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Brief research report

Supporting individuals with a visible difference: A UK survey of needs and preferences

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ABSTRACT

Individuals with visible differences, resulting from injuries, health conditions, or treatment, can face varied and lasting psychosocial effects. Existing psychosocial interventions are limited, with inconsistent support noted by specialists. Improved provision and accessibility are crucial; yet, the self-perceived needs remain underreported. This study explored the self-reported support needs of affected adults to better understand their needs and inform support provision. An online survey conducted in the UK from October to December 2022 inquired about support preferences, delivery methods, and current and future anticipated considerations when seeking assistance. Quantitative data were analyzed statistically, and open-ended responses were analyzed using qualitative content analysis. Five hundred and fifty individuals (aged 18–82 years; 489 (88.9 %) female) participated. The majority (80.5 %) wanted more information on potential treatments, while 53.6 % wanted insights into causes, and 61.3 % wanted help accepting their appearance. Preferred sources included healthcare professionals (89.3 %), online/digital platforms (websites 65.8 %, online support groups 47.6 %) and in-person support (counseling (45.8 %), support groups (37.5 %)). Participants' support-seeking decisions were influenced by access to condition-specific information, evidence-based practices, and healthcare professional awareness. Individuals with visible differences require holistic support from various providers, delivered in a range of formats. Findings can inform support strategies and services.

1. Introduction

Having an appearance that is different from 'the norm' because of an injury, health condition, illness, or treatment (sometimes referred to as visible differences, e.g., burn injuries, skin conditions, craniofacial conditions, hair loss, limb loss, scarring) can potentially have a varied, extensive, and enduring impact on those affected. This impact can be multifaceted and vary in intensity depending on physical appearance factors, personal experiences, and social circumstances (Keeling et al., 2023; Rumsey et al., 2004). Challenges faced by those affected include negative emotions such as depression and anxiety, negative self-perceptions, self-esteem issues and managing the reactions of others (Martin et al., 2017; Rumsey et al., 2004). Individuals often encounter challenging social situations including staring, avoidance and intrusive questions with many experiencing stigma and discrimination (Rumsey & Harcourt, 2012; Sarwer et al., 2022). This can lead to avoidance of social situations, including engaging with friends and family and forming intimate relationships (Sarwer et al., 2022; Tollow et al., 2023). While many people manage well, others could benefit from information and support to help them make sense of their experiences and manage the social and psychological challenges resulting from their appearance (Egan et al., 2011; Rumsey & Harcourt, 2004).

A range of people and organizations can be involved in supporting people with a visible difference, including healthcare professionals, people working within charitable organizations and family and friends. This support can be provided directly or by providing input to the evidence-based development of new interventions, including those based on social skills (Robinson et al., 1996), Cognitive Behavioral Therapy (CBT) (Beck, 1964) and Acceptance and Commitment Therapy (ACT) (Hayes et al., 2003). CBT interventions aim to help individuals with visible differences challenge unhelpful thoughts and behaviors, build confidence, and develop practical coping strategies to manage appearance-related distress (Clarke et al., 2013). ACT interventions encourage individuals with visible differences to accept their

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appearance, clarify personal values, and engage in meaningful actions despite appearance-related challenges (Powell et al., 2023; Zucchelli et al., 2022). Interventions using social skills combined with CBT, like those by Bessell et al. (2010), help individuals with visible differences improve interactions and manage social challenges, promoting confidence and adjustment. However, people with visible differences still have unmet psychosocial support needs, due to both a lack of recognition and reluctance to report these needs, stemming from concerns about appearing superficial or feeling unentitled (Davey et al., 2019; Thompson et al., 2020). This issue is exacerbated by insufficient training among healthcare professionals on the psychosocial impacts of visible differences and the best practices for discussing, addressing concerns, and referring individuals to appropriate support systems (Gee et al., 2019). Organizational barriers, such as funding constraints, capacity issues, and long waiting lists, further exacerbate the problem (Davey et al., 2019; Gee et al., 2019). Despite increased awareness of the psychosocial impact of having a visible difference, research on the specific support needs and preferences of individuals with visible differences remains limited. While some studies have explored professional perspectives (Harcourt et al., 2018), there is a lack of insight into the self-perceived needs of those with lived experience (Keeling et al., 2023).

