Rowing towards the shore: coping strategies in males living with lymphoedema
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Abstract
Lymphoedema is a swelling in part of the body due to an obstructed flow of lymphatic fluid. Extant literature mainly targets coping strategies in females having breast cancer related lymphoedema. This research aims to explore the coping strategies of males living with lymphoedema, secondary to cancer treatment. Semi-structured, in-depth interviews were conducted with 13 males aged between 50 to 85 years. Five themes emerged namely: adjusting attire, changing lifestyle activity, distracting the mind, leaning onto available support and immersing in spirituality. Males described wearing loose, easy-to-wear clothing over swollen body parts. Changes in lifestyle included pacing of activities, avoiding/modifying activities to avoid injury and incorporating treatment in their daily routine. Distraction was enabled though immersion in work, engaging in hobbies and humorous banter. Participants also coped by expressing gratitude, living in the present moment, accepting situations over which they lacked control, connecting with nature, and turning to their religious beliefs. There is a need for health professionals to explore the illness narratives and coping strategies of males living with lymphoedema as this impacts their overall well-being. Interventions targeting coping strategies for males with lymphoedema should address the physical, emotional, psychological and spiritual domains of well-being.

Keywords
Lymphoedema; Interpretative phenomenological analysis; Coping; Cancer; Males

1. Introduction
Lymphoedema is a chronic and progressive condition, characterized by impaired lymphatic return that results in swelling of extremities [1]. Traditionally, lymphoedema has been perceived as a trivial and untreatable consequence of cancer treatment. However, researchers and clinicians are increasingly recognizing the significant impact of lymphoedema on individuals, families and health care systems [2].

Coping with the impact of lymphoedema is influenced by various determinants. One such determinant is the chronic nature of lymphoedema, which requires individuals to adapt to this chronic condition and integrate self-management techniques into their daily lives [3]. Self-management strategies for lymphoedema include exercises, limb elevation, the use of compression garments, self-manual lymph drainage and compression bandaging [4]. Despite their necessity, these strategies are described as demanding in terms of time and energy [5]. Another determinant is the limited awareness of some healthcare professionals about lymphoedema [6]. This underscores the need to explore the coping strategies of persons with lymphoedema, especially when professional knowledge and support may be lacking. Generating such insights are crucial for a healthcare system that aims to deliver high-quality, person-centered care, amid the financial challenges of a rising number of lymphoedema cases [7].

While several quantitative studies have explored the coping mechanisms of persons having lymphoedema [8], most focus on Breast Cancer-Related Lymphoedema (BCRL), where the male perspective is often overlooked or underrepresented. This is significant as males tend to have poorer coping outcomes related to lymphoedema than females [9]. Qualitative studies on coping with lymphoedema also show an underrepresentation of the male perspective. For instance, Hamilton and Thomas [3] interviewed thirteen participants, with only two being males having lymphoedema secondary to cancer. These persons had been diagnosed with either breast, melanoma or a reproductive cancer. Their study revealed that coping and hope were influenced by: (i) symptom fluctuations, and (ii) the transition from cure-based conceptualisations during cancer treatment to action-oriented hopes relating to secondary lymphoedema. Another study by Tidhar and Armer [10] that included ten participants (of whom three were males), highlighted coping strategies such as accepting their condition, adapting to role and lifestyle changes, and self-managing to prevent exacerbations.

The present study aims to address this gap in literature by exploring how males with chronic lymphoedema secondary to...
2. Materials and methods

2.1 Research design

The chosen research design for this study is Interpretative Phenomenological Analysis (IPA). IPA allows for an in-depth exploration of the participants’ lived experiences whilst acknowledging the active interpretative role of the researcher. This design is based on three theoretical underpinnings: phenomenology, hermeneutics and idiography. Phenomenology seeks to describe participants’ experiences from their subjective first-person accounts, hermeneutics involves the researcher’s effort to make sense of participants’ sense making and idiography involves an in-depth analysis of each case individually, before making comparisons across cases [11].

2.2 Participants

Thirteen males who were undergoing treatment for lymphoedema following a cancer diagnosis, were recruited for the study. Six of the participants had been diagnosed with prostate cancer; four with a sarcoma and one respectively for testicular, melanoma and breast cancer. The participants were all adults with a mean age of 68.6 years, ranging between 50 to 85 years.

2.3 Data collection and data analysis

Semi-structured interviews were conducted using open-ended questions such as: “Can you describe your experience of striving to cope with lymphoedema?”. Probing questions such as “Can you provide me with more details?” or “Can you give an example?” were asked when additional information was required. The audio-recorded interviews varied in duration from 40–90 minutes.

