Novel insights into patient's thoughts about their body image in abdominal wall hernia

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Abstract

Background

Abdominal wall hernias (AWH) are frequently large and deforming. Despite this, little is known about how AWH impact upon body image. This study is the first study to qualitatively examine patients' subjective lived experiences of how AWH affects their body image.

Methods

Fifteen patients were interviewed from a purposive sample of AWH patients awaiting surgery until no new narrative themes emerged. Interviews explored patient thoughts and experiences of AWH and body image. Data were examined using interpretative phenomenological analysis (IPA).

Results

Two key themes pertaining to body image were identified: "Changes to perceptions of self" and "Fears concerning other's perceptions of them". Both themes were often interrelated and displayed detrimental effects AWH had on patients' body image.

Conclusions

Our findings illustrate that AWH detrimentally afected patients' body image. This aspect of patient care can be treated and managed through better pre-operative information, including on body image as part of a holistic needs assessment (HNA), and ensuring the results are addressed in a patient care package. These development suggestions may positively afect the AWH patient's experience and outcomes in terms of Quality of Life (QoL) by preparing patients better for realistic results regarding what can be achieved in terms of form, function thus making a more holistic recovery from surgery.

Keywords Abdominal wall hernia · Body image · Quality of life · Lived experience · Patient's thoughts

Background

The American Psychological Association (APA) defines body image as "the mental picture one forms of one's body as a whole, including its physical characteristics and one's attitudes toward these characteristics." (Ref. https://dicti onary.apa.org/body-image). Abdominal wall hernia (AWH) can be large, deforming and unsightly (see Fig. 1) and when untreated can have a detrimental effect on patients' body image [1–3]. Treatment for AWH can involve Complex Abdominal Wall Reconstruction (CAWR). These lengthy, significantly morbid procedures aim to reconstruct the abdomen, prevent complications of the hernia, and restore function of the abdominal wall.

Apart from restoration of function, surgery also involves aesthetically restoring the form of the abdomen, an aspect often absent in literature. Body image did not feature as a parameter within a recent systematic review of Health Related Quality of Life (HRQoL) in AWH patients [4]. This absence may be due to clinician's lack of acknowledgement of the impact of this since often surgeons, especially in the NHS, are geared towards functional issues and prevention of emergencies rather than aesthetics. This has led to a lack of patient involvement in the design of HRQoL tools, which is problematic given that aesthetic restoration commonly features in patients' complaints [4].

Fig. 1 Study participants' images showing the different body morphologies of the sampled hernia patients

Little is known regarding how patients perceive AWH impacts upon their Quality of Life (QoL). Understanding this may add much needed context to shared decision making with patients outlining what they perceive are their problems that surgery will provide an answer to. This understanding informs risks versus benefits discussions when counselling patients regarding the operation.

Through adopting a phenomological approach, our work identifies body image as one of the five themes affecting patients' QoL [5]. We explore this further in this paper.

Methods

Study design

This study applied phenomenology, a research methodology used to qualitatively explore human issues and emotionally laden subjects [6, 7]. This methodology is often adopted when examining the relationship between healthcare, surgery, and body image [8–10]. Deep insights into how AWH affected patients' body image were gained using interpretative phenomenological analysis (IPA) [11]. Four of the authors have been trained in IPA. Further to this, data and subsequent findings were triangulated by two abdominal wall hernia surgeons to ensure degrees of consistency in interpretation.

Ethics

This research received approval from the Hull York Medical School (HYMS), Integrated Research Approval System (IRAS) and Health Research Authority (HRA) of United Kingdom. It was conducted in accordance with the Declaration of Helsinki and has been reported according to COnsolidated criteria for REporting Qualitative (COREQ) guidelines. The study protocol, patient information leaflet, consent forms, topic guide and interview schedules were designed and subject to an iterative approval process. All patients provided written and verbal informed consent. Specific consent was sought to use medical photographs of patients' AWH for publication purposes, as presented in Fig. 1. Medical photographs were taken in the hospital studio where patients were accompanied by a chaperone.