This study aimed to gather insights from adults with visible differences in the UK to inform future support development. Specifically, we sought answers to the following questions:

1. What are the issues that adults with visible differences want support with?
2. How would they like that support to be provided/made available?
3. What factors do they consider when seeking support?

2. Method

2.1. Study design

An online survey was conducted in the UK from October to December 2022. Ethical approval was granted by the authors' institution [ref HAS.22.08.007].

The survey was informed by existing literature on visible differences, psychosocial interventions and the authors' expertise in this field. It incorporated principles of Community-Based Participatory Research (CBPR) (Collins et al., 2018) by refining questions through feedback from an adult advocate with lived experience of having a visible difference and prioritizing the self-perceived needs of the community. The survey, consisting of 10 questions, examined participants' current and future support preferences, delivery methods, and considerations for seeking assistance. Most questions were multiple-choice, with options for selecting multiple answers, while a few open-ended questions allowed further elaboration. See Table 1 for the survey questions, and Appendix I for the full survey (questions and potential responses). The survey was administered online through Qualtrics, a secure online survey platform.

2.2. Sampling and recruitment

The survey details were disseminated to adults with visible differences with the collaboration of a group of relevant charitable organizations, known as the Appearance Collective (https://vtctfoundation.org.uk/the-appearance-collective/). The promotion of the survey took place across various platforms including social media, websites, newsletters, and events organized by the Appearance Collective. Additionally, the survey was shared through social media channels of the authors' research center and with members of its participant pool mailing list. Participation was voluntary with no offer of payment for taking part.

2.3. Data analysis

Data analysis and reporting were informed by the biopsychosocial model, which proposes that health and wellbeing are influenced by biological, psychological, and social factors and experiences (Engel, 1977) (see Table 2). These domains have been usefully employed in previous appearance-related research and interventions (Rodgers et al., 2020). In this study the model was used to guide the grouping of survey questions for interpretation and develop categories during content analysis.

Quantitative data (from structured questions – see Table 1) were analyzed descriptively using SPSS (version 29) to calculate frequencies

Table 2
Biopsychosocial model domains and how they were applied to visible difference within this study.

Model Domain	Explanation	Application to visible difference
Biological	Includes physiological pathology, genetic vulnerabilities, and drug effects.	Causes of conditions leading to a visible difference, treatment, genetic heritability, and surgery.
Psychological	Includes thoughts (cognition), perceptions, emotions, and behaviors.	How individuals perceive their visible difference, appearance expectations, how they feel and how they act in relation to their visible difference (e.g., self-esteem, negative/positive emotions, and behaviors such as avoidance).
Social	Includes factors such as socio-economic, socio-environmental, and cultural factors (e.g., work, family, economic)	Social support, interpersonal networks, social norms, and values (positive and negative) placed on appearance (e.g., how an individual views themselves within these norms and experiences of stigma and discrimination in wider society and culture). Role of media and society. Access to resources.

Table 1
Survey questions.

Survey questions
1. How would you describe your gender?
2. How old are you?
3. What is your ethnicity?
4. How would you describe your visible difference?
5. Is there anything else that you would like to tell us about your visible difference?
6. If you wanted more support in relation to your visible difference, who would you ideally like to receive this support from?
7. Which of these areas do you think you would benefit from support with (now or in the future)?
8. What formats would you prefer when accessing support?
9. How important to you are each of these factors when accessing support? (Please rate each item from 1 'not important' to 5 'very important')
10. Is there anything else you wanted to tell us about how you would like to receive support?
Questions 1, 3, 4, 6, 7, 8, and 9 required responses to structured pre-defined responses.
Questions 2, 5, and 10 included open text response fields, while questions 4, 6, 7, and 8 allowed respondents to add text under the 'Other' option.

and percentages. Correspondence analysis (Greenacre, 2010) was conducted to visualize associations between conditions and support needs, identifying patterns across variables. Cross-tabulations and chi-square tests were used to further explore significant associations between key variables.

