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Sex and intimacy in people with severe asthma: a qualitative study

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ABSTRACT

Introduction People with severe asthma experience unpredictable daily symptoms requiring an intense treatment regimen impacting on health-related quality of life (QoL). Sexuality contributes to this, yet there is a dearth of research exploring intimacy in people with severe asthma. We aimed to explore the patient's perception of the impact of severe asthma on intimacy, establish their information needs and their perceived role of the healthcare practitioner.

Methods We have performed a qualitative study guided by Interpretive Phenomenological Analysis. We interviewed patients diagnosed with severe asthma recruited from a dedicated clinic using purposive sampling. Interviews were audio recorded and transcribed verbatim. Using thematic analysis, the data were analysed for emergent themes. Results The nine interviews provided unique and detailed insights into their perspectives on how living with severe asthma impinges on sexual intimacy. Four superordinate themes emerged: (1) 'Physical intimacy': including disclosure of physical limitations of severe asthma on intimacy; (2) 'Emotional intimacy': the cyclical impact of the often-negative emotional struggle of living with severe asthma on relationships; (3) 'The role of the healthcare professional': a perceived failure of healthcare professionals (HCPs) to tackle sexual intimacy in consultations and (4) 'Image of self': the reported struggle to deal with negative body image and confusion regarding changing relationship roles.

Discussion This study is the first to explore the impact of severe asthma on intimacy. We suggest an emphasis on education to raise awareness and help HCPs to address this sensitive topic in this cohort and adopt positive strategies to help improve QoL.

INTRODUCTION

Severe asthma affects up to 5%-10% of the global asthma population and is characterised by persistent asthma symptoms that require intensive treatment, including high dose corticosteroids.1 While a strong link between poorer health-related quality of life (HRQL) and living with severe asthma is widely acknowledged,2 its impact on sexual function and intimate relationships is rarely considered. The WHO³ asserts that irrespective of disease or disability, being able to achieve good quality sexual function and

Key messages

- How does living with severe asthma impact on intimacy/sexual quality of life (QoL)?
- Living with severe asthma significantly impacts on sexual QoL and relationships, as healthcare professionals we have a duty of care to be able to address this topic and support our patients.
- This study is the first known in severe asthma to address such a sensitive topic, providing a novel and fascinating insights into the complexities of living with severe asthma.

sexual quality of life (QoL) is a basic human right. Shortfalls by healthcare professionals (HCPs) in addressing issues around sexual function in people with respiratory disease are well recognised; potential explanations include ignorance, fear of causing offence, awkwardness and unease with such intimate topics.4 In addition, some HCPs may have perceptions of chronically ill patients being non-sexual, assuming that due to physical restrictions patients are unable or unwilling to participate in sexual activity.⁵

A recent patient survey undertaken by Asthma UK⁶ reported that two thirds of participants felt asthma negatively affected their sex lives; yet none of the available validated health related QoL questionnaires for asthma address intimacy or sexuality. Such questionnaires are used as key endpoints in clinical research and in evaluating treatment responses, which in turn inform decision-and policy-making.

Using a systematic approach to review and appraise the current literature pertaining to intimacy and severe asthma, an absence of empirical studies was identified; therefore, the search was amended to include intimacy and asthma. Six papers were identified that were relevant to the topic of pursuit. An identified correlation between asthma, stress and the negative impact on sexual function is reported while a comparison of the sexual assessments of mild female asthmatics



against a healthy cohort demonstrated loss of desire and a higher prevalence of emotional issues impacting on intimacy. Additionally, the physical limitations of asthma are reported to impact on QoL which then negatively compounds on sexual quality of life. 9-12 A cross sectional study of asthma and patients with Chronic Obstructive Pulmonary Disease also reported that as well as physical difficulties such as breathlessness impacting on intimacy, they additionally reported a difficulty articulating sexual difficulties within the clinical setting and consequently suggested that this should be raised by the HCP within consultations to enhance patient care. 11

Therefore, while the impact of severe asthma and its treatment on intimacy is almost absent within research, clinical practice and policy, a review of evidence within the milder spectrums of asthma demonstrates the potential negative impact of the disease on intimacy which is potentially transferable to severe asthma. We have therefore conducted a study which aimed to explore the impact of severe asthma on sexual QoL and intimacy. We also aimed to determine the information needs of patients with severe asthma regarding intimacy and relationships and whether these are being sufficiently met by HCPs.

