Title:

Lymphoedema and Heart Failure Staff Educational Needs Analysis: Insights from a UK Online Survey – Part 1: Qualitative Findings

Abstract

Background:

Heart failure (HF) and lymphoedema frequently coexist, particularly in older adults, yet their combined management presents challenges for healthcare professionals (HCPs). Compression therapy is central to lymphoedema care, but is used cautiously in HF due to safety concerns and inconsistent guidance.

Aim:

To explore HCPs' knowledge, experiences, and confidence when managing patients with coexisting HF and lymphoedema, focusing on compression therapy and the application of recent clinical guidance.

Methods:

This qualitative evaluation analysed free-text responses to two open-ended questions within a UK-wide online survey of 342 HCPs. Thematic analysis was used to identify key patterns.

Findings:

Three interlinked themes were identified: 1) uncertainty and lack of confidence in applying compression therapy; 2) collaboration gaps and conflicting views between HF and lymphoedema services; and 3) calls for clearer guidance and joint education. Many HCPs described difficulty distinguishing between types of oedema, reliance on external input, and variation in guideline awareness.

Conclusion:

Improved education, clearer clinical pathways, and better interdisciplinary collaboration are needed to support confident, consistent care for patients with coexisting HF and lymphoedema.

Keywords:

Heart failure, lymphoedema, compression therapy, coexisting conditions, interdisciplinary care, clinical education, uncertainty, service integration

Key Points:

1. Healthcare professionals experience uncertainty in applying compression therapy for patients co-existing with HF and lymphoedema.
2. Interdisciplinary collaboration between heart failure and lymphoedema services is critical to improving patient outcomes.
3. Tailored education programmes are necessary to build confidence and competence among healthcare professionals.
4. Clearer use of existing evidence-based guidelines to support consistent clinical decision-making.

Reflective Questions:

1. How confident do you feel in distinguishing between heart failure-related oedema and lymphoedema in your practice?
2. What local guidelines or pathways support your decision-making for patients with coexisting HF and lymphoedema?
3. How could collaboration with other services be strengthened to support compression therapy decisions?
4. What educational opportunities or resources would help you manage these complex cases more effectively?

5. How do you ensure a person-centred approach when navigating conflicting advice or uncertain treatment plans?

Background:
Heart failure (HF), also known as cardiac or congestive heart failure, arises from reduced cardiac function and output capacity (Wounds UK, 2023). The term heart failure can be misleading, as the heart continues functioning, albeit inefficiently (Wounds UK, 2023). Approximately 1 million people in the UK live with HF, with around 200,000 new diagnoses annually (Conrad et al., 2018). Beyond breathlessness and peripheral oedema, HF limits mobility, causes fatigue, and affects psychological well-being, profoundly altering individuals' self-perception and social engagement (McDonagh et al., 2021; NICE, 2022a, 2022b; Cooper-Stanton, 2022).

Peripheral oedema is a common HF symptom, often coexisting with lymphoedema—a chronic condition caused by impaired lymphatic function (Mortimer et al., 2014; Rankin, 2016; Rossitto et al., 2019). HF is among the three most prevalent comorbidities associated with lymphoedema (Keeley et al., 2019). Shared risk factors, including age, lifestyle, health inequalities, and social determinants, further link the conditions (NICE, 2022a, 2022b; Moffatt et al., 2017). Lymphoedema affects an estimated 4 to 29 per 1000 people, with the highest rates among those over 85 years (Moffatt et al., 2017). It may be primary (genetic abnormalities like Milroy’s disease) or secondary (arising from cancer treatments, trauma, or infection) (Cooper and Bagnall, 2016).

When heart failure and lymphoedema coexist, decisions about compression therapy become particularly complex. Compression therapy is essential for managing lymphoedema, but in patients with heart failure, it may shift fluid centrally and exacerbate cardiac symptoms. This clinical tension creates uncertainty for healthcare professionals (HCPs) and may lead to inconsistent or cautious treatment approaches.