Recruitment

Purposive sampling, a technique used frequently in qualitative research to identify "information-rich cases" was employed [12]. Participants were recruited from the AWH clinic in the York Abdominal Wall Unit. The

maximum variation purposive sampling technique was used and included patients with all elements of Ventral Hernia Fig. 1 Study participants' images showing the different body morphologies of the sampled hernia patients Hernia 1 3 Working Group (VHWG) grades as variables, e.g., those with previous cancers, previous wound infection, stoma, intestinal fistula, chronic obstructive pulmonary disease (COPD), diabetes, smokers and obesity [13]. A letter of invitation along with an information sheet pertaining to the study and interviews were arranged. A more detailed overview of the research process is provided in the in-depth publication concerning AWH patients' quality of life [5].

Research method

Interviews have proven to be "the gold standard" [14] and "the most productive mode for producing narrative data" within qualitative research [15]. Semi-structured interviewing techniques were adopted to explore how AWH affected patients' body image [16]. Adapted from Stumpfegger [17], a schedule and topic guide were used to ensure a systematic and rigorous interview process. The topic guide was designed by qualitative researchers, two gastrointestinal and two plastic surgical consultants who operate within the York Abdominal Wall Unit. Interviews based on exploratory topic guides included open questions on QoL followed by more focused questions pertaining to body image with examples outlined here—How comfortable are you with what you look like/are you with your physical appearance? How does the appearance of your hernia affect you? How does the appearance of your hernia affect your relationship with your partner/friends? Does this affect any other aspects of your daily life, for example, purchasing clothing?

Data collection

Fifteen semi-structured interviews were conducted by author OS. Three interviews were face-to-face and the rest were completed via telephone due to the Covid-19 pandemic. Each interview lasted between 45 and 90 min. Steps were taken to ensure trustworthiness by asking open questions, clarity check of answers, and using prompts and probes. The interview was audio-recorded and transcribed verbatim by OS and a medical secretary independent of the research team. Pseudonyms were used to ensure anonymity and confidentiality.

Data analysis

Data analysis was an iterative process until thematic saturation [18]. Participant transcripts were analyzed using IPA within NVivo v12 (https://www.qsinternational.com/nvivo/ home). The analysis of transcripts was done line by line to identify similar patients' views that could be grouped together into superordinate and subordinate themes concerning body image. Emergent themes were discussed with two gastrointestinal surgeons and two plastic surgeons who specialized in CAWR as well as an independent academic qualitative researcher, who does not have a surgical background (MM). This allowed triangulation of the findings as well as plausibility of results.

Results

Fifteen participants took part in this study (eight men and seven women) with an age range of 36–85 years (median=65 years). Table 1 provides a summary of participant characteristics. Figure 1 provides the images of the patients involved in the study. Patients often self-identified as "a patient" in their responses, therefore, to be clear and consistent, the term "patient" is adopted from here on in. The results presented here are only the body image aspects of QoL deemed important by AWH patients, with other themes reported elsewhere [13]. Two key themes pertaining to how AWH affected patients' body image were identified: "changes to perceptions of self" and "fears concerning perceptions of others". Figure 2 explores these aspects from the patient perspective.

Theme one: changes to perceptions of self

Pre-operative interview responses revealed how AWH negatively impacted patients' body image. Regardless of age, gender or socio-economic background, all patients struggled with negative self-perception to some degree, frequently describing the AWH silhouette negatively.

"I think that the biggest issue is that I feel like Mr Blobby. I walk like Mr Blobby or like Jar Jar Binks." (Betty, a 63-year-old retired non-smoker)

"I've got that many lumps and bumps now...I'm just like an elephant man…I look out of shape. I look like I've got a pot belly." (George, a 45-year-old employed in the trade industry)

"It's dreadful. Talk about vile body." (Eric, a 78-yearold retired athlete)

Whilst perhaps not accurate aesthetic portrayals, these metaphors illustrate how patients identified with unattractive or grotesque characters, potentially illustrating dysmorphic thoughts. The images evoked indicate the degree of patients' negative self-image, dissatisfaction with their body aesthetic, and heightened level of self-consciousness as a result of their AWH.

One particular image frequently cited in this respect was that of a pregnant person.