METHODS

Within this study, an ideographic approach to methodology was undertaken to augment and facilitate an in-depth, rich description of the participants' experiences which would otherwise have been difficult to capture using nomothetic methods. We used Interpretive Phenomenological Analysis (IPA), a qualitative methodology which aims to capture and understand the participants' narration of their experience of the phenomenon of interest ¹³ ¹⁴ and therefore was justified as the most appropriate methodology to facilitate meeting the study aims and objectives.

We used purposive sampling to recruit patients attending a regional severe asthma clinic in the North West of England. Potential participants were identified and approached to take part in the study by the asthma specialist nurses or consultant physicians whom were briefed in the study using the inclusion/exclusion criteria. Inclusion criteria included being >18 years with a confirmed diagnosis of severe asthma and in a current relationship. Potential participants were excluded if they had any known psychiatric disorders under the care of mental health team and/or an inability to communicate or speak English effectively.

Patients who were interested in the study were provided with written study information and were requested to contact the researcher if they wanted further information and to consent to participating. Participants were required to attend one face-to-face interview with one of the researchers (LJH).

The concept of conducting interviews within the family home was rejected following lone worker risk assessment and a possible risk of family distraction, due to lack of control over the home environment. The interviews were conducted in a quiet room within the familiar outpatient's department and often arranged to coincide with an existing hospital visit to reduce participant travel burden.

IPA fundamentally serves to extract the participant's description of their lived experience and in depth, semi structured interview is one of the most common methods used to facilitate this methodology. A simple predetermined semistructured interview schedule of six questions was developed in partnership with the specialist severe asthma clinical psychologist, to aid formulation of questions in advance (especially when considering the sensitive nature of the interviews) and was flexibly used to guide the interview and to guide participants if they veered away from topic of pursuit, thereby providing structure without restriction.

The interviews ran from March to May 2016 with no modifications to protocol based on the data collated. In alignment with IPA, cessation of recruitment occurred once data saturation was achieved.

Interviews were digitally recorded and transcribed *verbatim*, with data securely stored in encrypted password protected files. Each individual transcription was verified against the original recordings to facilitate both data immersion and assess the accuracy of the data enhancing trustworthiness and credibility. Emerging themes were developed by applying exploratory comments to individual participant narrative. Links and relationships between emergent themes were then identified and drawn together across all interviews to provide super ordinate themes and subthemes across the total data set. ¹⁴

All participants provided written informed consent and were fully informed of their ability to withdraw their participation at any time.

RESULTS

Twelve potential participants were approached, of whom one declined and two were unable to attend within the required timeframe. IPA methodology advocates recruitment numbers between 5 and 10 participants. Nine patients met the inclusion/exclusion criteria and participated in the one-to-one in-depth interview. Median (range) age of participants was 46 (34–59) years and six were female. All participants had a confirmed diagnosis of severe asthma as per ERS classification. Entire interview time comprised of 326.38 min; median (range) time for individual interviews was 37.39 (18.31–47.00) min.

Data are presented using the derived four super themes emerging from analysis. Subthemes were generated by using memorable titles, drawing on participant articulation (as described in table 1). Direct supporting participant quotations (ID number/gender/age) are found in tables preceding each section.

Table 1	Superordinate	and cube	rdinata	thomas
Table I	Superordinate	and Subc	rumate	unemes

Superordinate themes	Theme 1 Physical intimacy	Theme 2 Emotional intimacy	Theme 3 Image of self	Theme 4 Role of the Healthcare Professional
Subthemes	An overwhelming exhaustion	Pressure to perform	Self-loathing	Previous experience
	The 'third party'	Self preservation	Acceptance of self	A taboo topic
	Palpitations and paramedics	A problem shared	Carer vs lover	The ideal scenario
	Adaptation and experimentation			
	Practical difficulties			

Theme 1

Physical intimacy (table 2) portrayed the difficulties articulated by patients regarding the ability to participate in a physical sexual relationship as consequence of severe asthma.