While some guidance exists, such as the Wounds UK Best Practice Statement (2023) and the British Lymphology Society (BLS, 2024) educational resource, these are designed to support decision-making in the absence of formal clinical guidelines from national bodies such as NICE or SIGN. The Wounds UK document includes diagnostic flowcharts and clinical considerations for peripheral and lymphoedema-related oedema, while the BLS resource offers practical tools such as case studies and letter templates. Although helpful, these resources are not yet universally adopted across services (Wounds UK, 2023; BLS, 2024).

This lack of universal adoption, combined with the absence of national clinical guidance, can leave clinicians unsure how to safely apply compression therapy, particularly when diagnosing and treating overlapping symptoms such as bilateral lower limb oedema.

An unpublished audit from clinics across three Welsh health boards (2023–2025) found that over half of patients with heart failure presented with lower limb oedema, but fewer than 10% were known to their local lymphoedema service. This suggests a substantial care gap, underlining the importance of collaborative guidance and education.

This article presents a qualitative analysis of two open-ended questions from a larger UK-wide online survey exploring the management of coexisting heart failure and lymphoedema. The broader survey also generated quantitative findings, which are reported separately. These two qualitative questions focused on education/training needs and how recent guidance has influenced practice.

The study was developed through a collaboration in Wales between lymphoedema and HF nurses and the national Value in Health Care team. The survey was promoted across the four UK nations with support from the National Heart Failure Forum, British Lymphology Society, and an educational grant from Essity. Further methodological details are provided below.

Aim:

To explore the knowledge, perceptions, and experiences of HCPs in the delivery of care for individuals with heart failure and lymphoedema, with a particular focus on the use of compression therapy and the application of recent clinical guidance:

- What are the educational needs and perceived knowledge gaps of HCPs regarding the management of patients with both heart failure and lymphoedema?
- How do HCPs apply recent clinical guidance to their practice, and what changes or outcomes have been observed as a result?

Methods:

This evaluation consists of two parts: quantitative survey analysis and qualitative comment investigation. This article focuses on the qualitative findings that were explored within two specific survey questions [Table 1] to inform future service development and support. The evaluation aims to contribute to consistent, collaborative, and equitable care pathways for individuals living with both heart failure and lymphoedema, supporting local decision-making and improving service delivery (Moule et al., 2016; Backhouse and Fati, 2020).

The two qualitative questions were developed by a multidisciplinary group of lymphoedema and heart failure specialists, based on known areas of clinical uncertainty and themes emerging from recent education events. Both were open-ended and designed to capture participants' experiences and educational needs through free-text responses.

Table 1 – Qualitative Focused Questions

Question
Are there any other aspects of managing patients with both heart failure and chronic peripheral oedema (lymphoedema) for which you feel education/training would help?
If you changed your practice in response to one of the above documents, please can you give us an example of what that change was and any impact seen?

Recruitment and Participants

Participants included registered and non-registered HCPs from bands 3 to 8, involved in treating or supporting individuals with heart failure or chronic oedema/lymphoedema. They were based across the four UK nations: Wales, England, Scotland, and Northern Ireland. Only those currently practising within NHS-commissioned services at the time of survey completion were eligible to participate. Individuals who had previously worked in such services but were no longer practising were excluded.

Agenda for Change banding is the NHS's pay structure in the UK. Band 3 typically represents healthcare assistants or support workers, while Bands 5–8 indicate increasing levels of responsibility, with Band 6 often representing specialist nurses and Band 8 indicating consultant-level or advanced practice roles.

Purposive and snowball sampling methods were employed, with recruitment promoted through organisations such as Lymphoedema Wales Clinical Network (LWCN), NHS Wales, the British Lymphology Society (BLS), and the National Heart Forum (NHF).

The survey was distributed through professional networks, organisational bulletins, and direct email circulation lists. Snowball sampling was encouraged by inviting participants to share the survey link with relevant colleagues. While exact figures on reach are unavailable, the initial distribution extended to more than 30 services across the UK, with additional exposure achieved via social media and newsletters.