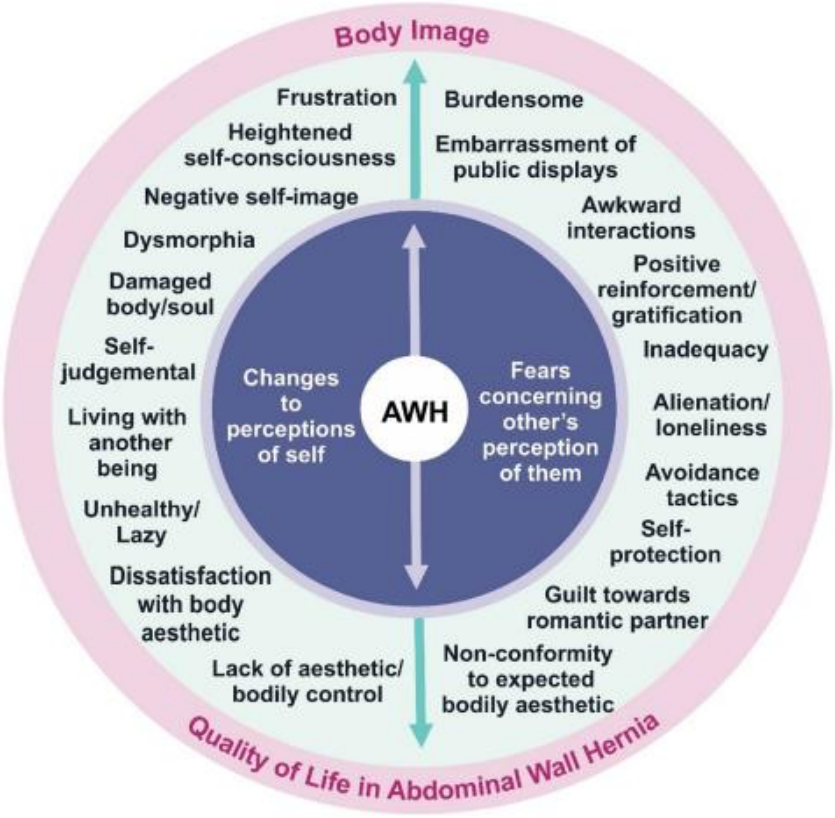
"My tummy, to me it looks awful…I look so many months pregnant, that's the problem." (Joan, a 75-yearold retired non-smoker previous cancer patient)

Table 1 Study participant demographics

Participant name	Sex	Age	VHWG grade	Hernia height × width (cm)	NHS/private	Smoker	Diabetic	Wound infection	Stoma	Cancer	Fistula	BMI	Socio-economic class	Employed	Post op/pre op	Telephone interview
Agnes	F	65	2	17×17	NHS	Ex-smoker	No	No	No	Yes	No	29.6	Middle	Yes	Pre-op	No
Betty	F	63	1	30×20	Private	Never	No	No	No	No	No	26.1	Upper	Retired	Pre-op	No
Charlotte	F	68	4	30×20 and 60×12	NHS	Ex-smoker	Yes	Yes	No	No	No	38.6	Middle	Retired	Pre-op	No
David	M	61	2	7×7 and 9×9	NHS	Never	Yes	No	No	No	No	31.2	Lower	Yes	Pre-op	Yes
Eric	M	78	1	12×30	NHS	Ex-smoker	No	No	No	No	No	29.9	Middle	Retired	Pre-op	Yes
Frank	M	75	4	27×26	NHS	Ex-smoker	No	Yes	No	Yes	Yes	25.8	Middle	Retired	Post-op	Yes
George	M	45	4	7×8 and 9×13 and 16×20	NHS	Ex-smoker	No	Yes	Yes	No	No	30.5	Lower	Yes	Pre-op	Yes
Harry	M	84	2	23×15	NHS	Ex-smoker	Yes	No	No	Yes	No	28.8	Upper	Yes	Post-op	Yes
Ian	M	58	4	17×21	NHS	Ex-smoker	No	Yes	No	Yes	No	30.2	Middle	Yes	Pre-op	Yes
Joan	F	75	3	22×18 and 19×17 and Parastomal	NHS	Never	No	No	Yes	Yes	No	26.2	Middle	Retired	Pre-op	Yes
Kevin	M	74	3	20×15 and 15×15	NHS	Ex-smoker	No	No	Yes	No	No	32.4	Middle	Retired	Post-op	Yes
Lisa	F	39	1	10×12	NHS	Never	No	No	No	No	No	29.2	Middle	Yes	Post-op	Yes
Marge	F	36	1	5×20	NHS	Never	No	No	No	No	No	20.4	Middle	Yes	Post-op	Yes
Norman	M	77	3	30×20	NHS	Ex-smoker	Yes	No	No	Yes	No	24.1	Middle	Retired	Post-op	Yes
Ophelia	F	44	1	2×3 and 4×5 and 2×3	NHS	Never	No	No	No	No	No	30.7	Middle	Yes	Post-op	Yes

Names given to participants throughout the thesis are pseudonyms, ensuring anonymity

Fig. 2 Body image themes relating to AWH patient's Quality of Life



"I did still look nine months pregnant…My body did look diferent and I wasn't happy about that" (Lisa, a 39-year-old non-smoker, Physical Education teacher and mum of two children under 6 years).