Open-ended responses were analyzed using a qualitative content analysis approach (Hsieh & Shannon, 2005) using NVivo (version 14) to manage data and coding. The content analysis used both conventional (inductive) and directed approaches (Hsieh & Shannon, 2005). The lead author (CC) iteratively developed initial codes based on key ideas related to the research questions, grouping them into categories and subcategories reflecting patterns and relationships. Categories were then deductively organized using the biopsychosocial model domains (by CC) and discussed and agreed upon with the study team (AC, MT, and DH).

A 'following a thread' approach was used to integrate the quantitative data from structured survey questions and qualitative data from open ended questions (O'Cathain et al., 2010).

2.4. Reflexive statement

We acknowledged our team's diverse roles (psychologists, social scientists, and methodologists with varied experience in visible differences), influencing data interpretation. The authors have experience researching psychosocial issues and support for people with visible differences, but none have personal experience of living with a noticeable visible difference. Regular meetings ensured acknowledgment of bias and nuanced interpretation and reporting of qualitative and quantitative data, revealing varying perspectives among team members and potential readers.

3. Results

3.1. Respondent characteristics

Five hundred and fifty adults completed the survey. Participants were aged 18–82, with a mean age of 47 years (SD = 14.0) and 489 (88.9 %) were female. The majority of respondents (n = 525, 95.5 %) were White. The most common condition reported was Lipoedema (n = 318, 57.8 %), followed by alopecia (n = 60, 10.9 %), Psoriasis (n = 56, 10.2 %) and Facial Palsy (n = 45, 8.2 %). See Table 3 for respondent characteristics.

Table 3
Respondent characteristics.

Respondent Characteristics	Frequency	Percent
Gender (n = 550)		
Female	489	88.9
Male	48	8.7
Non-binary	6	1.1
Agender	1	0.2
Gender Fluid	2	0.4
Prefer not to say	4	0.7
Ethnicity (n = 550)		
Asian or Asian British	10	1.8
Black, Black British, Caribbean, or African	7	1.3
Mixed or multiple ethnic groups	6	1.1
White	525	95.5
Other ethnic group*	2	0.4
Condition/injury* *		
Lipoedema	318	57.8
Alopecia	60	10.9
Psoriasis	56	10.2
Facial Palsy	45	8.2
Other/Prefer to self-describe* **	38	6.9
Eczema	29	5.3
Scarring (not caused by any of the other conditions listed)	25	4.5
Nerve tumors/Neurofibromatosis	20	3.6
Limb difference	19	3.5
Cleft lip and/or palate	16	2.9
Burns	11	2.0
Vitiligo	10	1.8
Congenital Melanocytic Naevi (CMN)	5	0.9
Microtia	5	0.9
Capillary malformation (Port wine stain/PWS)	3	0.5
Lipodystrophy	3	0.5
Craniosynostosis	2	0.4
Epidermolysis Bullosa	2	0.4
Ectodermal Dysplasia	1	0.2
Self-reported number of visible differences		
1	477	86.7
2	59	10.7
3	13	2.4
4	1	0.2

* Ethnicity reported for other included Arab.
* *Respondents could select multiple conditions/injuries and consequently percentages do not sum to 100 %
* **Conditions reported for the other option included Facial Synkinesis, Functional Neurological Disorder (Paralysis), Juvenile Dermatomyositis, Porokeratosis, facial marks, Lymphedema, Rosacea, limp, overweight, acne, hyperpigmentation, hirsutism, strabismus, Lichen Planus, vascular disease, ptosis, mastectomy, Moebius Syndrome

3.2. What are the issues adults with visible differences want support with?

Responses indicated that participants would want support across all three of the biopsychosocial model domains: 484 (87.8 %) wanted support within the biological domain, 466 (84.6 %) in the psychological domain, and 412 (74.8 %) the social domain. Open-ended responses suggested that past support experiences influenced preferences (e.g., respondents discussed previous experiences of support when explaining what support they would like).

The majority of respondents (n = 443, 80.5 %) would want more information on potential treatment options for their condition, while 53.6 % (n = 295) wanted insight into causes. Moreover, 61.3 % (n = 337) wanted help accepting their appearance, 59.3 % (n = 326) desired support for confidence and self-esteem, and 56.3 % (n = 312) for mental health. Many participants (n = 229, 41.9 %) would want guidance on communicating about their appearance, addressing questions and reactions (n = 175, 31.8 %), and managing social situations (n = 166, 30.2 %). See Table 4.