Of the 348 responses received, 342 were eligible after excluding those from outside the four nations (e.g., Australia and Croatia) [Table 2]. Inclusion and exclusion criteria are outlined in Table 2, with participant demographics in Table 3.

Table 2 – Inclusion and Exclusion Criteria

Inclusion	1. Registered or unregistered Healthcare Professional. 2. Working in an NHS-commissioned service. 3. Working with people diagnosed with heart failure, chronic peripheral oedema and/or lymphoedema. 4. Residing in one of the four nations: 1) Wales, 2) England, 3) Scotland and 4) Northern Ireland.
Exclusion	1. Administrators or project staff. 2. Not working in an NHS-commissioned service. 3. Not working with people diagnosed with heart failure, chronic peripheral oedema and/or lymphoedema. 4. Not residing in one of the four nations: 1) Wales, 2) England, 3) Scotland and 4) Northern Ireland.
Note: Inclusion required current employment in one of the above roles/settings at the time of survey completion.	

Table 3 – Participant Demographics

Detail	**Number**	**Percentage**
Country		
England	170	50%
Wales	94	27%
Scotland	59	17%
Northern Ireland	19	6%
Job Category		
Lymphoedema	143	42%
Nurse (Non-Specialist)	116	34%
Heart Failure Specialist	71	21%
Other (Service lead, GP, foot or leg practitioner, healthcare assistant)	12	3%
Agenda for Change Banding		
3	8	2%
4	9	3%
5	51	15%
6	104	30%
7	120	35%
8	29	9%
Other	21	6%
Workplace		
Community	161	47%
Hospital	123	36%
GP Surgery	23	7%
Other (Hospice, Private Clinic, Charity, for example)	35	10%

Ethics

Ethical approval was not required for this evaluation, as it followed the established process within the NHS Research and Development Department. LWCN ensured oversight through the Research and Development, Information Governance teams, and the LWCN Research and Evaluation Steering Group.

Funding

An educational grant from Essity enabled LWCN to complete this evaluation. Essity has not been involved in analysis or report writing.

Data Collection

Data collection was conducted through an anonymous online survey using MS Forms from December 2023- March 2024. The questionnaire consisted of 18 questions (see supplementary source) and took approximately 10 minutes to complete. All answers were anonymous, with each question answered before proceeding to the next. Completion of the questionnaire was considered as consent for the researchers to use the anonymous data for the service evaluation.

Analysis

The anonymised data was cleansed and transferred into an Excel document for analysis. Initial data cleaning was undertaken by two researchers, who removed duplicate or incomplete entries and ensured consistency in formatting. To ensure a comprehensive approach, multiple researchers reviewed the data, fostering a deeper understanding of the findings.

Thematic analysis followed Braun and Clarke’s (2006) six-phase framework (Table 4). Three researchers were involved across all phases of the process, from familiarisation and coding to refining themes, to enhance rigour and ensure consistency. Regular discussions supported reflexivity and consensus at each stage.

While Braun and Clarke's approach was originally developed for interview transcripts, its flexible design is suitable for analysing written responses such as online survey free text. The main adjustment involved greater attention to brevity and context during coding.

Thematic analysis was chosen for its flexibility and ability to generate a detailed, nuanced interpretation (Braun & Clarke, 2013, 2006; Table 4). Subthemes were developed through an integrated analysis of all responses, regardless of which of the two qualitative questions they addressed. This allowed for richer cross-cutting themes to emerge.

Reflexivity was maintained throughout the analysis to enhance the rigour and credibility of the findings. All authors contributed to the development and finalisation of the themes, ensuring a collaborative and robust process (Braun & Clarke, 2006; Table 4).

Table 4 – Six-Phase Thematic Analysis

Phase	Description
Familiarisation with the data	Transcribing data (if necessary), followed by reading and re-reading the data to immerse oneself in the content and noting down initial ideas.
Generating initial codes	Systematically coding key features across the entire dataset and collating data relevant to each code.
Searching for themes	Collating codes into potential themes and gathering all data relevant to each theme.