"Mentally it (the hernia) really was large…it was quite a biggy…Finding clothes to ft, and mentally thinking that I was a pregnant man..." (Harry, a 84-year-old previous athlete and now athletics coach)

A pregnant profile caused by AWH negatively affected patients' self-perception. Female patients tended to cite frustration and distress, with males citing more embarrassment, and, feelings of emasculation. Patients felt overwhelmed with what they perceived as an inability to change or control their bodily profile. This narrative of despair and despondency was particularly salient for patients with sporting, athletic and/or fitness backgrounds, who expressed growing dissatisfaction with their perceived 'unhealthy' and 'lazy' bodies. Furthermore, this profile epitomised a broader narrative that patients referred to, articulated by 61-year-old employed grandfather David as, "living with another being".

Patients' negative body image also affected how they lived and the range of coping strategies they employed.

"How does it affect my life? I won't look at myself in the mirror, not even if I'm buying clothes because I don't see a skirt or trousers sitting nice and pretty, what I see is an ugly big bulge." (Charlotte, aged 68-year-old retired ex-smoker)

"You tend not to look at yourself anymore because it (his body and hernia) really is quite a horrible looking thing and I avoid mirrors." (Eric, a 78-year-old retired athlete)

Avoiding visual reminders further illustrates patients' distaste and even disgust of their hernia silhouette. One avoidance strategy was concealment. "Clothing?! It was just covering up!" (Kevin, age 74 years retired ex-smoker)

“I’d just hide it (the hernia), but then even if I was wearing something that was hiding it, I was very aware that I was just looking ten times bigger than I actually was” (Ophelia, age 44, never smoked, mother of two under 9 years)

“I kind of resigned to the fact that I was never going to wear a bikini or anything like that ever again” (Lisa, aged 39, a sporting background).

The strategy of avoiding figure-hugging clothing and opting instead for baggy attire, thereby providing pragmatic concealment, served to abate patients’ feelings of fatness or ugliness. Negative self-judgements and subsequent coping strategies, like visual avoidance, concealment, humour and withdrawal, extend further to concerns over the perceptions that others have of them.

Theme two: fears concerning others’ perceptions of them

A negative body image and heightened self-consciousness drove, and was partly influenced by, patients’ fears concerning how other people perceived their hernia. Other people included the general public, friends, loved ones and medical staff.

The following detailed narrative epitomises how various fears manifested.

“It felt like a burden I was carrying around, but the main burden not being the pain of the condition, but the weight of what other people were thinking. Constantly when I would be choosing clothes, I would then turn side profile immediately. That’s the default setting, not to look at me from the front but to the side. Then I’d think to myself, do I look pregnant in this? If I think I look pregnant in this then someone else is going to ask me if I’m pregnant… (when asked when her baby was due) I was embarrassed and I’d correct them in a sort of joking, laughing it of kind of way, but I could see that they were mortified that they had got that so wrong. I ended up covering for them and trying to make them feel better. I’d come away from that situation thinking, God that’s made me feel really crappy. I just felt really, really fat and ugly… the only thing you can see in life when people have babies is your celebrity pin ups who have a baby and three minutes later are back to their size zero bodies, and that’s what you aspire to and it makes you feel really crappy (when you don’t achieve that) …I just wanted to hide my body completely” (Ophelia, age 44, never smoked, mother of two under 9 years).

Like Ophelia, many patients feared awkward social interactions based on presumption. On other occasions, people would confront any awkwardness by asking patients numerous questions about the AWH. Patients reported how, whilst well intended, such questions could feel exposing and objectivising. This was particularly difficult for Marge and Lisa, who are young women with careers needing physical fitness, and both expressed views that they should and are expected to “look a certain way” (Marge, age 36, mother of three children, works for HM prison service).