Respondents were presented with 22 potential support options and were instructed to select all that applied (see Appendix I). All options were selected by at least one respondent. Respondents indicated they would want support with multiple issues; the mean number of support types was 7.4 (SD = 4.65).

In addition, responses to open-ended questions indicated that respondents wanted biomedical information about their condition and wanted to be updated when new information was available.

> "Regular updates when new information or treatment is known." (scarring)

Some respondents with inheritable conditions also wanted specific genetic information, such as *"genetic counseling" (cleft lip and/or palate*).

Respondents also wanted support navigating access to medical treatment including guidance on speaking to healthcare professionals about possible treatments and dealing with difficult situations, such as feeling dismissed and ignored in healthcare settings.

> "Support with dealing with medical professionals." (Lipoedema)

> "I have been ignored and gaslit my entire life by the NHS [National Health Service]." (Psoriasis)

Other psychosocial support needs included strategies for challenging appearance norms and discrimination. (See Appendix II for the full table of support needs categories and subcategories.)

> "How best to challenge the social culture that invalidates those with a visible difference." (Nerve tumors/Neurofibromatosis)

Table 4
Types of support wanted.

Model Domain	Support type	Frequency	Percent	Lower 95 % CL	Upper 95 % CL
Biological	Information about possible treatments	443	80.5	77.0	83.6
	Information about condition/ altered appearance cause	295	53.6	49.5	57.8
	Pain management	241	43.8	39.7	48.0
	Genetic heritability information	4	0.7	0.3	1.9
Psychological	Accepting my appearance	337	61.3	57.1	65.3
	Confidence and self-esteem	326	59.3	55.1	63.3
	Mental health	312	56.7	52.6	60.8
	Body image	270	49.1	44.9	53.3
	Managing stress	185	33.6	29.8	37.7
	Support with decision making	133	24.2	20.8	27.9
Social	Talking to other people about my appearance	229	41.6	37.6	45.8
	Responding to questions and other people's reactions to how I look	175	31.8	28.1	35.8
	Social situations	166	30.2	26.5	34.1
	Intimacy and romantic relationships	161	29.3	25.6	33.2
	Employment and work-related issues	126	22.9	19.6	26.6
	Support for partners	108	19.6	16.5	23.2
	Managing negative experiences on social media	103	18.7	15.7	22.2
	Using social media positively	98	17.8	14.8	21.2
	Support for family	99	18.0	15.0	21.4
	Bullying	85	15.5	12.7	18.7
	Education	77	14.0	11.3	17.2
	Returning to work after treatment and/or appearance altering injury	62	11.3	8.9	14.2
	Legal issues	37	6.7	4.9	9.1
n/a	Other	18	3.3	2.1	5.1

> "I would like not to be fat-shamed anymore and bullied by the medical profession." (Lipoedema)

3.3. How would adults like support to be provided?

Respondents most often wanted support to be provided by healthcare professionals (n = 491, 89.3 %), followed by people with personal experience of the same condition/injury (n = 337, 61.3 %) and charities/support organizations (n = 197, 35.8 %) (see Table 5).

Respondents most frequently wanted support from multiple sources: 151 (27.4 %) wanted support from two sources, 154 (27.9 %) from three, 121 (22.0 %) from four and 67 (12.2 %) from five sources. Three (0.5 %) did not select any sources. Additional insights from open-ended responses revealed a preference for support from the National Health Service (NHS) through General Practitioners (GPs) and specialists in clinics, as well as private practitioners such as psychologists and life coaches. They also indicated that wig and garment suppliers might also have a role in support provision. See Table 6.

Table 5
Who respondents would like support from.