Reviewing themes	Validating the themes against the coded extracts (Level 1) and the entire dataset (Level 2) and generating a thematic map of the analysis.
Defining and naming themes	Conducting ongoing analysis to refine the specifics of each theme and the overall narrative of the analysis, generating clear definitions and names for each theme.
Producing the report	The final opportunity for analysis involves selecting vivid, compelling extract examples, conducting a final analysis of these extracts, relating the analysis to the research question and literature, and producing a scholarly report of the findings.

Findings:

The analysis of free-text survey data identified key themes highlighting the challenges HCPs face in gaining knowledge across heart failure and lymphoedema, alongside the influence of pre-existing beliefs about compression therapy and its effects [Table 5]. Participants expressed varying levels of confusion, confidence, and educational needs across both conditions, particularly when these conditions coexisted. Each theme will delve deeper into these aspects, shedding light on the complexities of managing heart failure and lymphoedema in clinical practice.

Table 5 – Main and Sub Themes

Main Themes Details	Description
Uncertainty and Confidence in Compression Therapy for Heart Failure Patients	HCPs face confusion and hesitation in using compression for heart failure patients due to inconsistent interpretation and application of guidelines, unclear oedema distinctions, and safety concerns, emphasising the need for clearer guidance and training.
Sub Theme 1: Collaboration and Conflict in Multidisciplinary Care	Bridging collaboration gaps in lymphoedema and heart failure care by addressing conflicting guidelines, miscommunication, and training gaps.
Sub Theme 2: Education and Knowledge Exchange in Managing Coexisting Heart Failure and Lymphoedema	Education and Management for Heart Failure and Oedema focuses on providing ongoing training for HCPs on the safe application of compression therapy and holistic management strategies.

Main Theme - Uncertainty and Confidence in Compression Therapy for Heart Failure Patients.

Many HCPs reported significant uncertainty when using compression therapy in patients with heart failure, especially when coexisting lymphoedema was suspected or diagnosed. Concerns centred around safety, guideline interpretation, and appropriate compression levels. A lack of clarity regarding the distinction between heart failure-related oedema and lymphoedema contributed to delayed or inconsistent treatment decisions:

“I find it hard to determine if peripheral oedema is heart failure or chronic peripheral oedema. Therefore, compression is not applied at all, or only after a long time” (District Nurse)

“I am unsure of identifying the difference between the two conditions” (Heart Failure Practitioner)

Several respondents highlighted the challenge of interpreting conflicting or ambiguous guidelines, with many expressing low confidence in applying compression without specialist input. There was also confusion around different types and levels of compression, particularly about heart failure staging.

“Uncertainty about different types of compression, and conflicting guidelines” (District Nurse)

“I would like a deeper understanding of the stages of heart failure. Is there more information I am missing?” (Lymphoedema Practitioner)

"Clarity on current recommended practice would be really useful to support patients with dependent oedema as we are always under expectation, or even pressure to use diuretic therapy, which is often less than successful" (Heart Failure Practitioner)

“Understanding benefit versus burden? The role of diuretics instead of compression and vice versa” (Lymphoedema Practitioner)

These comments illustrate the daily dilemmas practitioners face, often having to rely on informal or external advice. Several HCPs described their caution in using compression due to their lack of confidence:

“I would benefit from more education regarding compressing patients with heart failure. I am not always confident” (Lymphoedema Practitioner)

"I don't have any knowledge of this, just what I read in patients' records before my visit, so I would like to have more knowledge on this, then I can be confident in looking out for the symptoms" (District Nurse)

In contrast, a smaller number of participants reported feeling supported and confident, often due to seeking guidance locally, strong team structures, or established referral pathways:

“As a team, our workplace has taken on board the most updated guidelines... We know who to speak to if we have concerns and we have a great lymphoedema service who are also very supportive.” (Tissue Viability Nurse)

Sub-Theme 1 - Collaboration and Conflict in Multidisciplinary Care

Many respondents described a lack of integrated working between heart failure and lymphoedema services, leading to fragmented care and inconsistent decisions around compression therapy. Participants frequently cited miscommunication, conflicting perspectives, and the absence of formal referral pathways as barriers to effective collaboration:

