

**Symptoms and Experiences of Chest Binding: A Cross-Sectional Survey Using a
Patient Oriented, Harm Reduction Approach**

by

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Abstract

Objective: People bind their chest to relieve gender dysphoria and most people that bind experience negative physical symptoms as a result. The purpose of the current research is to: 1) explore the incidence, overall impact, and level of concern of adverse symptoms related to chest binding, and 2) describe the experiences of chest binding-related symptoms that would be most likely seen by health care providers.

Methods: A cross-sectional, online, purpose-made survey was conducted using a patient engaged, harm reduction approach. The survey asked about binding history, symptom experiences, and demographics. Twenty-nine symptoms from seven physiological categories were included.

Results: 356 people responded to the survey, which represents 1.1% of the target population. Symptom incidence, overall impact, and level of concern were used to calculate an importance rating for each symptom. The symptoms rated as most important were shortness of breath, overheating, and chest pain. Back pain, chest pain, shoulder pain, shortness of breath, shoulder instability, and rib and spine changes are most likely to be seen by general care providers in relation to chest binding. The frequency and intensity of these symptoms was less when not binding but was still present and impacted social/recreational activities. Despite moderate frequency and intensity of these symptoms, participants rarely modified their binding habits.

Conclusion: Patterns of symptom presentation suggest underlying physiological changes from chest binding. Chest binding was important enough to participants to warrant enduring significant discomfort. Treatment should focus on symptom management and minimizing the physiological effects without suggesting or requiring modifications to binding behaviours.

Treatment can include education on clinically concerning symptoms and screening for symptoms that are most important to patients.

Research Impact: We provide a novel and detailed exploration of chest binding related symptoms, especially focusing on symptom management. Findings give HCPs clear guidance on what to look for and how to address symptoms with patients who bind their chest.

Preface

This thesis is original work by Meaghan Ray Peters. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Symptom management strategies used by gender minority individuals who bind their chest”, No. Pro00120596, June 21 2022.

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Glossary of Terms

The first two definitions are from CIHR's Institute of Gender and Health referenced on Feb 1, 2022 at <https://cihr-irsc.gc.ca/e/48642.html>

Sex

“A set of biological attributes in humans and animals. It is primarily associated with physical and physiological features including chromosomes, gene expression, hormone levels and function, and reproductive/sexual anatomy. Sex is usually categorized as female or male but there is variation in the biological attributes that comprise sex and how those attributes are expressed.”

Gender

“The socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people. It influences how people perceive themselves and each other, how they act and interact, and the distribution of power and resources in society. Gender identity is not confined to a binary (girl/woman, boy/man) nor is it static; it exists along a continuum and can change over time. There is considerable diversity in how individuals and groups understand, experience and express gender through the roles they take on, the expectations placed on them, relations with others and the complex ways that gender is institutionalized in society.”

The following definitions are from Egale Canada's 2SLGBTQI Terms and Concepts referenced on Feb 1, 2022 at <https://egale.ca/awareness/terms-and-concepts-updated/>

Assigned Sex

The biological classification of a person as female, male, or intersex. It is usually assigned at birth based on a visual assessment of external anatomy.

Gender Identity

A person's internal and individual experience of gender. It is not necessarily visible to others and it may or may not align with what society expects based on assigned sex. A person's relationship to their own gender is not always fixed and can change over time.

Gender Expression

The way gender is presented and communicated to the world through clothing, speech, body language, hairstyle, voice and/or the emphasis or de-emphasis of body characteristics and behaviours.

Cisgender

A person whose gender identity corresponds with what is socially expected based on their sex assigned at birth (e.g., a person who was assigned male at birth and identifies as a man).

Transgender, Trans

A person whose gender identity does not correspond with what is socially expected based on their sex assigned at birth. It can be used as an umbrella term to refer to a range of gender identities and experiences.

Nonbinary

An umbrella term to reflect a variety of gender identities that are not exclusively man or woman. Identity terms which may fall within this category include genderqueer, agender, bigender, genderfluid, and pangender.

Transmasculine

An umbrella term for trans people who identify with or express masculinity and may or may not also identify as a man.

Gender Dysphoria

A term that has been used to describe the varying degrees of discomfort and/or distress that trans people experience when they are unable to live as and be affirmed in their true gender. It is a term that has been used in psychiatric contexts and has replaced the outdated term “gender identity disorder” in the DSM-5. It is important to note that not all trans people experience gender dysphoria in the same way, or at all.

Gender Euphoria

The internal sense of joy, satisfaction and comfort a person experiences when they feel affirmed in their true gender identity.

Misgender, Misgendering

To refer to a person as or consider them to be a gender that they do not identify with. Often misgendering is unintended although it can still be invalidating to the person who is subjected

to it. People who harbour cissexist beliefs or attitudes will often engage in purposeful acts of misgendering trans people. Misgendering can include using incorrect pronouns, using incorrect gendered forms of address (e.g., sir, ma'am, guys, girls, ladies) or incorrect gendered titles (e.g. Mr., Miss or Mrs.). Organizations and administrative systems and processes can also misgender people, which is an example of institutional, or bureaucratic transphobia.

Passing

Refers to when a marginalized person is perceived to be, or blends in as a member of the dominant group. This could include a trans person who is perceived to be cisgender. For some, the idea of passing is an important part of accessing safety and acceptance and/or feeling affirmed in one's gender identity. Others may feel that passing is less important or negative overall because it comes at the expense of invisibility or erasure of one's trans identity.

A person's ability to pass says more about the dominant gender norms in the given context and about the interpretive lens of the onlooker than it does about the person in question. Attacking a person's inability to pass (ex., "You're too pretty to be a boy") or fixating on a person's ability to pass, (ex., "Wow, I wouldn't have guessed you were trans") is a common pattern of transphobia and cissexism.

For the purposes of this study, the following definition for **chest binding** was used:

Flattening of the chest via compression such as by wrapping any material firmly around the chest or wearing compressive clothing or a commercial binder. This does not include using tape across the front of the chest or obscuring the shape of the chest for example by wearing baggy clothing without any compression.

Introduction

People wear compressive garments known as chest binders to flatten the appearance of their chest. This is predominantly done by those who identify as transmasculine and nonbinary (1–4). In 2018, it was found that 0.24% of the Canadian population aged 15 and older identified as transgender (trans) or nonbinary, which represents approximately 75,000 individuals (5). Approximately 50% of trans and nonbinary people are transmasculine (6). The vast majority of transmasculine people have experience using a chest binder (2) which means approximately 33,000 people in Canada have used or are currently using a chest binder or bound their chest in some way. This does not include the people who identify as cisgender women, trans women, or trans feminine people who have bound or currently bind their chest for comfort, safety, or another reason.