Data analysis followed guidelines outlined by Smith et al. [11]. This process involved a thorough reading and re-reading of the transcripts for each participant. Exploratory statements were identified addressing linguistic, descriptive, and conceptual aspects. These statements were then organized into emergent themes. Connections among these themes were then explored to discern their relationships. Themes that shared similar understanding were grouped under an overarching super-ordinate theme.

2.4 Trustworthiness

Trustworthiness was evaluated using Yardley’s [12] four principles. Sensitivity to context was enabled through the provision of verbatim extracts and the inclusion of relevant literature. Commitment and rigour were exemplified by providing insight regarding the research design, participant recruitment and the data analytic process. Coherence and transparency were ensured by providing a rationale for decisions taken and ensuring that the research was consistent with the theoretical assumptions of IPA.

3. Results

The superordinate theme “Rowing towards the shore” acknowledged the challenges of coping with lymphoedema. One participant (Frank) stressed the importance of actively addressing the challenges imposed by lymphoedema, comparing it to rowing towards the shore instead of succumbing to the waves. Frank emphasized the significance of one’s perspective and approach in dealing with lymphoedema, advocating for proactive engagement rather than helplessness.

If there is a staircase with a steep gradient and you consider that it is too difficult to climb, it will take forever, you would have already given up. If you take the initiative and start climbing, you will eventually reach the top. (Frank)

The themes listed in Table 1 incorporate the following coping strategies namely adjusting attire; changing lifestyle activities; engaging in distraction; leaning onto available support and immersing in spirituality.

3.1 Adjusting attire

While participants acknowledged the challenging nature of the treatment regimen, they emphasised the importance of adhering to self-management strategies for lymphoedema. They perceived that active engagement in self-management improved their prognosis and ensured further time with their family. This conviction motivated a substantial number of them to actively adhere to their treatment regimen.

It’s not easy, but I keep going back to the same point, wearing a stocking is a small price to pay for the discomfort, not adhering leads to greater repercussions. By following my treatment, I can spend more time with my wife and my family. (Mark)

Many participants strived to cope by adjusting their clothing and footwear to alleviate discomfort resulting from swelling in affected areas. For instance, Andrew shared that he opted for loose-fitting shirts to accommodate the swelling in his upper body after undergoing breast cancer treatment.

The shirts or T-shirts that I started choosing from my wardrobe were of a bigger size, they were more loose-fitting to feel comfortable with a swollen upper body part. (Andrew)

Likewise, Karl described that after undergoing treatment for prostate cancer, he switched to convenient slippers equipped with Velcro closures. This adjustment aided in addressing his diminished flexibility, which posed challenges in putting on shoes with laces.

I bought these shoes, but they are like slippers with velcro and not with laces. You need something easy to put on, as bending over to dress up can be a struggle. (Karl)

Some participants also adopted a pro-active approach to avoid staining clothing. For instance, Mark described carrying bandages along everywhere to address any fluid leakage.

If it happens (leakage of fluid) it happens, and what I try to do is, I try to be aware of it. I’m used to carrying around bandages in my briefcase just in case. (Mark)
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### 3.2 Changing lifestyle activity

The participants stressed the importance of taking control of their circumstances, underscoring that proactive efforts to handle their condition would lead to favorable outcomes. You can control the lymphoedema if you, for example, take control of your life. In other words, if you don’t want the legs to be swollen then make that effort. Now you may not, for example, like jogging but you can walk, and you can wear a compression garment. And if you walk every morning you will start to see a difference over time. You can also raise your legs on a chair when watching television, as leaving them hanging increases swelling in the legs. (Mark)

The importance of staying active was also considered crucial, yet at times fatigue would hamper their efforts. This challenge was tackled by pacing daily activities.

I’d get too tired trying to clean my house properly... I’d do the living room and the kitchen one day, two bedrooms the next and then the final bedroom and the bathrooms. A bit of cleaning each day because you can’t do it all at once. (Stephen)

Another strategy used was merging one’s treatment to a daily routine. For instance, Isaac merged prescribed exercises with his television-watching routine to prevent boredom, whilst ensuring that the exercises were completed.

He (the physiotherapist) gave me these exercises... I do these exercises as soon as I get up from bed. I raise my leg, move it to the side, pull one leg up and raise the other one... I do them in front of the television so that I do not get bored. (Isaac)

Some participants shared the need to exercise caution to avoid injury to swollen limbs. This was required as they recognised that injury could be linked to infection and further complications.