“Closer working links with heart failure team, education of each other’s roles and appropriate referral pathways.” (Lymphoedema Practitioner)

“Collaboration of all professionals” (District Nurse)

A recurring frustration was the belief that some HCPs viewed heart failure as a blanket contraindication for compression, regardless of patient presentation or risk level:

"Most HCPs believe that any type of heart failure is a contraindication for compression. This leads to a lack of treatment and an increased burden on the patient and the wider healthcare system. More collaboration is needed between heart failure teams and lymphoedema services" (Lymphoedema Practitioner)

“Our heart failure nurses do not seem to be aware of the use of compression. They have asked our patients to discontinue using it, which may pose risks, due to thinking in the silo of their speciality.” (Tissue Viability Nurse)

Despite these challenges, a small number of respondents highlighted successful joint working and acknowledged the value of shared decision-making and role clarity. These examples were the exception rather than the norm and were often associated with local initiatives or informal relationships.

Sub-Theme 2 - Education and Knowledge Exchange in Managing Coexisting Heart Failure and Lymphoedema

The most consistent theme across responses was a clear call for structured, accessible education on managing patients with coexisting heart failure and lymphoedema. Respondents wanted both foundational knowledge and practical guidance to apply in real-world settings:

"A regular update is always good, as things change all the time, so it's good to be kept up to date with all aspects of HF and compression bandaging. Coupled with more training to be given in heart failure and oedema relating to managing leg ulcer patients" (District Nurse)

“We have no information or support in this area and rely upon tissue viability. We need it in areas of class of compression, managing heart failure patients and their symptoms” (General Practice Nurse)

Several HCPs also expressed a desire for cross-disciplinary training that could reduce conflict and improve shared understanding between teams. Participants felt that education should be relevant to their scope of practice and that compression therapy should be demystified through case studies, risk assessments, and shared learning.

“I think it would be useful to have some formal training on heart failure for lymphoedema specialists and vice versa, education on compression for heart failure services. Might save some conflict between services and less confusion for the patient” (Lymphoedema Practitioner)

“Complex patients where heart failure and lymphoedema overlap in their clinical presentation.” (Heart Failure Practitioner)

These findings suggest that joint education and clinical guidance could support more consistent, confident care and reduce variation in treatment access. However, participants noted that such resources are not routinely available or embedded in most services.

Discussion

This study is, to our knowledge, the first UK-based qualitative analysis to explore healthcare professionals' experiences and perceptions when managing coexisting heart failure and lymphoedema, particularly about compression therapy. While compression is a cornerstone of lymphoedema care (ILF, 2012), its use in patients with heart failure remains contested, with concerns about safety, diagnostic uncertainty, and guideline clarity. Our findings confirm previous reports of variation in practice (Wounds UK, 2023; Cooper and Brown, 2024), but also provide new insights into the emotional and organisational factors that shape frontline decision-making.

The first key theme—uncertainty and confidence—revealed that even experienced professionals struggle to distinguish between lymphoedema and heart failure-related oedema. This diagnostic grey area created hesitation, risk aversion, and dependence on external opinion. Although Wounds UK (2023) and the British Lymphology Society (BLS, 2024) offer flowcharts, case examples, and referral templates, many participants appeared unaware of these resources or lacked confidence in applying them independently. This reflects wider challenges in translating guidance into clinical practice, particularly where formal NICE or SIGN pathways are absent (Cooper-Stanton, 2022). Studies in other specialisms, such as venous leg ulcer care, have shown similar patterns, where variation stems not just from knowledge gaps but from conflicting messages and risk-sensitive environments (Moffatt et al., 2017).

Importantly, this uncertainty was not confined to generalist roles—specialists also voiced concern about compression safety and diagnosis. This was unexpected and suggests that inconsistency is embedded across settings and professions. A potential contributor may be the lack of structured, interprofessional education addressing how to apply compression safely in patients with fluctuating cardiac function.