Binding their chest helps to relieve or mitigate dysphoria (distress due to the difference between an individual's sex assigned at birth and their gender identity), feel more authentic in their body, influence others' perceptions of them, and enable participation in broader society (2–4,7). While binding, they experience an increase in mood, self-esteem and confidence, decrease in suicidality, and an increased sense of safety in public spaces (1–3).

Binding is of particular importance to transmasculine youth between onset of feminizing puberty (in the absence of puberty blockers) and when they undergo top surgery (if desired). Eighty to 90% of people who bind would prefer to have top surgery (double mastectomy with chest masculinization or radical breast reduction) (1,2,7,8), however they typically have to be over the age of 18 and navigate significant systemic and financial barriers to do so (8,9). Until receiving top surgery, or for those who do not want top surgery, binding is the primary way of achieving a similar effect. Thirty percent of people who bind begin before the age of 18 with 56% beginning before age 21 (10). Approximately half of people who bind do so every day for an average of 10 hours per day (1,2,11).

Unfortunately, 95-100% of people that bind experience negative physical symptoms as a result (1–4,10). Twenty-nine symptoms have been identified and can be categorized as pain, musculoskeletal, neurological, gastrointestinal, generalized, respiratory, and skin/tissue related.

They range in severity from itching to infections and rib fractures (1–4,12). See Appendix B for a list of symptoms and categories. The majority of these symptoms are experienced within the first month of binding (10). The one experimental study to date found that 20 habitual binder wearers showed decreased total lung capacity even while not wearing the binder suggesting possible chronic effects of binding on lung function (12).

Binding often requires complex decision making, including deliberating safety risks, planned activities, weather, who they will interact with, amount of dysphoria, and current mental and emotional state. People who bind will often endure significant physical discomfort to experience the positive benefits of wearing the binder and lessen the emotional distress related to chest dysphoria (2–4). This mimics other contexts where a harm reduction approach has proven useful. Harm reduction approaches are most applicable to contexts where a behaviour has negative consequences but where abstinence is not feasible, desirable, or valued by the patient. The central focus of harm reduction interventions is to mitigate the negative effects of the behaviour without requiring any change in the behaviour itself (13–16). It has been suggested that future research on binding take a harm reduction approach and focus on strategies for mitigating or managing binder related symptoms rather than recommending people bind less (1–3,10,11).

Any level of ongoing physical distress warrants the attention of a health care provider. Unfortunately, trans people experience significant structural, interpersonal, and anticipation barriers when accessing health care (17–20). People who bind are often aware of the potential negative health impacts of binding and express a desire to address these symptoms and risks with a health care provider (11,19). However, there are low rates of care seeking for binding-related symptoms due to lack of access to ‘safe’ providers and negative and stigmatizing responses from clinicians (3,11). Symptoms that triggered the most care-seeking were musculoskeletal, neurological, and pain-related in nature (11).

People who bind often have to manage the resulting symptoms on their own. The recommendations from the literature to date include decreasing the frequency (days per week), intensity (wearing time), and duration (number of years) of binder use (1,10). Community based guidelines offer similar recommendations along with using an appropriately

sized binder and avoiding binding during exercise and sleep (21–25). These recommendations target the behaviour of binding specifically rather than addressing the resulting symptoms and could result in greater harm in terms of mental health, participation limitations, or safety risks (3). Decreasing duration (number of years of binder use) in particular would require starting to use a binder as late as possible, which would be facilitated by access to puberty blockers, or stop as early as possible, which would require having better access to top surgery for those that want it. Both of these require significant reduction of health care barriers, navigation of complex health systems, and are not accessible options to individuals experiencing symptoms on a given day.

To date there are no recommendations for how people who bind can attempt to manage binding related symptoms in the context of having limited to no access to a safe and knowledgeable health care provider, or how healthcare providers should address these concerns in the context of a patient who will continue to bind. The purpose of the current research is to explore the incidence, overall impact, and level of concern of adverse symptoms related to chest binding and describe the detailed experiences of the six symptoms related to chest binding that would be most likely seen by health care providers.

Methods

Study Design

We conducted a cross-sectional survey. The University of Alberta's Health Research Ethics Board approved this research.

Patient engagement planning was completed using the template provided by the Alberta Strategy for Patient Oriented Research Support Unit (26). A Community Advisory Group (CAG) consisting of five community partners and five external members was formed.

Community partners were involved in determining study focus, survey development, design and dissemination of recruitment materials, and interpretation and presentation of results. External members assisted with survey design and pilot testing. Patient partner engagement and impact was assessed at the midpoint (during data collection) and upon completion of the study.

Harm reduction interventions in clinical settings have incorporated many principles (13,15,16). Six principles were proposed by Hawk et. al. as applying to broader health contexts (13). These principles were applied throughout the development, design, and presentation of this research (see Appendix A for details).

Population, Recruitment and Data Collection

The survey was distributed online via email contact with community organizations that serve this population across Canada. Participants were included if they had experience binding their chest for personal reasons, lived in Canada during the majority of the time they were/have been binding, and were 14 years of age or older. No specific exclusion criteria were used. See Limitations section below for design-related exclusions.

Data were collected anonymously using a purpose-made online survey through the Research Electronic Data Capture (REDCap) platform from June to September 2022. A second email was sent as a reminder to the same organizations one month after initial recruitment.

Survey Development

The survey topics were determined through consultation with community partners. The binding history questions and the list of 29 symptoms with corresponding categories were drawn from The Binding Health Survey with permission (1). Each symptom was categorized as either acute (more commonly understood with acute onset, transient or fluctuating presentation, and consistent presentation between people) or insidious (less commonly understood with insidious onset, chronic presentation, and less consistent presentation between people). A standard set of questions was developed that applied to all acute symptoms. This set of questions was adjusted for insidious symptoms where certain questions did not apply and other questions were added for clinical relevance. See Appendix B for symptom categorization and relevant questions. While this variability in question format decreased the available comparisons between symptoms, it improved the relevance of data to each symptom and thus the meaningfulness to the participant and potential for clinical application.