Support source	Frequency	Percent	Lower 95 % CL	Upper 95 % CL
Healthcare professionals	491	89.3	86.4	91.6
People with personal experience of the condition/ injury	337	61.3	57.1	65.3
Charities	197	35.8	31.9	39.9
Friends/family/partner	177	32.2	28.4	36.2
Employer	119	21.6	18.4	25.3
Other	8	1.5	0.7	2.8

3.3.1. Format of support

Overall, the majority of respondents preferred support through online platforms, (i.e., requiring a form of digital access) (n = 457, 82.9 %) including websites (n = 362, 65.8 %) and online support groups (n = 262, 47.6 %). In-person support was also valued (n = 313, 56.8 %) with a preference for in-person counseling (n = 252, 45.8 %). Support groups were similarly valued, whether online (47.6 %) or in-person (37.5 %), but more respondents preferred in-person counseling (45.8 %) over online/telephone support (24.7 %). Fewer respondents

Table 6
Sources of support (who can provide support).

Category	Subcategories	Example quotes	Frequency
Healthcare Professionals	NHS	*"Ideally I would like to receive support through the NHS, as surely that's what it's there for and what I pay my taxes and NI [National Insurance] payments for!" (Lipoedema)*	31
	GPs	*"GP's and NHS Commissioning groups." (Craniosynostosis) "Specialist GPs with a team of support for holistic needs." (Lipoedema) "I'd start with GP's!!" (Facial Palsy)*	13
	Specialist Clinics/ practitioners	*"Mental health specialists." (Lipoedema) "Nurse specialist type support." (Microtia) "Lipoedema clinic." (Lipoedema)*	8
	Private Practitioners		5
	Life coaches	"Life coach (already helping me)." (Lipoedema)	3
	Psychologists	*"Privately I think… psychological." (Microtia) "Private psychotherapist." (alopecia)*	2
Non-Professionals	Peer support	*"Contact with a local sufferer in order to discuss and encourage each other." (limb difference) "From people that have experience of the condition". (Lipoedema)*	3
	Family and Friends	*"Support from family or for family is key as it starts from family." (Lipoedema) "Neighbors." (Lipoedema)*	2
Manufacturers/ Suppliers	Wig, garment, and clothing suppliers	*"Dressing and garment manufacturers to open feedback channels to improve offerings." (Lipoedema) "Wig suppliers." (alopecia)*	2

preferred support through physical resources like hardcopy books (n = 180, 32.7 %). See Table 7.

The majority of respondents indicated that they would want support to be available through multiple formats such as online and in-person. Specifically, 56 respondents (10.2 %) chose only one format, 128 (23.2 %) preferred two formats and 350 respondents (63.5 %) indicated they a desire for support in all three formats.

3.4. What factors do adults with a visible difference consider important when seeking support?

The rankings of factors relating to intervention preferences reveal that the most important considerations are the specificity to the individual's condition (Mean = 1.94, SD = 1.40), evidence-based practices (Mean = 3.55, SD = 1.76), and provider reputation (Mean = 3.61, SD = 1.85). The majority of respondents ranked condition specific as the most important (54.3 %), with 76.4 % placing it in the top three. Similarly, 51.4 % and 54.1 % ranked evidence-based practices and provider reputation in the top three.

Factors such as location (Mean = 4.22, SD = 1.71), cost (Mean = 4.35, SD = 1.89), format (Mean = 4.49, SD = 1.52), and accessibility (Mean = 5.83, SD = 1.43) were of secondary importance. Accessibility was ranked No. 7 by 41.7 % of respondents, suggesting that it is less important relative to other considerations.

These findings highlight the higher priority placed on condition-specific, evidence-based interventions, while logistical factors such as accessibility and cost, although still important, are less emphasized. See Table 8.

3.4.1. Factors influencing access to support

Analysis of free-text responses highlighted key factors affecting support-seeking. Some respondents expressed frustration towards healthcare professionals, citing a lack of knowledge and awareness about visible differences and their potential impact. This appeared to lead to feelings of vulnerability and futility, especially after negative healthcare experiences were reported. Limited understanding of their conditions by healthcare professionals appeared to have exacerbated this, particularly in older individuals facing prolonged challenges and inadequate support.

The most frequently mentioned category in free-text comments (35 occurrences) highlighted challenges in interacting with healthcare professionals and access to support. Additionally, a few respondents noted insufficient diversity and representation in services, which may hinder engagement, particularly for ethnically diverse and neurodivergent individuals. See Table 9.