All participants implied an expectation that a good sexual experience necessitated 'physical exertion'. However, even moderate effort was reported to limit sexual performance through worsening asthma symptoms: 'There's been times when were in full flow and I've had to stop because I cannot breathe' (ID12/F/48). Limitations of asthma were also perceived to impact on the physical act of intercourse and restricted other physical aspects of sexual intimacy such as the impact of breathlessness on kissing.

An overwhelming exhaustion signified the fatigue that all patients portrayed as a consequence of living with asthma and the side effects of high-dose corticosteroids in particular. One participant described how their sleep deprivation caused marital strain as their partner felt they were

trying to evade intimacy, when in fact they were simply exhausted, seeking sleep at any opportunity.

The third party

Eight participants discussed the implications of having to organise equipment such as syringe drivers or having to adapt to using inhalers or nebulisers while being intimate with their partners: 'We sort of have to think 'where's my nebuliser' before I get romantic, is everything on standby?' (ID6/M/45). The response to this varied from patient to patient, from generalised normalisation and acceptance of it being part of everyday life to revulsion, ruining the intimacy and spontaneity of the moment: 'well (my partner says) "we can get the machine" (nebuliser) and I think "I'm NOT having that!'" (ID12/F/48)

Palpitations and paramedics

Five interviewees reported fear that sexual climax can induce severe bronchospasm requiring emergency medical intervention. This reduced satisfaction and

Table 2 Physical intimacy; subthemes and direct quotations			
Physical intimacy			
1.1 An overwhelming exhaustion	' if I was tired I wanted to go up to bed. I'll be thinking, 'right I might go up to bed and get some sleep here', you know rather than that [implying intimacy] at the time. Until people have not had some sleep it's hard to explain how bad it is!This was hard for me to try explaining to my partner; she thought that I was pushing her away. I wasn't' (ID1/M/34)		
1.2 A third party	'My Bricanyl pump's a big part of our relationship as well, we have to manoeuvre the pump around the actions in the bedrooms. There's times when he has to hold the pump, so it's like three people in the relationship' (ID5/F/32)		
1.3 Palpitations and Paramedics	'Then you get to that peak where I basically feel like I'm going to die, if you know what I mean I'm getting light headed because your body's doing all sorts and your heart's racing. There were some scary times to the point where [my partner said], "we'll have to phone the ambulance", I'll [say] "No, are you mad?" We can't do that, when they say, "well, what happened, what have you done to her?" But I do have panics' (ID12/F/48)		
1.4 Adaptation and experimentation	'I have now noticed that I can't take the weight on my chest; so we've experimented. And all I can say is thank God for cushions and pillows, because you can sort of wedge yourself upwards and help with different positions which are comfortable for your chest basically. And it is experimentation' (ID9/F/47)		
1.5 Practical Difficulties	'There's certain parts that you do like, you know, intimate things that you have to be really careful about because obviously they're restricting your airways and you can't breathe' (ID13/F/59)		

enjoyment due to anxiety about reaching orgasm. Additionally, the trepidation, embarrassment and taboo nature of explaining to the paramedics and healthcare professionals the reason for their exacerbation hindered relaxation and enjoyment of sexual encounters and also procured palpitations at the prospect of having to explain the rationale for exacerbation: 'phone the ambulance? I'm like, "no, are you mad?" (ID12/F/48).

Adaptation and experimentation

Some participants described positive coping mechanisms of adaptation and experimentation within sexual relations in adjusting to the limitations such as using pillows as props to find sexual positions: 'there are different positions you can't do, there are a lot of positions that you can…we call it the "Asthma Sutra" (ID13/F/59). Additionally, seven interviewees noted that the emotional intimacy of being a couple is more important than the physical element. Participants described their adaptation with a positive perspective, expressing strength in adversity.

Practical difficulties

All participants echoed that the physical act of sex itself was limited by their asthma and imposed restrictions on ability to perform. All female participants spoke of difficulty in positioning, describing how differing sexual positions can constrict breathing or exacerbate breathlessness: 'I can't have him on top...I cannot breathe...lying flat is a no-no...you get so out of breath' (ID5/F/32). Male participants described perceived restricted sexual performance due to the requirement for physical effort.