To avoid prescription when asking about management strategies and have consistency across symptoms to decrease cognitive burden, management strategies were grouped into four categories: ignoring or masking the symptom, preventing the symptom from occurring or

worsening, treating the symptom independently, and treating the symptom with the help of a health care provider. An initial version of the survey was reviewed by the CAG and revised. The survey was then pilot tested. Cognitive interviews were completed as the survey was being completed by CAG members. Primary revisions included separation of the symptom list into three parts to limit any priming effect and adjusting wording in questions and response categories. It was then reviewed a second time by the CAG, converted to the online platform, and tested by the community partners and research team to ensure links and branching logic were operating correctly.

Survey Structure

See Appendix C for a visual representation of the survey structure, branching logic, and number of responses per section. Upon clicking the link to the survey, participants were presented with the information letter. Consent was obtained by choosing to continue to the survey. The survey consisted of predominantly closed-ended questions in single- or multi-choice format. Many questions included an open-ended response option to allow participants to provide answers that were not covered in the closed-ended list. The survey was divided into three sections: binding history, symptom experiences, and demographics. The symptom experiences section was divided into three parts: pain symptoms, skin/tissue symptoms, and other symptoms. This division was a result of the high incidence of symptoms in the pain and skin/tissue categories and a much lower incidence of symptoms in the other categories. At the end of each category, three questions were asked regarding any symptoms experienced within that category: other management strategies they would have preferred to use but didn't have access to, barriers experienced related to those preferred management strategies, and how long it took for the symptoms to resolve once they stopped binding. At the end of the survey there was one question about trusted sources of information related to binding and several open-ended questions regarding feedback, further experiences, and future research.

Due to the detailed nature of the survey and the high number of symptoms an individual may have experienced, the length of the survey was a concern for attrition as well as cognitive burden. One strategy to prevent attrition was starting with the sections that had the most meaning to respondents, leaving demographic questions (that often carry lower cognitive

burden but may also be triggering of adverse psychological symptoms) to the end. As greater attrition rates occurred as the survey progressed, this led to the fewest responses for the demographic questions. Additionally, branching logic was used extensively throughout the survey to ensure that participants were only shown questions that were relevant to their experience using appropriate wording. Participants were asked whether they were still binding currently at the beginning of the survey, their response to which controlled whether all following questions were phrased in present tense or past tense. When participants reported experiencing a particular symptom, they were asked to rate the overall impact of that symptom on a scale of 1-10. Only those participants who rated the impact as 4 or higher were asked detailed questions pertaining to that symptom. This cut-off was tested and confirmed to be optimal and necessary during pilot testing in the cognitive interviews. While this ensured that participants only had to answer questions about symptoms that had meaningful impact on them, it led to the data being somewhat skewed to experiences of higher impact.

Analysis

For acute symptoms, asking the same set of questions resulted in these data being comparable. For insidious symptoms, the variety of questions resulted in these data being less comparable but provided greater description and detail required for clinical relevance.

Quantitative data were analyzed using relevant descriptive and inferential statistics using IBM SPSSv28 software (Chicago, IL). Qualitative data were re-categorized within the quantitative options where possible. Where this was not possible, they provided additional context for interpretation and discussion of results and recommendations for future research. All ordinal data were collected on a four-point scale and collapsed to a two-point scale for ease of reporting. Frequencies are presented in the following tables as percent of valid data. All missing data were removed, not replaced.

Binding frequency was collected as either days per week or days per month. Days per month was converted to days per week using $(x/30)*7$. Binding duration was collected using year of onset for those currently binding (2022-year of onset = duration) and years and months for those no longer binding (months/12 and added to their reported years for total duration). Age of onset was calculated using current age-(2022-year of onset). Binding years equivalent is

the number of years someone will have been binding if they spent the same number of hours binding but were binding 10 hours a day, 7 days a week. It was calculated using the same equation as previous research ($[\text{duration in years} * 52 \text{ weeks per year} * \text{frequency in days per week} * \text{intensity in hours per day}] / 3640$) (1).

A rating of symptom importance was used to provide a global ranking of symptoms. It was derived from a combination of symptom incidence, average overall impact rating, and frequency of high concern ($[\text{incidence} * (\text{impact} * 10) * \text{high concern}] / 1000$). See Table 3 and Figure 1 for these data. Combining these three aspects provided a more holistic and patient-oriented way to rank symptoms than looking solely at the incidence or each factor separately. The importance rating identifies the symptoms that are most important to patients and thus would most likely be disclosed to an HCP or discussed with others in the community.

Six symptoms were identified as the most likely symptoms that health care practitioners would see in relation to chest binding. The purpose of highlighting these symptoms was to present more detailed results for the most relevant symptoms. To identify these symptoms from the list of 29, the symptom incidence was combined with the frequency that participants accessed an HCP to manage that symptom ($\text{incidence} * \text{HCP}$).

For pain symptoms, impact on activity was measured using the Pain Disability Index, a standardized measure of the impact of chronic pain on seven categories of life activities (27). Impact of pain is rated on a scale of 0 to 10, to which we added a 'N/A' option. Total score out of 100 was calculated for all responses with at least 5 of the 7 scales completed. Due to the length of the PDI and the consistency of experiences across pain symptoms, the PDI was asked regarding all symptoms experienced within the pain category rather than each symptom separately. For all remaining symptoms, impact on activity was asked for each symptom and separated into ADLs, occupational, and social/recreational. This variability in question format lead to less comparability between pain symptoms and non-pain symptoms. This was deemed an appropriate limitation for the increased validity of the data on the impact of pain symptoms as pain symptoms had the highest incidence.

Results

The total number of people who accessed the survey was 570, 356 of whom completed at least the first question and 278 completed the entire survey. 356 respondents represents approximately 1.1% of the people who bind their chest in Canada who are 14 years of age or more (5,6,11).

Table 1 shows the demographic information for this sample. The mean age of the sample was 25.5 years, significantly younger than the Canadian population (28). The majority of participants (58.3%) reported no relevant medical conditions. The majority of participants (53.3%) reported living with a parent or guardian at some point while binding their chest.

Table 1: Demographic information for all participants who responded to these questions and equivalent demographic information for the Canadian population.