Table 7
Preferred format of support provision.

Support category	Support format*	Frequency	Percent	Lower 95 % CL	Upper 95 % CL
Online	Written format on a website	362	65.8	61.8	69.7
	Online support groups	262	47.6	43.5	51.8
	Apps	157	28.5	24.9	32.5
	Podcasts	137	24.9	21.5	28.7
	Telephone/ online counseling	136	24.7	21.3	28.5
	Videos/ animations	108	19.6	16.5	23.2
In-person	In-person counseling	252	45.8	41.7	50.0
	In-person support groups	206	37.5	33.5	41.6
	Residential weekends/ camps	89	16.2	13.3	19.5
Physical	Self-help guides/books	180	32.7	28.9	36.8
n/a	Other* *	13	2.4	1.4	4.0

*Tick all options question and consequently percentages do not sum to 100 %
* *Other formats included "in-person one-to-one", "NHS resources" and "access to clothing and shoes" (open-ended responses)

3.5. Differences between conditions when seeking support

Correspondence analysis indicated a relationship between an individual's condition and the support they would want ($p < .001$). Exploration of associations suggested that individuals with various conditions would want a broad spectrum of support types. Noteworthy significant associations include those between Lipoedema and wanting information about possible treatments ($\chi^2 = 54.563, df = 1, p < .001$) and support with body image concerns ($\chi^2 = 11.360, df = 1, p < .001$). Additionally, having alopecia and wanting support with responding to questions about their appearance ($\chi^2 = 4.116, df = 1, p < .042$) and having a cleft lip/palate and wanting information about treatments ($\chi^2 = 19.487, df = 1, p < .001$) and responding to questions and other people's reactions to their appearance ($\chi^2 = 4.534, df = 1, p < .033$).

No significant associations were found between an individual's condition and who they would like support from and the format of support ($p > .05$).

4. Discussion

This study highlights the varied and multifaceted needs of individuals with visible differences. These needs span biomedical (e.g., information on treatments, understanding the condition's causes), and psychosocial issues (including self-acceptance, confidence, mental health, and social interactions). Preferred sources of support varied, most often from healthcare professionals, followed by peers with similar experiences, and charitable organizations. Respondents preferred both online and in-person support groups but favored in-person counseling over online options. A small number of respondents reported negative healthcare experiences, which could lead to feelings of futility, particularly among older individuals, who face prolonged challenges and limited support. Respondents emphasized the importance of healthcare professionals' awareness and acknowledgment of visible differences and their psychosocial impact.

This study reinforces previous research showing that individuals with visible differences want both medical and psychosocial assistance (Clarke, 2001). Notably, the demand for biological/medical support appears to be more significant than previously documented, with 87.8 % of respondents expressing this need, compared to the 31 % reported earlier by Clarke (2001), despite both cohorts being recruited through charitable organizations. Individuals may seek medical interventions to address psychosocial concerns related to appearance and measure the success of such interventions in terms of their impact on psychosocial outcomes (Clarke et al., 2021). Respondents in this study indicate a desire for both biomedical and psychosocial information and support. Therefore, while patients may seek medical support, it is essential to consider the potential benefits of psychosocial support, especially when biomedical treatments are limited or may not meet expectations. This more holistic approach is crucial as psychosocial interventions can enhance medical care by addressing psychological and social factors affecting well-being (Clarke et al., 2013; Powell et al., 2023).

This study suggests that while individuals may seek support from healthcare professionals, negative past experiences, such as feeling dismissed or unheard, can shape their support preferences. Unlike Fournier et al. (2023), who found a stronger preference for peer support, our findings indicate that individuals generally prefer professional support. However, some participants wanted healthcare professionals to be more aware and understanding about their circumstances. This may reflect the desire for specialized knowledge but also highlights the need

Table 8
Importance of factors when accessing support ranking.