To pre-empt such situations, patients often withdraw from public life where possible or used comedy to distil any further embarrassment for all. Despite these self-protection mechanisms, patients still expressed embarrassment and internalised the shame they felt associated with the stigma of having a ‘different’ and ‘abnormal’ bodily aesthetic. This then fuelled patients’ concerns regarding the perceptions of others, be that loved ones or healthcare staff. When discussing the medical photography process, where avoidance and concealment was not an option, patients reported emotional distress and diminished confidence at having to expose their AWH.

“My wife is not allowed to look at me anymore…I have a vile body. I had the embarrassment of having to have it photographed at the hospital. That was really embarrassing. Terrible.” (Eric, a 78-year-old retired athlete)

Like Eric, given their own feelings of disgust, patients often felt that others would be equally sickened by their perceived grotesque body. Patient narratives included avoiding nude displays or sexual intercourse.

Lisa, 39-year-old non-smoker, Physical Education teacher and mum of two children under 6 years, expressed, “the way I feel about being naked has had an impact on our sexual relationship”. Associated feelings of guilt were common and will be discussed further in other planned papers relating to the impact AWH has on patients’ relationships, work and employment.

Discussion

Key findings in this paper illustrate the strong and complex relationship between patients’ AWH, their body image, and their QoL pre-CAWR surgery. The use of purposive sampling in our qualitative research allowed for identification and selection of information-rich cases related to the phenomenon of interest and the use of maximum variation sampling captured all elements that go to make up varying VHWG grades. Despite variation in VHWG grade, hernia size, age or sex, we did not observe a difference within the body image themes patients themselves identified. Irrespective of the severity of the body disfigurement the consistent detrimental effects that AWH has on patients’ body image stresses the importance of focusing on this topic. This perhaps illustrates how body image is a subjective individual state of mind which is affected by emotional and identity-based associations, not necessarily rational cognisant thinking.

A growing inability to complete physical tasks and declining fitness levels contributed to heightening patients’ self-consciousness and their growing body dissatisfaction. Patients’ body image was also affected by fears concerning Hernia 1 3 how others perceived their AWH, displaying elements of Cooley’s “the looking glass self”, a concept that highlights “the tendency for one to understand oneself through the perception which others may hold of them” [19]. Such fears are somewhat perspicuous when placed in the context of a prevailing body-beautiful complex that permeates across many Western societies within the twenty-first century [20–23].

Key findings presented here contribute to evidence of the impact that body image has on self-perception and patient care, which is not new, but now recognized as a growing problem [21, 24]. In recent years, research on the relationship between body image, embodiment, and behaviour has found that a negative body image has strong links to mental health issues like depression [25], low self-esteem [20], anxiety [26] and body dysmorphic disorder [22]. However, body image research in the field of hernia is poor [27].

Body image is not a factor considered in most existing “specific” AWH HRQoL tools [28, 29], or is only mentioned anecdotally [28]. Only two AWH specific HRQoL tools (the EuraHS-QoL and the AHQ) include body image within their item list, but this was based on expert surgical opinion and not informed by the patients themselves [1, 27]. The findings of our study indicate all patients experienced body image disruption. This is consistent with previous research where patients with incisional hernia reported lower scores for HRQoL and body image [2].

While the main objective in managing the soft tissues in patients undergoing complex abdominal wall reconstruction must be to achieve uncomplicated primary wound healing, it should also try and restore and/or improve the appearance of the abdomen. Management of redundant soft tissue should lead to an improvement in body image in a similar way to that seen in bariatric patients who undergo delayed plastics reconstruction [30].

Though the amount of soft tissue management varies between patients, factors such as an excess amount of skin and soft tissue, presence of multiple abdominal scars and stomas may need special consideration using a combined general surgeon and plastic surgeon approach.

Study limitations

Whilst key benefits of a qualitative study are evidenced above, this research approach can lead to some potential limitations due to the inherent humanistic nature of qualitative research. We tried to manage potential limitations to ensure credibility and trustworthiness throughout the research process using the steps outlined in methods section (i.e. sampling and triangulation) [6]. In this study, most of the interviews

had to be completed via telephone due to COVID-19. Some subtle nuances in patient body language may have been missed. Two further limitations of this study both include sampling.