Variable	N	Freq (%)	Canada Freq (%) ^o	Mean (SD)	Min/Max	Canada mean [§]
Age (years)	284			25.5 (7.5)	14/57	41.9
Race	282					
-Indigenous	20	7.1	7.7			
-Black or Person of Colour	24	8.5	26.1			
-White	247	87.6				
-Other	6	2.1				
Racialized in healthcare settings	280					
-Yes	19	6.8				
Education	282					
-Grades 6-8	2	0.7				
-Grades 9-11	26	9.2				
-High school grad or GED	104	36.9				
-Post-secondary or professional training	148	52.5				
Two-Spirit*	17					
-Yes	11	64.7				
Gender	284					
-Nonbinary	187	65.8				
-Girl, woman, trans woman	26	9.2				

-Boy, man, trans man	156	54.9				
Province	281					
-Alberta	77	27.4	11.5			
-British Columbia	23	8.2	13.5			
-Manitoba	11	3.9	3.6			
-New Brunswick	29	10.3	2.1			
-Newfoundland and Labrador	3	1.1	1.4			
-Northwest Territories	0	0	0.1			
-Nova Scotia	33	11.7	2.6			
-Nunavut	0	0	0.1			
-Ontario	76	27.0	38.5			
-Prince Edward Island	0	0	0.4			
-Quebec	8	2.8	23.0			
-Saskatchewan	18	6.4	3.1			
-Yukon	2	0.7	0.1			
Urbanicity	283					
-City or suburban	236	83.4	69.8			
-Town or rural	44	15.5	30.2			
Living Situation	282					
-Alone	47	16.7				
-Parent/guardian	151	53.3				
-Sibling/other family	80	28.4				
-Children/dependent minors	4	1.4				
-Partner/spouse	84	29.8				
-Roommate	72	25.5				
Medical History	264					
-Lung related conditions	37	14				
-Bone and joint conditions	15	5.7				
-Neurological conditions	38	14.4				
-Chronic pain	21	8.0				
-GI conditions	25	9.5				
-Autoimmune disorders	13	4.9				
-Cardiovascular conditions	11	4.2				
-Other	24	9.1				
-None	154	58.3				
Smoking	281					
-Yes	44	15.7				

° (29–31) § (28). Freq = Frequency, GED = General educational development, GI = Gastrointestinal, N = Number, SD = Standard deviation.

*Question about two-spirit identity was only visible to participants who responded that their race was Indigenous.

Table 2 shows the binding behaviours of this sample. Fifty percent of participants had started binding by 19 years of age and 25% had started binding by 15 years of age. The median binding experience was binding for nine hours, five days per week for three years.

Table 2: Chest binding behaviours, Binding Years Equivalent, and binding methods.

	N	M (SD)	Min/max	Median (IQR)	Freq (%)
Age of onset (years)	285	20.3 (6.2)	9/44	19.0 (15.2,24.0)	
Duration (years)	396	3.9 (3.1)	0/22	3.0 (1.6, 5.2)	
Frequency (days/week)	393	4.9 (2.0)	0.2/7	5 (3, 7)	
Intensity (hours/day)	389	9.9 (3.6)	1/24	9 (8, 12)	
Binding Years Equivalent	396	3.1 (4.2)	0/48	2.0 (0.6, 4.3)	
Binding Method	396				
-ace wrap/tensor bandage					6.6
-compressive clothing					11.9
-sports bra					33.1
-multiple sports bras					13.9
-athletic compression wear					5.8
-commercially made half binder					79.0
-commercially made full binder					35.9
-other method (neoprene, duct tape, plastic wrap, or homemade)					3.0

Freq = Frequency, IQR = Interquartile range, M = Mean, N = Number, SD = Standard deviation.

On average, participants experienced six to seven binding related symptoms (mean 6.6, std. 4.3) with a range of no symptoms (3.4%) to 21 of the 29 symptoms. Incidence, overall impact, and level of concern were used to calculate an importance rating for each symptom, as displayed in Table 3 and Figure 1. The symptoms with the highest importance rating were shortness of breath (215.8), overheating (154.4) and chest pain (148.0). Symptoms with a moderately high importance rating were back pain (81.1), shoulder pain (75.9), rib and spine changes (70.0), abrasions (56.5), and shoulder joint instability (55.2). When ratings of

importance were averaged across the symptoms within categories, Pain and Respiratory had the highest importance rating (231.0; 205.6).

Table 3: Incidence, overall impact, level of concern, and rating of symptom importance for all adverse physical symptoms associated with chest binding, grouped into categories based on physiological characteristics.

	Incidence		Ratings of overall impact on life		Level of concern		Symptom Importance
	N	Freq (%)	Mean (SD)	Min/Max	Freq (%)		
					Low	High	
Total responses	356						
No Symptoms	12	3.4					
1-2 symptoms	40	11.2					
3-4 symptoms	78	21.9					
5-6 symptoms	65	18.3					
7-8 symptoms	61	17.1					
9-10 symptoms	38	10.7					
11-15 symptoms	42	11.8					
16-21 symptoms	16	4.5					
Pain	355*						231.0
-Back	219	61.7	5.5 (2.5)	0/10	76.1	23.9	81.1
-Chest	219	61.7	5.3 (2.5)	0/10	54.9	45.1	148.0
-Shoulder(s)	171	48.2	5.3 (2.5)	0/10	70.5	29.5	75.9
-Abdomen	41	11.5	4.7 (2.6)	0/10	65.2	34.8	18.8
-Other	44	12.4	6.5 (2.6)	0/10	41.7	58.3	46.8
-Ribs	17	4.8	7.1 (2.2)	3/10	21.4	78.6	26.9
-Neck, hips, underarms	26	7.3	6.1 (2.8)	0/10	54.5	45.5	20.2
-One or more	314	88.5					
-None	41	11.5					
Skin/tissue	336*						125.2
-Acne	172	51.2	3.9 (2.9)	0/10	76.1	23.9	47.9
-Itching	169	50.3	4.7 (2.5)	0/10	84.2	15.8	37.3
-Abrasions	77	22.9	5.6 (2.4)	1/10	55.9	44.1	56.5
-Scarring	13	3.9	3.7 (2.7)	0/8	85.7	14.3	2.1
-Swelling	15	4.5	5.5 (2.7)	0/10	45.5	54.5	13.6