[The second theme—collaboration and conflict—highlighted tensions between heart failure and lymphoedema services. Participants described inconsistent advice, reluctance to engage with shared management plans, and limited opportunities for joint review. In some cases, patients were advised to stop compression despite guidelines suggesting otherwise (Wounds UK, 2023; BLS, 2024). These findings echo those in complex, comorbid conditions where fragmentation reduces continuity and increases burden on patients and providers (Backhouse and Ogunlayi, 2020). Where collaboration was reported, it was often reliant on individual relationships rather than formalised systems.

The third theme—education and knowledge exchange—was a consistent thread across all responses. HCPs requested regular updates, structured training, and shared learning opportunities across disciplines. They wanted practical guidance on interpreting heart failure stages, safe compression levels, and referral pathways. While some educational content is available via manufacturers or webinars (Essity, 2025; Wound Care Today, 2023), access varies and is rarely embedded in formal training or organisational pathways. There is a clear case for developing co-designed, cross-speciality training, particularly for community teams and non-specialist settings.

Collectively, these themes point to a deeper need for systemic change, beyond individual education or updated guidance. They suggest that consistent care for patients with coexisting HF and lymphoedema requires integrated pathways, shared language, and multidisciplinary working as standard practice. Interprofessional care planning, like models used in diabetes foot care or frailty, could reduce confusion and support more timely intervention (Backhouse and Ogunlayi, 2020).

The audit data referenced earlier reinforces this concern. Although over half of the patients in HF clinics had lower limb oedema, fewer than 10% were known to the lymphoedema services. This suggests a substantial unmet need and under-recognition of lymphoedema within heart failure services, despite the overlap in symptom profiles (Itkin et al., 2021).

Reflexively, it was surprising to see such consistent expressions of low confidence and confusion—even among those with specialist roles. This underlines how persistent uncertainty can endure despite the presence of guidance, especially when it lacks national standardisation or practical application.

Limitations of this evaluation include the self-selecting nature of survey responses and the absence of patient perspectives. While responses were rich and diverse across the four nations, those who completed the survey may have had stronger views or more engagement with the topic. Future research could explore patient experiences of conflicting advice or investigate how local pathways influence decision-making. Longitudinal evaluation of educational interventions and pathway implementation would also be valuable.

In summary, this evaluation reveals a pressing need for clearer, more consistent guidance, co-designed training, and embedded interdisciplinary working in the care of patients with coexisting heart failure and lymphoedema. Without this, uncertainty will continue to limit timely and effective intervention. As awareness grows, these findings can inform national and local efforts to standardise care, improve outcomes, and support confident, collaborative clinical decision-making.

Implications for Practice

This evaluation identifies key areas for improving care for patients with coexisting heart failure and lymphoedema:

- **Use existing guidance effectively:** Encourage consistent use of resources such as the Wounds UK and BLS documents to support decision-making around compression therapy.
- Strengthen education across disciplines: Provide joint training for heart failure and lymphoedema teams to reduce uncertainty and promote shared understanding.
- **Develop integrated care pathways:** Establish clear referral routes and shared protocols to improve coordination and avoid delays.
- **Support generalist and community staff:** Offer practical tools and education to build confidence where specialist support is limited.
- **Maintain person-centred care:** Ensure that compression decisions consider comorbidities, patient risk, and individual preferences.

Conclusion

This qualitative evaluation has highlighted the uncertainty, variation, and gaps in care experienced by healthcare professionals managing patients with coexisting heart failure and lymphoedema. Despite the availability of specialist guidance, many practitioners remain unsure how to interpret and apply it in practice, particularly regarding compression therapy. Improving outcomes for this patient group will require the development of clearer guidance, interdisciplinary education, and more integrated pathways that reflect real-world care settings. These changes should be co-produced with frontline professionals to ensure relevance, uptake, and sustainability. By responding to the needs identified in this evaluation, services can move towards more confident, consistent, and collaborative care for patients with complex oedema presentations.

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