Factors	Mean ranking	Std. Deviation	Overall ranking	Percentage ranked at No. 1	Percentage ranked top 3	Ranked at No. 7
That it is specific to my condition	1.94	1.40	1	54.3	76.4	0.7
That it is evidence based	3.55	1.76	2	9.6	51.4	4.5
The provider is reputable	3.61	1.85	3	9.4	54.1	11.4
The location	4.22	1.71	4	6.7	31.6	9.6
The cost	4.35	1.89	5	8.3	28.5	16.0
The format	4.49	1.52	6	2.2	23.6	7.1
Accessibility	5.83	1.43	7	0.5	7.8	41.7

for healthcare professionals to be more attuned to the specific challenges faced by those with visible differences. Additionally, prior experiences, whether positive or negative, play a key role in shaping how and from whom individuals choose to seek support (Barke et al., 2014; Changing Faces, 2019).

Respondents in this study preferred support tailored to their specific condition, likely because it addresses their unique challenges. Tailored support may also be perceived to be more relevant and effective (Rumsey & Harcourt, 2004).

Research findings show that people with visible differences frequently prefer seeking online assistance, potentially influenced by perceived stigma in social situations (Barke et al., 2014). Online forums and groups can provide a more distant yet understanding environment, allowing individuals to share experiences without direct focus on appearance (Barke et al., 2014). Safety may be heightened through features such as turning off cameras and using avatars, providing a sense of distance and security. Accessing information remotely may also contribute to this perceived safety. However, the preference for and value of in-person counseling or support groups that help foster relationships with peers should also be recognized (Fournier et al., 2023). Awareness that stigma may be a factor in seeking support is crucial, as is the need to provide support in a variety of formats to meet individual needs. A substantial number of respondents desire provision in multiple formats.

This study reveals minimal differences in support needs and preferences across conditions. However, certain conditions show a notable link to specific support requirements. For example, Lipoedema was associated with seeking medical information and treatment, while alopecia was associated with a need for support in dealing with questions from other people.

4.1. Strengths and limitations

This study addresses a research gap by offering valuable insights into the support preferences of adults with visible differences. It benefits from a large and diverse sample, encompassing individuals with various conditions and injuries. The incorporation of qualitative data enriches the comprehension of quantitative responses. However, there are limitations including uneven sample sizes, particularly the overrepresentation of Lipoedema and the scarcity of others such as burns or limb differences. This imbalance may stem from limited research on Lipoedema and fewer opportunities for those affected to participate in research or feel their condition is of research interest. Additionally, there is a gender imbalance, with a predominance of women, necessitating further exploration of support needs in other gender identities not captured here. While open text responses added insight, many lacked detail and context, limiting depth of analysis. Further qualitative research into support-seeking issues could enhance understanding. The predominantly white respondent demographic underscores the need for more inclusive research. As a cross-sectional survey conducted in the UK, the study is limited in its ability to provide insights into how support needs may change over time or differ in other countries. The online and charity-based recruitment may have attracted participants with limited medical support, increasing their need for biomedical assistance. In contrast, recruitment in clinical settings might emphasize a need for unmet psychosocial support.

4.2. Implications for practice and/or future research

Findings underscore that awareness, knowledge, and acknowledgement from healthcare professionals pose challenges in support-seeking for some individuals with visible differences. Healthcare professionals acknowledge limitations in assessing and addressing the psychosocial needs of individuals with conditions or injuries that affect appearance (Harcourt et al., 2018). They express openness to training but may encounter institutional barriers such as time and financial constraints (Williamson et al., 2018). Evidence has shown the benefits of training healthcare professionals with dealing in appearance-related concerns (Zucchelli, Persson, et al., 2023). However, both training opportunities and resources to meet patients' support needs are limited, necessitating further development of both training resources and supportive interventions. It would also be useful to know more details about the types of healthcare professionals that adults want and seek support from, and in which settings.

Survey respondents value peer support, known to benefit individuals with limb loss (Lee et al., 2024), burns (Won et al., 2021) and alopecia (Davey et al., 2019) by fostering connections with others who share similar experiences, enabling mutual learning, and validation of feelings.