-Skin changes	64	19.0	3.6 (3.0)	0/10	87.0	13.0	8.9
-Skin infection	9	2.7	5.4 (2.4)	2/10	28.6	71.4	10.5
-Breast changes	72	21.4	3.8 (3.2)	0/10	69.0	31.0	25.4
-Breast tenderness	112	33.3	4.9 (2.7)	0/10	75.7	24.3	39.7
-Other (rash, eczema)	10	3.0					
-One or more	283	84.2					
-None	53	15.8					
Other Categories	302*						
Generalized							127.1
-Overheating	177	58.6	6.35 (2.6)	1/10	58.5	41.5	154.4
-Fatigue	90	29.8	5.42 (2.7)	0/10	81.0	19.0	30.7
-Weakness	53	17.5	5.79 (2.4)	1/10	65.0	35.0	35.5
-One or more	206	68.2					
-None	96	31.8					
Respiratory							205.6
-Shortness of breath	200	66.2	6.1 (2.5)	0/10	46.3	53.7	215.8
-Cough	36	11.9	5.2 (2.8)	0/10	69.6	30.4	18.9
-Respiratory infection	10	3.3	7.3 (2.8)	2/10	37.5	62.5	15.1
-One or more	205	67.9					
-None	97	32.1					
MSK							131.1
-Shoulder joint instability	46	15.2	6.5 (2.9)	0/10	44.1	55.9	55.2
-Rib and spine changes	51	16.9	6.5 (2.6)	1/10	36.6	63.4	70.0
-Rib fracture	16	5.3	7.6 (2.1)	4/10	12.5	87.5	35.1
-Muscle wasting	11	3.6	6.8 (2.5)	3/10	50.0	50.0	12.3
-One or more	90	29.8					
-None	212	70.2					
Neurological							52.0
-Dizziness	63	20.9	6.1 (2.5)	0/10	67.4	32.6	41.8
-Headache	49	16.2	5.9 (2.9)	0/10	77.8	22.2	21.4
-Numbness	37	12.3	4.8 (2.9)	0/10	68.2	31.8	18.6
-One or more	97	32.1					
-None	205	67.9					
GI							30.6
-Heartburn	29	9.6	5.1 (2.7)	0/10	60.0	40.0	19.7
-Digestive issues	37	12.3	5.4 (2.3)	0/9	74.1	25.9	17.2
-One or more	53	17.6					

-None	249	82.5				
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Freq = Frequency, GI = Gastrointestinal, MSK = Musculoskeletal, N = Number, SD = Standard deviation.

*Number of valid responses to survey question. Used to determine frequencies for all symptoms and/or categories included in that section.

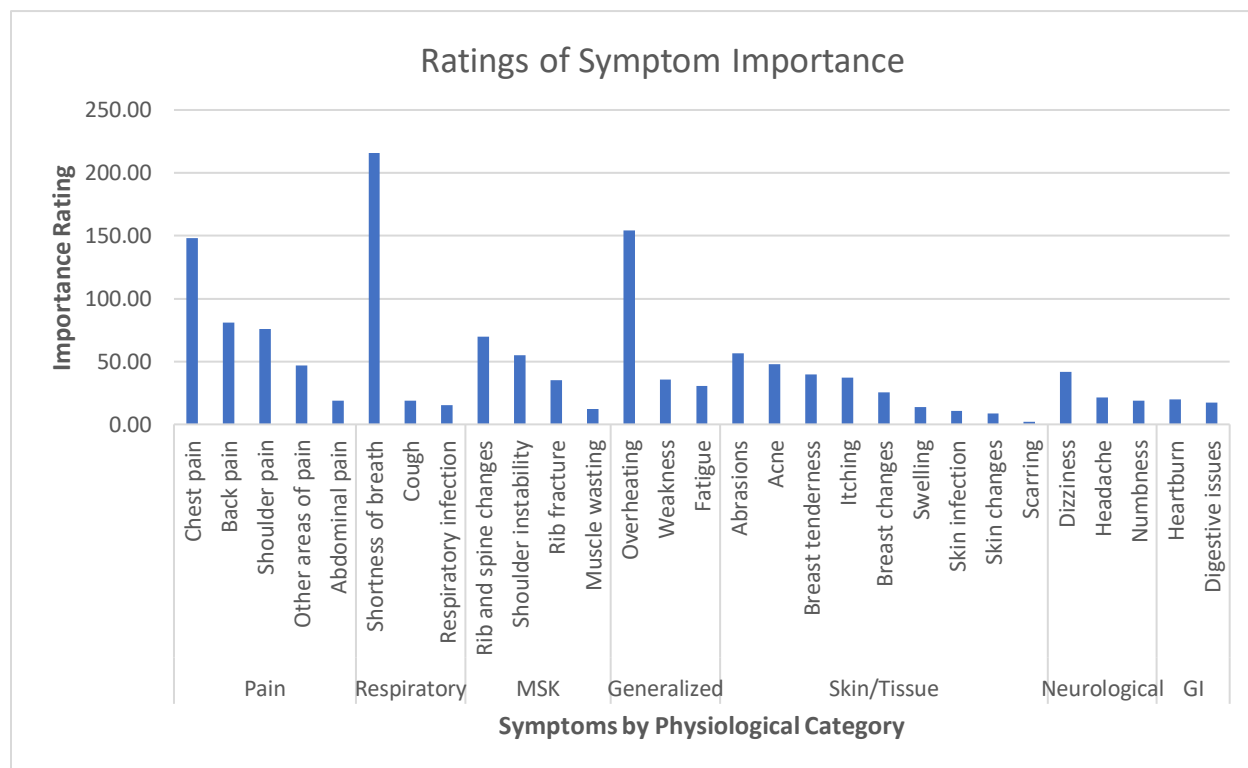


Figure 1: Ratings of symptom importance as calculated from incidence, overall impact, and concern ratings. Symptoms are shown within their physiological category from highest symptom importance rating to lowest. Categories are in order from highest average symptom importance rating to lowest. GI = Gastrointestinal, MSK = Musculoskeletal.

As shown in Table 4, back pain, chest pain, shoulder pain, shortness of breath, and shoulder instability all showed improvement when not binding with symptoms occurring less often and at lower intensity. Shortness of breath showed the biggest improvement with 66.5% of participants reporting it occurring often or always while binding and 13.4% when not binding. Intensity of shortness of breath was rated on average 6.3 when binding and 2.8 when not binding. Shoulder instability showed the least difference between binding and not binding and had the highest frequency and intensity ratings when not binding (54.3% reporting shoulder instability often or always when not binding; intensity rated 5.6 on a scale of 0 to 10 when not binding).

Rib and spine changes are an insidious onset, chronic symptom and thus included a question asking participants to characterize the changes. Stiffness was the most common change reported (82.9%), followed by hunched shoulders (63.4%) and ribs sticking out or flaring at the bottom (41.5%). Other changes reported were rib and spine asymmetry and new onset or worsening of existing scoliosis.