Theme 2

Emotional intimacy (table 3) articulated the participants' interpretation of the layers of intimacy ranging from physical to emotional closeness. While many negative constructs were discussed, some interviewees also echoed a positive emotional aspect of living with severe asthma. *Pressure to perform* resulted in feelings of frustration and guilt. Frustration with their physical self; that the mind was willing but the body was restricted. Guilt that physical intimacy has not occurred and they have not satisfied their partner. Four participants described feeling an 'unintentional pressure' from partners to have sexual intercourse. A common premise displayed was that despite

having perceived strong and close relationships, patients acknowledged embarrassment in broaching sexual intimacy problems within the relationship: 'that was part of the issue, I didn't want to talk about it' (ID9/F/47).

Self-preservation

Five female participants (83%) spoke of how they gave their partners 'permission' to seek sexual gratification outside the relationship, for fear of losing them completely from the relationship; 'I actually said to my husband...I wouldn't blame you for going, because I wouldn't want to be with me' (ID9/F/47). All five reported this was prompted by guilt in not being able to provide what they perceived as adequate sexual and everyday partner roles.

A problem shared

Often participants felt that problems related to their asthma were solely for them to carry' 'You just have to... try to keep a smile on your face or else you'd make other people depressed, and you know they don't need that' (ID10/F/46). Concern was expressed that sharing the burden confirmed that a problem existed and would only serve to impose such worries on their partners. However, it was acknowledged that putting on a façade in the long term would likely cause contention and negativity within the relationship and only when discussed would the burden ease

Theme 3

Image of self (table 4) tended to reflect participants' vision of themselves and their perceived roles within their relationships while living with severe asthma.

Self-loathing

Self-loathing was evident in all participants, frequently reported as consequence of long-term corticosteroid exposure, which significantly impacted on body image. Additionally, physical limitations of asthma hindered the ability to undertake physical exercise to counteract weight gain and also impacted on even the simplest of tasks required to make oneself feel more attractive, such being able to style one's own hair. Ultimately, such limitations all contributed to poor perception of self, negative body image and reduced feelings of sexuality. Even more practical aspects such as wearing sensual underwear were

Table 3 Emotional intimacy: subthemes and direct quotations

Emotional intimacy

2.1 Pressure to perform	'It's like, with the tiredness side and with the chest side, you sort of do have to think about it a lot more and feel under pressure yourself that you need to perform' (ID6/M/45)
2.2 Self preservation	'Honestly, I've even said, "(male name), if you want to go out, and find yourself someone just for one night and just enjoy yourself I will give you the permission to", because I feel really guilty' (ID10/F/46)
2.3 A problem shared	'Like a massive weight was lifted for me, so yeah! Because I was trying to hide things from her and make excuses about going to bed early and so on and I didn't have to. She fully understood then, and she was by my sideand its something we've grown to live with together' (ID1/M/34)

lover

Table 4 Image of self; subthemes and direct quotations

Image of self	
3.1 Self loathing	'I look in the mirror and I just don't see myself anymore, you know what I mean? I justsee someone else. It just doesn't look like me. My face and a big double chin, and all that, it depresses me' (ID10/F/46)
3.2 Acceptance of self	'I still love you', he said, 'because it's the person inside, not the outside'. 'That's just you', he said, 'you are inside there, fighting to come out all the time'; and that's what he's always said about me, I'm a fighter' (ID9/F/47)
3.3 Carer vs	'I love him as my lover, but I struggle with him as my carer One minute they're wiping your bum and then

the next minute you're ripping each other's clothes off. It does vary' (ID5/F/32)

fraught with difficulty due to reported restriction on the chest wall: 'You don't feel very sexy when you've put so much weight on with the steroids...I cant wear nice underwear anymore, because underwired bras hurt' (ID11/F/42).

Acceptance of self

The participants voiced that 'moving forward' was facilitated by a combination of partner's constant affirmation, pulling together as a couple and sheer determination to not let asthma control every component of life: 'learning to work with the cards that you've been dealt' (ID5/F/32). However, this was expressed to be a constant battle and fluctuated day to day.

Carer versus lover

Transformation of roles within the relationship was described in great difficulty by seven of the patients, who struggled to cope with their partner's fluctuating role between carer and lover. Two participants attributed this as having a significant contribution to the breakdown of previous marriages where dyadic dysfunction occurred as consequence of the caring responsibilities overtaking the personal relationship: 'clearly she fell out of love with me...she was my nurse...not my wife anymore' (ID3/M/52).