Research evidence suggests that the psychosocial impact of having a visible difference is similar across conditions (Rumsey & Harcourt, 2012; Zucchelli et al., 2023). However, this study also highlights the importance of support that addresses individuals' specific condition, even though their needs may be broadly similar. To better meet these needs, it is crucial to develop a resource to enable care providers (e.g., healthcare professionals, charitable organizations) to assess and guide individuals toward appropriate assistance or interventions. Alongside training healthcare professionals, involving psychosocial specialists like psychologists or counselors can ensure individuals receive vital emotional and psychological support. This may be achieved using a stepped care approach, with varying levels of intervention intensity, and raising awareness of visible differences among doctors and nurses (e.g., see Rumsey & Harcourt, 2012). Support providers may consider the BATHE approach (Background, Affect, Trouble, Handling, and showing Empathy) (Lieberman et al., 1999) to structure consultations, ensuring effective identification and acknowledgment of individuals' concerns.

5. Conclusion

Individuals with visible differences report a wide range of medical and psychosocial support needs, requiring holistic support from multiple providers in varied formats. While there might be shared needs and preferences, a personalized approach to assessment and assistance is vital. This ensures that individuals receive tailored support based on their specific circumstances.

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Table 9
Factors that can influence support-seeking.

Category	Subcategory	Example quotes	Frequency
Healthcare professional awareness and knowledge	Increasing knowledge, understanding and awareness of conditions and impact	*"Educate the NHS as awareness is abysmal." (Lipoedema)* *"I have currently been waiting a year to see a plastic surgeon who specializes in the treatment of long term visible facial differences." (Facial Palsy)* "I want people to understand my condition, most Drs have never heard of Lipoedema, and either are skeptical or confuse it with lymphoedema which I also have." (Lipoedema)	35
	Acknowledgement of condition and impact	"I feel my visible differences are classed as 'not as important' as other patient's needs." (Facial Palsy) "Not be dismissed by medical professionals as 'cosmetic' when it causes pain and mental distress." (Lipoedema)	4
Vulnerability	Futility	"Too old to care I am exhausted with fighting Drs." (Lipoedema) "Just carry on." (Nerve Tumors/ Neurofibromatosis) "A bit late now at my age. No support and no diagnosis and found out at age 58. Way too late." (Lipoedema)	6
	Lack privacy, dignity, and respect	"My issues have felt intensely private, and the whole process has made me feel robbed of my dignity and privacy and I feel somewhat threatened by those who want/expect me to be out and proud about my scars." (Scarring) "I paid for a private bowel screen kit, rather than show my bottom and legs having NHS bowel screening, for example. An experience where I'd miscarried and was admitted for removal of products, when an anesthetist thought it was his job to lecture me on obesity while I was flat on my back post-op, in a disposable gown, with cramping pain and sadness, out in a corridor where other patients could overhear - and the porters I'd actually worked with professionally - was a low point." (Lipoedema)	3
	Financial barriers	*"Have more events accessible to everyone. Whilst the [condition] charities are wonderful, to become a member is expensive (incredibly so) and to go to events it is extortionate." (Lipoedema)*	5
	Lack of diversity/ representation	*"When there is something for someone with my type of visible difference, it's normally attended by or features people who are predominantly white. As a person of color, I find this isolating. I have declined opportunities to go and meet others in the past because I know I will be the only person of color there. It's just another point of difference that becomes the feature of the event as opposed to being around people I identify with. More needs to be done to provide specific services/ groups for those of different ethnicities." (Facial Palsy)* *"Accessibility needs to be considered for those who are neurodivergent, not neurotypical." (Lipoedema)*	3
	Timing of support	*"Considering my transition to a post work identity as a retiree and preparation for older old age." (Capillary Malformation)*	2

CRediT authorship contribution statement

Clare Clement: Writing – original draft, Formal analysis, Data curation. **Wylde Roberts-Mills:** Writing – review & editing, Formal analysis, Data curation. **Maia Thornton:** Writing – review & editing, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Alex Clarke:** Writing – review & editing, Formal analysis. **Abbi Matthews:** Writing – review & editing, Methodology. **Fabio Zucchelli:** Writing – review & editing, Methodology. **Paul White:** Writing – review & editing, Formal analysis. **Amy Slater:** Writing – review & editing, Methodology, Conceptualization. **Diana Harcourt:** Writing – review & editing, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.bodyim.2024.101840.

Data availability

Data will be made available on request.

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