The impact of back pain, chest pain, and shoulder pain on activities was very similar with mean PDI scores of 39.5, 39.6, and 37.6 respectively. For all three symptoms, the area of highest disability was Recreation (median of 6/10, 6/10, and 5/10 respectively). For shortness of breath and shoulder instability, the majority of respondents reported low impact on ADLs (73.2% and 71.4% respectively) and approximately half of respondents reported low impact on social/recreational activity (47.6% for shortness of breath and 57.1% for shoulder instability). Shortness of breath was reported to have low impact on occupational tasks by 61.3% of respondents, whereas for shoulder instability this was only 54.3% of respondents.

On average across the six symptoms most likely to be seen by an HCP, management strategies used from most often to least often were to ignore or mask the symptom (65.4%), self-management (58.0%), avoiding triggers/prevent worsening (45.8%), and accessing an HCP (18.2%). Shoulder instability showed the highest frequency of ignoring the symptom (80.0%) as well as accessing an HCP (34.3%). Shortness of breath showed the highest frequency of avoiding triggers to prevent worsening (66.3%). Back pain showed the highest frequency of using self-management strategies (71.4%).

In general, respondents were able to manage these symptoms well enough to continue binding using their preferred amount and method. Rib and spine changes were reportedly the easiest to manage (80.5% mostly or yes) and SOB was the most difficult to manage (57.7% mostly or yes). Participants rarely adjusted their binding habits despite experiencing these symptoms. The symptom that caused a change in binding habits most often was SOB, with 72.6% still reporting sometimes or never.

Table 4: Details for the six binding-related symptoms that a general care provider is most likely to encounter (back pain, chest pain, shoulder pain, shortness of breath, shoulder instability, and rib/spine changes)

					Frequency (%)	
		N	M (SD)	Min/max	Low/no	High/yes
Back Pain	Frequency	163				
	-while binding				34.4	65.6
	-while not binding				58.9	41.1
	Intensity	161				
	-while binding		5.8 (2.1)	0/10		
	-while not binding		4.1 (2.7)	0/10		
	Pain Disability Index score	182	39.5 (22.0)	0/91.4		
Impact on Binding	162			81.5	18.5	
Able to manage	162			26.5	73.5	
Management strategies used	161					
-ignore/mask					62.1	
-avoidance/prevent worsening					39.8	
-self-management					71.4	
-HCP directed management					18.0	
Chest Pain	Frequency					
	-while binding	155			45.8	54.2
	-while not binding	152			74.3	25.7
	Intensity	155				
	-while binding		5.7 (2.1)	0/10		
	-while not binding		3.5 (2.5)	0/9		
	Pain Disability Index score	178	39.6 (22.9)	0/91.4		
Impact on Binding	155			74.2	25.8	
Able to manage	155			34.8	65.2	
Management strategies used	155					
-ignore/mask					66.2	
-avoidance/prevent worsening					42.9	
-self-management					65.6	
-HCP directed management					5.8	
Shoulder Pain	Frequency	121				
-while binding					40.5	59.5

	-while not binding				60.3	39.7
	Intensity	122				
	-while binding		5.7 (2.2)	1/10		
	-while not binding		4.0 (2.7)	0/10		
	Pain Disability Index score	139	37.6 (23.4)	0/91.4		
	Impact on Binding	122			83.6	16.4
	Able to manage	122			27.0	73.0
	Management strategies used	122				
	-ignore/mask					71.3
	-avoidance/prevent worsening					38.5
	-self-management					63.1
	-HCP directed management					15.6
SOB	Frequency	164				
	-while binding				33.5	66.5
	-while not binding				86.6	13.4
	Intensity					
	-while binding	164	6.3 (2.1)	1/10		
	-while not binding	163	2.8 (2.5)	0/10		
	Impact on activities					
	-ADLs	164			73.2	26.8
	-Occupational	163			61.3	38.7
	-Social/recreational	164			47.6	52.4
	Impact on Binding	164			72.6	27.4
	Able to manage	163			42.3	57.7
	Management strategies used	164				
-ignore/mask					56.4	
-avoidance/prevent worsening					66.3	
-self-management					52.1	
-HCP directed management					6.1	
Shoulder Instability	Frequency	35				
	-while binding				22.9	77.1
	-while not binding				45.7	54.3
	Intensity	35				
	-while binding		6.8 (1.6)	4/10		
	-while not binding		5.6 (2.7)	2/10		
Impact on activities	35					

	-ADLs				71.4	28.6
	-Occupational				54.3	45.7
	-Social/recreational				57.1	42.9
	Impact on Binding	35			88.6	11.4
	Able to manage	35			31.4	68.6
	Management strategies used	35				
	-ignore/mask					80.0
	-avoidance/prevent worsening					45.7
	-self-management					54.3
	-HCP directed management					34.3
Rib and spine changes	Onset (binding duration in years)	42	2.1 (2.3)	0/13		
	Characterize	42				
	-Negative					85.7
	-Neutral					14.3
	Type of change	42				
	-shoulders hunched					63.4
	-stiffness					82.9
	-ribs sticking out					41.5
	-other (asymmetry, scoliosis)					29.3
	Able to manage	41			19.5	80.5
	Minimize changes	41			36.6	22.0
	Management strategies used	42				
	-ignore/mask					56.1
	-avoidance/prevent worsening					41.5
	-self-management					41.5
	-HCP directed management					29.3

ADLs = Activities of daily living, HCP = Healthcare professional, M = Mean, N = Number, SD = Standard deviation, SOB = Shortness of breath.

Discussion

Despite experiencing moderate to high frequencies, intensities, and impact of symptoms, the participants rarely modified their binding strategy. This indicates how important the practice of binding is – that after weighing the risks and benefits, people still decide to bind despite experiencing symptoms. Thus, a HCP suggesting they stop binding is an inadequate

recommendation. If stopping was an adequate option, they would have done it already to halt the symptoms.

Of the symptoms most likely to be seen by a HCP in relation to chest binding, shortness of breath showed the biggest improvement when not binding. This suggests that it is primarily caused by the constriction of the material and less by permanent physiological changes, in agreement with previous research that showed decreased vital capacity while binding only (12). Back, chest, and shoulder pain and shoulder instability showed less improvement when not binding suggesting that they are resulting to some degree from physiological changes related to binding. Data on rib and spine changes suggest this could be the case as stiffness of ribs and/or spine were identified as the most common change. Rib stiffness can make breathing more effortful, decrease lung capacity and induce shortness of breath. However, as we can compensate somewhat with a diaphragmatic breathing pattern, this impact would be less than that on back, chest, and shoulder pain or shoulder instability. The possibility of physiological changes is particularly concerning as fifty percent of respondents reported starting to bind before 19 years of age and thus still had active musculoskeletal growth and development while binding.