Theme 4

The role of the healthcare professional is given in table 5.

Previous experience

There was a clear consensus across all interviews that no HCP had initiated discussion of sexual intimacy during clinical interactions. Two participants described extremely negative responses from HCPs (one a general practitioner and one a counsellor) when trying to broach the topic.

A taboo topic

Seven participants perceived intimacy to be a sensitive topic which they themselves would not be comfortable to raise, but would welcome a discussion if raised by the HCP 'if you're not asked, you don't say' (ID6/M/45). Five patients perceived that doctors only considered primarily clinical aspects of a consultation rather than address intimacy due to the taboo nature. Four felt it was important that medical staff should be able to discuss the limitations asthma imposed on intimacy and relationships: 'your sex life...it's a good thing for doctors just to speak about it' (ID9/F/47).

An ideal scenario

Seven out of nine participants felt that they would be most comfortable discuss sexual issues with their specialist nurses, rather than consultants or GP's. The preferred environment was felt to be in the outpatient setting rather than a clinical ward area: 'In the clinical setting, ... a private room, or office is fine' (ID6/M/45).

DISCUSSION

To our knowledge, this is the first study to conduct a qualitative assessment of the patient's perspective of how living with severe asthma influences sexual QoL and intimacy and the potential role of the HCP in addressing this.

Our findings substantiate the concept that fatigue in severe asthma has a significant impact on sexual QoL in patients with severe asthma, which was perceived as

Table C	The role of the healthcare	f	
Ianie 5	The role of the healthcare	professional, sliptnemes	and direct dilotations

intensifying pressure on the relationship. A new but perhaps unsurprising observation was the fear of exacerbation during sexual intercourse. The participants described this as a barrier to engaging in sexual activity and also felt it had negative consequences for their relationship. In particular, it transpired that the fear and embarrassment of having to call for an ambulance was perceived as being worse than the physical asthma attack itself. Existing literature 16 recognises that, across an undifferentiated health complaint sample, an individual's decision to call an ambulance can be hampered by multifactorial indecisiveness involving emotions of trepidation, embarrassment and the hope that symptoms will resolve spontaneously. In a study of patients with chronic health conditions, individual's prior experience of emergency services was a key influencing factor in phoning an ambulance. 17 It is therefore clear that the decision-making process as to whether to call an ambulance is complex and individualised; however, this study has clearly identified that the embarrassment of revealing sexual activity as the cause of an exacerbation of asthma increases patients' reticence to call for an ambulance. In light of recent National Registry of Asthma Deaths, 18 findings which reported 45% of asthma deaths occurred before patients sought assistance, mechanisms must be put in place to ensure patients seek assistance at the earliest point regardless of the mechanism of exacerbation.

The study identified that intimate contact from kissing, to more complex different sexual positions could cause dyspnoea and feelings of suffocation. Spontaneity was often reduced, which again was described as having a negative impact on the relationship. Premedicating prior to exertion is often discussed in clinical consultation with patients with asthma. This study highlights that HCPs could consider sexual intimacy as a form of exercise for patients with severe asthma, perhaps simply advising to adopt usual pre-exercise precautions prior. However, tackling the psychological impacts of sexual intimacy difficulties may be more challenging for many HCPs.

Alongside physical limitations, a huge emotional burden is apparent as a consequence of the disease. This observation is widely supported by existing evidence, identifying a correlation between low sexual function and poor psychological state. Poor health and reduced intimacy may maintain a vicious circle, with a lack of intimacy as a consequence of ill health negatively influencing desire. On the second second

Frustration was an emotion frequently voiced by participants, who had significant difficulty adapting to the conflicting roles of being cared for and being a sexual partner. Additionally, feelings of guilt and uselessness were common phenomenon expressed by participants in relation to the demands placed on partners as a consequence of participants being too unwell to undertake routine household chores or to provide sexual gratification. A novel insight identified within this study is that of participants encouraging their partners to seek sexual activity outside the relationship out of feelings of guilt

and inadequacy. The rationale for this was not expanded on and we are left to speculate whether this was deemed to be a test of commitment, self-protection or if the participant truly felt they were restricting their partner.