I take great care during my walks, sort of if there is a hedge..., I try to avoid it, for fear that some pointed branch will injure my swollen leg. (Isaac)

Over time, many participants refined their skills to effectively manage their lymphoedema. For example, Michael detailed how he adapted his bedtime routine and incorporated an elevated bed to mitigate the gravitational impact on his swollen limb.

I sometimes have to assist the leg with my hands to get on the bed. I sit on the bed and I then, I have to swing up on the bed and I’m actually most comfortable sitting on my bed which has an elevated end, rather than sitting on a chair, because if I sit in a chair, I can feel the water gathering in my leg and in my genital area. The elevated bed reduces the gravitational effect of the lymphoedema. (Michael)

### 3.3 Engaging in distraction

Distraction emerged as a popular coping mechanism among participants, primarily through engagement in work to redirect their focus and reduce self-rumination. Work offered cognitive activity, provided a sense of purpose and left little room for rumination.

One should not stop working, going to work is better for the person because one distracts oneself instead of overthinking. When you are at your workplace you need to think about what you are doing. Now if you stay in bed, you’re going to think about yourself. (Frank)

Furthermore, involvement in employment created opportunities for participants to engage in diverse social interactions and activities, contributing to an enhancement in their overall well-being.

The thing about my work is that I get to meet a lot of people, running around here and there, going to watch lots of football...
and so on. I mean, that helps a lot because you’re on the move, you’re not at home all the time. (Adam)

Aside from work, oftentimes hobbies served as a means of distraction helping the participants to steer away from repetitive thoughts on lymphoedema. This was perceived as providing both enjoyment and also therapeutic benefits.

Television and reading, help me distract myself... for me they are a bit like therapy. (Adam)

The use of humour was also highlighted as a means to replace negative thoughts with positive ones. One participant (Frank) described using humour during his hospital visits to kill time but also to distract himself from distressing thoughts that surfaced.

We joke and laugh at hospital. Once a guy told the lady next to him that I was behaving as though we were at a hotel. I’m supposed to be going to hospital with a heavy heart. I’d stay quiet at a hotel but in hospital I want to joke around to kill the time, instead of remaining with a heavy heart. (Frank)

3.4 Leaning onto support

All the participants reiterated the importance of a support network when living with lymphoedema. Spouses, adult children and/or close friends were often cited as sources of encouragement and reassurance.

My wife played a huge part in my cancer experience as she was like a sponge absorbing all the emotions. She used to be very positive in my regard. If she was preoccupied she would not show me and that helped me. I realised that my emotional strength came from my wife and a very few close friends. (Andrew)

Nevertheless, the degree to which participants depended on this support network differed. For instance, Mark was firm in his belief that his children should not shoulder the extra weight of his own issues. He also revealed that he only confided his concerns to his spouse when a specific problem arose.

First of all I don’t discuss it (lymphoedema) with my children. I don’t want it to become an issue which they then become concerned about. And I only raise it with my wife if I see there is a problem. (Mark)

The encouragement and reassurance received from health care professionals, (especially physiotherapists with expertise in lymphoedema), were unanimously appreciated by the participants. These professionals were seen as a vital source of both encouragement and guidance. Hence, although the treatment regimens imposed a burden they were perceived as necessary.

Because he (physiotherapist) tells you to do these things if you want to, but well, they are for my own good, not for his benefit or anyone else. Although it is a sacrifice, I mean just imagine going for this treatment every day from Monday to Friday for a whole week, coming home with a bound leg which looks like an elephant’s leg because you have 16 metres of bandaging at the very least and that is no joke... it is necessary. (Adam)

A few participants also proposed the potential engagement of a variety of professionals to address their overall wellbeing. Recommendations were made for the incorporation of more frequent hospital appointments to offer reassurance and address any inquiries.

I feel that more frequent follow-ups after the operation would be very helpful. They help put your mind at rest, even if they tell you are doing well, that is a result in itself. I also don’t know if there is treatment in addition to physiotherapy that can be availed of. (Isaac)

Many of the males also acknowledged the quality of support provided by persons who have experienced lymphoedema. This point is articulated by Mark, who is advocating for a “buddy system” to support people with lymphoedema:

I think the best way to support people with lymphoedema is with people who have had lymphoedema, and who are managing it like myself. A buddy system or the support system, not from health professionals, but from actual people who’ve experienced it and managed it because otherwise if you haven’t experienced what they are suffering from, these patients will tell you ‘But you don’t understand.’... and if you say ‘Not only do I understand but I’ve suffered from it as well and guess what I did, I have controlled it by doing the following thing. Let’s see if you can do that. (Mark)

The regular meeting of these males during physiotherapy sessions was greatly appreciated. One participant (Kevin) described that camaraderie thrived during their treatment, extending to social gatherings. This afforded the men an opportunity to exchange experiences with fellow males coping with lymphoedema, fostering a deeper understanding and a more empathetic perspective.