The highest area of impact across the six symptoms presented in detail was social/recreational activities. Combined with the observation that participants rarely modified binding strategies, this suggests that people who bind are more likely to avoid activities that trigger binding related symptoms. This is especially evident for SOB where prevention strategies (such as avoiding triggering activities) were the most frequently used management strategy. Trans people already experience significant barriers with accessing physical and recreational activities (32–36). When considering that the majority of people who bind their chest are aged 15 to 24 years, avoiding recreational activity could lead to a more sedentary lifestyle that could have long term negative effects both physically and mentally.

Shoulder instability had the highest impact on occupational activity. In an occupational context, people would have less ability to avoid activities that would make it worse. As the data shows, people who bind are most likely to ignore shoulder instability or have it addressed by an

HCP. Shoulder instability is a common injury and easier to present to an HCP without having to mention chest binding and thus may feel safer to access care for than other symptoms.

Some symptoms showed a lower level of concern despite being clinically concerning. These include numbness, dizziness, muscle wasting, and swelling. This may indicate a lack of understanding of the physiology associated with these symptoms or that level of concern is based on other factors such as amount of impact and their ability to sufficiently manage the symptom. Patients may be experiencing these symptoms but not deem them concerning enough to mention.

Skin changes, specifically a loss of elasticity, is a binding-related symptom that has been identified by clinicians (primarily surgeons performing masculinizing chest surgery or ‘top surgery’) as being of high concern due to its possible negative effects on surgical results (37,38). However, it was rated as low impact and low concern by people who bind. It is possible that people who bind do not understand the impact of skin changes on their potential top surgery outcomes or that it simply is of low priority for them.

Some symptoms show higher importance ratings but a lower rate of accessing HCPs to help with management. The most notable of these was overheating which had the second highest importance rating but a 0% rate of accessing HCPs for management. Other important symptoms with low rates of accessing HCPs include abrasions, acne, and dizziness.

The majority of participants were nonbinary and/or men, however some were women. Additionally, binding is often used to manage dysphoria early in transition. This means that people who bind may appear masculine, feminine, or androgynous. The majority of participants reported living with a parent or guardian at some point while binding their chest. Lack of parental support can lead to more secrecy around binding, longer binding times, and significant difficulty accessing trans-affirming care (2–4,11). For people living in a rural setting, there may be few alternatives to an unsupportive living situation.

There appeared to be no relationship between symptom incidence and past medical history.

Clinical Implications

When discussing symptoms related to binding, it is important to employ a harm reduction approach. This means all treatment interactions would focus on helping patients manage binding related symptoms without requiring modifications to binding behaviours. Some symptoms persist even when patients are not binding their chest. Thus, simply reducing the amount of binding or even stopping binding altogether would not be adequate to address these symptoms. This approach will build trust, support the therapeutic alliance, and result in better care for patients.

As the binding-related symptoms presented in detail primarily impacted social/recreational activities, improving symptom management is one way that HCPs can facilitate trans patients' social and recreational engagement.

Some clinically concerning symptoms were not concerning to patients. It is important to screen for these symptoms, as patients may not mention them, and provide education regarding physiology, symptom identification, and management. Other symptoms showed a lower rate of accessing HCPs to help with management despite higher importance ratings. Clinicians should ask about these symptoms when seeing a patient who binds and offer to assist in management or refer to an appropriate professional if relevant.

People who bind may identify as men, women or nonbinary and may appear masculine, feminine, or androgynous. HCPs should avoid making assumptions about binding based on a patient's appearance or identity. Many people who bind are living with their parents or other caregivers. HCPs need to be aware of the challenges of navigating the influence of potentially unsupportive parents/caregivers including the safety risks related to disclosing patients' chest binding.

Strengths and Limitations

This study consistently applied a harm reduction approach and engaged members of the community throughout study design, survey development, data collection and analysis, and reporting. This ensures that resulting data and recommendations are supportive of the community and actionable for people who bind and the HCPs they access for symptom management. The survey was designed to match the experiences of people who bind and

ensure that resulting data would be clinically relevant even if this resulted in a reduction in the available comparisons between symptoms. The survey explored symptoms in detail, providing essential depth of information that is missing in the current literature yet necessary for clinical practice.

As this research employed a cross-sectional design it cannot determine causation. Symptoms reported as binding-related could result from poor posture due to dysphoria, physiological manifestations of social and emotional stressors, or other unknown factors. The survey was only available online in English which limited the sample to people who can read and understand English and have internet access. By primarily recruiting through community and social organizations, the sample was also limited to individuals who are connected with these groups. Due to the sampling strategy used, self-selection bias may be a factor. The survey itself was not a standardized measurement tool and though it underwent significant review and pilot testing, it was not assessed for reliability and validity. As with any survey data, there remains the possibility of response bias and positivity bias despite careful wording of the recruitment materials and survey questions.

Conclusions

This study supports recommendations made by previous research such as encouraging at least one day off from binding per week if possible and facilitating access to top surgery for those that want it to decrease binding duration.

However, chest binding was so important to our participants that despite moderate to high frequencies, intensities, and impacts of binding related symptoms, they rarely modified their binding strategy. Thus, treatment for binding-related symptoms should focus on symptom management without requiring modifications to binding behaviours.

Patterns of symptom presentation suggest compression from binding material as well as ongoing physiological impacts may contribute. Physiotherapists are well qualified to manage binding-related symptoms as the six symptoms most likely to be seen by HCPs are within their scope of practice and they can address physiological, biomechanical, recreational, and occupational impacts. The high frequency of using self-management strategies to address symptoms suggests people who bind may engage well in active treatment options.

Future Research Directions

It is unknown if medical conditions unrelated to binding correlate with specific aspects of binding-related symptom experiences such as symptom intensity, impact on activities, or the ability to manage symptoms.

More detailed information is needed on all binding-related symptoms, especially those that are most clinically concerning, even if they are rare. Likewise, further research is needed on how people who bind are managing binding-related symptoms and how effective these strategies are in reducing the frequency, intensity, and impacts of symptoms. Research focusing specifically on youth would be particularly valuable as this age is when binding is most prevalent, most impactful, and when their access to treatment and trans-affirming care is most limited.

Further research is needed to determine a causal relationship between binding and reported symptoms, assess the degree of restriction caused by the binding material and potential physiological changes, and develop self-management and HCP-led treatment guidelines.