Image of self incorporates perception of body image.²² Low self-image can threaten sexual wellbeing²³ and is associated with relationship difficulties.²⁴ A commonly occurring theme within this study was the impact of body image on low self-esteem, secondary to corticosteroids and restricted physical ability. Despite their partner's assurances, all participants spoke of how their pessimistic image self negatively compounded on their sexual relationship; this is supported by wider literature which suggests that a subjective view of appearance has further reaching psychosocial implication than any external objective opinion.²²

Targeted treatments to help support the patient dealing with low image of self are required, as emotional distress exacerbates physical symptoms.²⁵ The recurrence of poor self- further supports a recognised need for increased psychology input to assess patients and support HCPs. NHS England²⁶ have recently recommended health psychology as an essential component of the severe asthma team. Adequate psychology support is underfunded in an increasingly financially constrained health economy and provision for demand remains very limited.²⁷ These findings suggest that we are failing to truly capture and demonstrate the burden of psychological ill health in asthma, yet this is an area where tangible outcomes are crucial to maximise patient well-being.

Despite the overt presence of sexuality within society, it remains typically taboo within the respiratory clinical consultation. None of the participants during consultation with a HCP had been asked whether they had encountered any difficulties pertaining to sexuality and all stated that while intimacy is an uncomfortable topic to bring up, if it was broached by a HCP then it would facilitate disclosure and discussion. They reported that if they had received professional support or referral, they and their partners might have been saved from difficult emotional times within their life. However, this may appear an unrealistic expectation of the HCP within a severe asthma service as targeted psychological intervention may be required to address such issues.

We have identified a need for HCPs to be trained to appropriately address sensitive issues relating to sexual health; to facilitate an open discussion, increase awareness, imbue knowledge and perhaps overcome HCPs discomfort and embarrassment in conversing about intimacy with patients which has been documented in the literature. Such open discussion would hope to identify patients who would benefit from further psychological support in this area. Additionally, as observed within this study and supported by wider literature that despite the emotional challenge of discussing such as sensitive topic patients report a positive and cathartic effect once the issue has been raised. Regarding location for this discussion, patients identified that private consulting

rooms in the Outpatient department as the most appropriate. They also noted a preference for discussion with nursing (rather than medical) staff in the first instance, possibly due to the more frequent exposure of this cohort to specialist nurses within the clinical setup of the severe asthma service, although it should be noted that the study interviewer was a nurse specialist. Greater patient satisfaction has been recorded with the expansion of specialist respiratory nurse roles as patients report longer consultation times, ³² which consequently may facilitate disclosure when discussing intimate topics. Furthermore, medical staff report a lack of privacy and limited clinical time as major factors impacting on discussing complex issues such as sexual concerns.³³ Normalisation will help to share experience and consequently reduce isolation, as isolation is compounded by a reticence to share a problem.³²

Limitations

While qualitative approaches facilitate an in-depth exploration of a topic, the compromise is often in sample numbers. Our study did not seek the views and opinions of HCPs involved in the care of people with severe asthma and as such, we cannot make assumptions about their opinions in regards to addressing sexual activity as part of the asthma consultation.

Only patients in a current relationship were recruited largely due to ease of defining the sexual relationship. Furthermore, the researcher was known by all participants as a lead nurse within the service and while deemed a strength of the research, juxtaposed this can be considered a limitation as it may have induced bias in the participants' attempts to respond in a way to please the researcher.

CONCLUSION

In conclusion, we have demonstrated that there is a perceived significant impact of living with severe asthma on sexuality and sexual OoL. The symptoms and impact on QoL are heterogeneous and impact widely, meaning our approach and adaptation to addressment needs to be individualised. The research highlights that in assessing QoL in severe asthma, the HCP needs to go beyond standard clinical assessment and the currently used questionnaires, which arguably do not provide an accurate measurement of the impact of HRQL within everyday clinical practice. We propose that newly developed QoL measures for severe asthma should address sex and intimacy explicitly. With the introduction of training and discussion within teams, HCPs will hopefully be able to incorporate an assessment of patient intimacy issues in a professional and appropriate manner in an outpatient clinic setting.

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