I think there were about eight of us, and we used to go for physio every Saturday morning and we also considered that an important date. Physio on Saturday morning and we became friends. Following our physio session we ended up going for coffee to talk a little bit, so the person moved on instead of staying at home with no one to talk to, no one to share your feelings with, yes trust me, these things make a huge difference... believe me any suffering is decreased. (Kevin)

Yet not all the participants concurred with this viewpoint. One participant (David) preferred to share his experiences with a “normal male” the conversation could target a variety of issues, that could also include health related ones.

I feel more at ease discussing my experiences and challenges with a male but not with someone going through the same experience that I am. I like speaking to normal persons, I have a friend whom I go out with and we speak about all sorts of topics and we do so many things together. (David)

The importance of engaging in active information seeking was also cited by several participants. These males described coping by seeking information, critically analysing that information and assertively discussing that information with professionals.

My eyes are wide open when you read stuff on the internet it’s usually terrifying. It’s a bit like reading the disclaimer on a packet of pills. You know if you read the disclaimer on paracetamol it’s terrifying because you might not understand it completely. But, yes, I do (read it), because I need to understand the impact of treatment on me but this is followed up with a good discussion with my doctor... that gave me great confidence to take a pill yesterday. (Stephen)

Another participant (Andrew) highlighted the media’s role
as a valuable source of information and encouragement, particularly beneficial for individuals who are more reserved and may not actively seek assistance.

There are persons who are like clams in the sea, they build up a shell around themselves and do not reach out for help from others, should these persons receive positive messages through the media it can make a difference in some cases, because when a person is reserved it is difficult to encourage them to share their experiences. (Andrew)

3.5 Immersing in spirituality

Frank emphasized the significance of choosing one’s “battles”. He explained putting effort into situations where he could exert control, while accepting situations beyond his control without resistance.

I accept whatever comes. If I can (exert control) I’ll try fighting it, if I can’t, I won’t. But I take life the way it comes, not the way I’d want it myself, the way it comes. (Frank)

The importance of “living the moment” and avoiding excessive worry about the future was stressed by several males.

At times I think why do these things happen to me? These thoughts do come to your mind, I mean, such thoughts harm and burden you, so you have to work on them and take matters on a day-to-day basis. (Chris)

Some participants described how they transcended the physical and psychological impact of lymphoedema by seeking a meaningful connection with a higher power that supported them through their journey. In this manner, they were not alone but rather were sharing this “burden”.

I do not consider myself a saint but prayer, prayer helps and repeating it, I believe in the importance of having a dialogue with God, I mean with the creator. Therefore, if you say, if you believe there is someone up there and you speak with Him and tell Him that you know your condition is curable and you ask Him to guide you through this difficult experience then you are not alone. (Adam)

Likewise, a grateful mindset was identified as a coping resource by some participants. They described making downward comparisons with others who were perceived as worse off. In this manner they felt grateful for not being in that position.

I’ve always led a healthy life and there is a sort of feeling sometimes you sort of think “Why me?” but then there are others worse off than me... I haven’t yet got Dementia. You know, I mean frankly I’m so fortunate that even though I have lymphoedema I can still look after myself. (Michael)

The importance of connecting with nature was also highlighted as a means of managing negative emotions. It also helped replenish their psyche and physical well-being in multiple ways:

On my roof I have a few plants, I would go up there for some fresh air; then I would do some gardening. At the same time, I’m out in the open, those walks in the public garden used to help me greatly regenerate myself both physically and mentally. I used to go for the quiet there, to read a bit. (Andrew)

4. Discussion

The paper contributes to extant literature by providing a rich narrative of the coping strategies in males living with lymphoedema. The various coping strategies identified are discussed in the following sections.

4.1 Changes in lifestyle and attire

Individuals coping with lymphoedema incorporated self-management practices into their daily routines. For instance, one participant (Isaac) included exercises in his routine whilst watching television to avoid the monotony. Such behavioural strategies empower patients to adhere to their treatment regimen, providing them with a sense of control over their treatment. Perceptions of control in turn, are positively linked to psychological well-being, social functioning and vitality, and negatively associated with psychological distress [13].