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Appendix A: Harm reduction principles as applied to this research

Humanism

Definition:

- Providers value, care for, respect, and dignify patients as individuals in all aspects of their identities.
- It is important to recognize that people do things for a reason; harmful health behaviours provide some benefit to the individual and those benefits must be assessed and acknowledged to understand the balance between harms and benefits.
- Understanding why patients make decisions is empowering for providers.

Research Development:

- Grounded in the understanding that binding provides various benefits, unique to each individual.

Research Methodology:

- Assumptions and judgements based on any aspect of a participant's identity or experience will be avoided.
- Research materials will use inclusive language that reflects the diversity of this population.
- Participants will be given the opportunity to expand on their experiences via open-ended questions to capture as much of the experience as possible.

Research Presentation:

- Recommendations and results will be presented as a form of support for continuing to bind at their own discretion.

Pragmatism

Definition:

- None of us will ever achieve perfect health behaviours.
- Health behaviours and the ability to change them are influenced by social and community norms; behaviours do not occur within a vacuum.

Research Development:

- Binding will be viewed and discussed in neutral terms that acknowledge both the risks and benefits.

Research Methodology:

- Decreasing or stopping binding will be presented as one of many possible management strategies.
- All strategies will be treated as equally valid options.

Research Presentation:

- Symptoms that warrant discontinued binding will be recognized but for all other symptoms, decreasing binding will not be recommended as an ideal treatment or management strategy.

Individualism

Definition:

- Every person presents with their own needs and strengths.
- People present with spectrums of harm and receptivity and therefore require a spectrum of intervention options.

Research Development:

- Intersectionality will be recognized and assessed where possible.
- It will not be assumed that everyone who binds experiences negative health effects.
- It will not be assumed that all negative symptoms experienced while binding are related to use of the binder.

Research Methodology:

- A variety of management strategies and treatment options will be incorporated and discussed, including self-management strategies as well as HCP-led strategies.

Research Presentation:

- Participants' health care related harm will be recognized and respected as a legitimate factor in accessing care.

Autonomy

Definition:

- Though providers offer suggestions and education regarding patients' medications and treatment options, individuals ultimately make their own choices about medications, treatment, and health behaviours to the best of their abilities, beliefs, and priorities.

Research Development:

- Participants will be treated as the experts on their experiences and needs.

Research Methodology:

- Patient-partners will be able to influence the project throughout the research process.
- Negative effects of symptoms and positive change related to use of management strategies will be assessed using patient-derived meaningful outcomes rather than clinical ones.

Research Presentation:

- All resulting recommendations will be derived directly from participant responses.

Incrementalism

Definition:

- Any positive change is a step toward improved health, and positive change can take years.
- It is important to understand and plan for backward movements.

Research Development:

- This research will be situated in an area that has much work left to be done and will only address one small part.

Research Methodology:

- Changes in symptoms will be presented as a range rather than absolute.
- Results will be analyzed and discussed with the recognition that the need to bind and the resulting symptoms may fluctuate in either direction over time.

Research Presentation:

- Symptom management strategies will not be presented as a 'cure' or 'optimal treatment' but rather a variety of options for ongoing management to ideally prevent worsening of symptoms.

Accountability without termination

Definition:

- Patients are responsible for their choices and health behaviours.
- Patients are not 'fired' for not achieving goals.
- Individuals have the right to make harmful health decisions, and providers can still help them to understand that the consequences are their own.

Research Development:

- Participant's choice to bind in whatever capacity or format they see fit will be recognized as their own and will not be judged or questioned.

Research Methodology:

- Participants will not have to answer every question for their responses to be counted.

Research Presentation:

- Knowledge translation procedures will be emphasized and completed but we recognize that each individual is responsible for adopting recommended management strategies or not.

Appendix B: Symptoms, categories, and survey questions

Twenty-nine symptoms were included in this survey. They were grouped together by physiological category as shown in Table 5. Each symptom was identified as acute or insidious. Acute symptoms all had the same set of questions (listed under ‘Standard Questions’ in Table 6) and insidious questions were adapted to the symptom (as shown in Table 6).

Table 5: List of physiological categories and their associated symptoms identified as acute or insidious.

Physiological Category	Symptom	Acute	Insidious
Pain	Back pain	X	
	Chest pain	X	
	Shoulder pain	X	
	Abdominal pain	X	
	Other area of pain	X	
Skin and Tissue	Acne	X	
	Itching	X	
	Abrasions	X	
	Scarring		X
	Swelling	X	
	Skin changes		X
	Skin infection		X
	Breast/chest changes		X
	Breast/chest tenderness	X	
Generalized	Overheating	X	
	Fatigue	X	
	Weakness	X	
Respiratory	Shortness of breath	X	
	Cough	X	
	Respiratory infection		X
Musculoskeletal	Shoulder instability	X	
	Rib and spine changes		X
	Rib fracture		X
	Muscle wasting		X

Neurological	Dizziness	X	
	Headache	X	
	Numbness		X
Gastrointestinal	Heartburn	X	
	Digestive issues	X	

Table 6: Questions asked for all symptoms identified as insidious.

Standard Questions:	Scar.	Sk.Ch.	Sk.Inf.	Br.Ch.	R.Inf.	R.S.Ch.	Rib#	M.W.	Numb.
Amount of concern	X	X	X	X	X	X	X	X	X
Frequency while binding									X
Frequency while not binding									X
Intensity while binding									X
Intensity while not binding									X
How often modifying binding	X		X		X		X	X	X
Impact on activities			X		X		X		X
Able to continue binding	X							X	X
Management strategies	X	X	X	X	X	X	X	X	X
Effectiveness of management strategies			X		X				X
Additional Questions:									
Positive, negative, or neutral				X		X			
Binding duration at onset	X	X	X	X	X	X	X	X	
Location									X
Characteristics		X				X			X
Number of occurrences			X		X		X		

Severity of worst occurrence	X		X		X		X	X	
Binding with symptom present		X	X	X	X	X	X		
Binding after symptom resolved			X		X		X		
Able to minimize symptom		X		X		X			

Br.Ch. = Breast/chest changes, M.W. = Muscle wasting, Numb. = Numbness, Rib# = Rib fracture, R.Inf. = Respiratory infection, R.S.Ch. = Rib and spine changes, Scar. = Scarring, Sk.Ch. = Skin changes, Sk.Inf. = Skin infection.

Appendix C: Survey design and number of responses

