facilitates detailed exploration of individual experiences. An understanding of these experiences may help guide assessment and treatment of psychological comorbidity in the clinic.

## Acknowledgments

The authors would like to thank the study participants. Thanks to Janet Bristow, (Priority Research Centre for

Healthy Lungs, University of Newcastle, Australasian Severe Asthma Network) for assistance in recruitment. Special thanks to Amber Smith and Olivia Lewis (Priority Research Centre for Healthy Lungs, University of Newcastle) for assistance with eligibility status and purchasing of materials.

## Funding

This study was funded through a Seed Grant from the National Health and Medical Research Council Centre for Research Excellence in Severe Asthma, Australia and The University of Newcastle Postgraduate Research Scholarship.

## Disclosure

M.A. Stubbs reports personal speaker fees from AstraZeneca, outside the submitted work. V.L. Clark receives a fellowship from the National Health and Medical Research Council, Centre of Research Excellence in Severe Asthma, and also reports a grant from AstraZeneca to cover research-related costs, received for providing education to AstraZeneca staff, outside the submitted work. M. Cheung has nothing to disclose. L. Smith has nothing to disclose. B. Saini has nothing to disclose. J. Yorke reports personal fees from Dyspnea-12 questionnaire, personal fees from SGRQ-I questionnaire, outside the submitted work. E.C Majellano has nothing to disclose. P.G reports personal fees from AstraZeneca, GlaxoSmithKline and Novartis, grants from AstraZeneca and GlaxoSmithKline, outside the submitted work. V.M. McDonald reports grants and speaker fees from GlaxoSmithKline and AstraZeneca, and advisory board fees from Novartis, all outside the submitted work.

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