Firstly, our sample was an exclusively Caucasian population who were identified as predominantly middle class (73%). This sample is representative of North Yorkshire in United Kingdom, which has a 96.7% white population and above national average on many socio-economic status indices (Census, 2021). Homogeneity could shape views on hernia's affects on body image, with possible variance due to ethnicity and social class. Therefore, our study is not generalizable, but we suspect relatability given the narratives provided and the nature of body image. Future research should collect comparative data to ascertain degrees of variance based on demographics.

Secondly, largely due to Covid-19, we only collected participants' experiences and reflections at one time period. In future research, we aim to collect data concerning body image at pre- and immediate post-operative and six-month points. This comparative data would enable us to more clearly determine the effects hernia has on body image. It could also allow us to evaluate the impact of pre-optimisation, counselling and education materials etc.

Development suggestions

The findings of this study suggest that formal enquiry into body image disruption should be part of a holistic needs assessment (HNA) for all patients with AWH. At York Abdominal Unit all patients are invited to complete a health screening questionnaire which asks about the impact of AWH on QoL including body image. A free text box provides space for the patient to describe their body image.

This initial assessment could then be extended through the routine completion of psychometric measures for body image satisfaction/dissatisfaction such as the Body Image Disturbance Questionnaire (BDIQ). Given the relationship between dissatisfaction with body image and anxiety/depression [31] administration of a psychometric measure such as The Hospital Anxiety and Depression Scale (HADS) would be important.

The clinical picture gathered from the HNA and psychometrics measures administered could then be used to guide the level of intervention put in place as outlined in the stepped care model below (Fig. 3).

Step 1: Informational care—all patients would be provided with patient information which addresses the impact of AWH on body image, introducing steps the AWH patient can take to protect their mental health given these known difficulties.

Step 2: Psychoeducation—patients expressing body image and mood disturbance could be invited to attend a support group, facilitated education session or provided with more in-depth self-help materials. These could include an introduction to brief interventions such as mirror exposure which involves deliberate, planned and systematic exposure to body image whilst adopting a non-judgemental focus [32].

Step 3: Formal intervention—patients also scoring poorly on psychometric measures could be referred for assessment by a trained mental health clinician either within the Hospital Trust or via their local NHS Talking Therapies for Anxiety and Depression Service (formerly known as IAPT). Here, specialist psychological interventions such as cognitive behavioural therapy and compassion focused therapy, which have been shown to be effective in the treatment of body image disturbance can be provided [33].

Our hope would also be to compare patients pre- and post-surgery and examine how these perceptions and feelings change with intervention. Anecdotally, patients were very happy with the results and outcomes on review at approximately 3 months, but a deeper understanding of these changes would allow differentiation between what aspects may be function related and those aesthetically related.

Fig. 3 A stepped care approach to body image concerns in patients with AWH

AWH patients expressing body image/mood disruption obtaining clinical scores on psychometric measures	Referral to a mental health professional who can provide specialist assessment and intervention
AWH patients expressing mild body image and mood disruption	Support groups, facilitated educations sessions, written guided self-help materials
All AWH patient	Patient information which addresses impact of AWH on body image

Conclusion

This is the first study to qualitatively examine how AWH affects patients' body image and provides rich descriptive patient narratives of living with and managing AWH that demonstrates body image to be a multidimensional construct. Patients expressed how their body image had changed due to their AWH. Changes were detrimentally experienced through heightened self-consciousness, growing dissatisfaction with their changing/new body aesthetic and evoked feelings of embarrassment, shame and fear concerning the perceptions of others. These experiences were partially managed through coping strategies including humour and avoidance. However, these only served to minimise the profound effects of holding negative self-judgements and fearing social awkwardness.

Despite these experiences body image is often overlooked by surgical terms as a QoL domain in AWH patients. This relationship can be better catered for and managed with a more open, holistic, and patient-centred care approach as advocated in the development suggestions above.

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Availability of data and material Not applicable.

Code availability Not applicable.

Declarations Conflict of interest All authors declare that they have no conflict of interest.

Ethics approval Research Ethics Committee (REC) reference: 19/ SC/0565, Integrated Research Application System (IRAS) Number: 271652.

Human and animal rights No animals were used in study. Human rights and Ethics considerations were discussed in Health Research Fig. 3 A stepped care approach to body image concerns in patients with AWH Hernia 1 3 Authority of United Kingdom which gave permission for study to proceed.

Consent to participate Formal consent received.

Consent for publication Formal consent received.

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