This emphasises the significance of personalized care plans, that integrate treatment regimens into the lifestyles of males.

In relation to attire, a few participants expressed concerns about the visibility of their affected limb. This aligns with prior research by Rio-González et al. [2] however where the sample predominantly consisted of female participants (i.e., 91%). Despite this, most male participants in this study regarded clothing adjustments more as a practical necessity than a strategy to appear socially “normal”. Nonetheless, caution is needed when interpreting this finding due to the male participants being predominately in middle and late adulthood. Further research is required to determine whether differences in intent behind adapting clothing, relate to age-related factors.

4.2 Engaging in distraction

Male participants actively engaged in distraction to prevent excessive rumination about their health. This finding concurs with the coping strategy of self-distraction identified in females with BCRL [14]. Although self-distraction provides relief from anxious thoughts, its overreliance could lead to neglecting lymphoedema or exacerbating it during strenuous activities.

In this study, males frequently turned to work as a preferred distraction. By engaging in gainful employment, they upheld an occupational identity reflective of masculine ideals, including positions of authority, financial dominance, and physical strength [15]. Sustaining gainful employment has also been linked to satisfactory levels of self-esteem, social connections, financial stability, and overall well-being in male cancer survivors [16]. Nevertheless, the prioritization of work, possibly at the detriment of their health, highlights the importance of educating employers and management about the challenges associated with living with lymphoedema. This emphasizes the need for fostering a workplace culture that supports employees dealing with lymphoedema. Additionally, there is a need to offer psychological support to individuals compelled into early retirement due to having lymphoedema. The utilization of humour has also emerged as a coping strategy, particularly in anxiety-inducing situations like hospital visits. Humour, as a coping mechanism, is more frequently employed by males, aiding in moderating psychosocial stress.
while enhancing social skills and support [17].

### 4.3 Leaning onto available support

Support for males with lymphoedema was received from various sources, including professional assistance from healthcare providers; informal help from friends and family, and supportive exposure to media. These diverse support systems offer practical benefits and act as a protective buffer when dealing with the emotional aspects of lymphoedema [9]. However, seeking support, may require males to confront vulnerability, potentially conflicting with traditional Western male gender roles emphasising stoicism, autonomy, and success [18]. Hence, when seeking support, males may need to re-define their masculinity scripts [19], with potential implications for their overall well-being and the quality of their care experience.

Despite the known benefits of remaining active for improved vitality and functionality [2], male participants in the study perceived this as a challenge. They emphasised the crucial role of dedicated professionals in inspiring them to sustain physical activity. Addressing non-adherence to treatment can be accomplished by raising awareness that both time and effort are essential for the treatment to produce positive outcomes [7]. The feedback provided by professionals is also vital, as it can boost hope among lymphoedema patients [3]. By promoting shared decision-making and care negotiations with patients, professionals become key partners, collaborating with patients to achieve person-centred care [20].

Another valuable source of information and support identified in this study is the internet. This holds particular relevance given the traditional masculinity norms that might impede males from seeking assistance for mental health issues [21]. In fact, one participant (Andrew) likened such persons to clams, having difficulty to reach out for assistance and making the internet a vital source of information. However, clinicians should create a context where males can openly discuss their concerns, including information obtained from internet searches.

Participants also expressed the need for a “buddy system” to connect with other males having lymphoedema. This is of importance considering that chronic conditions can threaten the male’s self-image; masculinity and ability to fulfil social roles [22]. Moreover, body image concerns in males may prove distressing since they are often interpreted as a female concern, rather than affecting both genders equally [23]. In fact, the “buddy” system provides an avenue for sharing experiences, seeking peer support, and reducing feelings of isolation. It enables males to navigate their “new normal” and exchange practical strategies for managing lymphoedema. By engaging in physical activities, (such as group physiotherapy sessions mentioned in this research), group solidarity and the facilitation of connections can be fostered among participants [24]. This emphasizes the importance of integrated care that addresses not only medical but also social and emotional support structures.

### 4.4 Spirituality

Spirituality emerged as a coping mechanism in this study with acceptance, mindfulness, and belief in a higher power serving as sources of strength and resilience for the participants. This underscores the importance of a holistic healthcare approach, that encompasses not just physical but also psychological, emotional and spiritual aspects of managing a chronic illness.

Hope, faith and gratitude were identified as key contributors to coping with lymphoedema. The male participants expressed hope for positive outcomes in tandem with an acceptance of their chronic condition. However, these findings emerged from research with males in mid and late adulthood having lymphoedema. They may not fully apply to younger males with lymphoedema, who according to Michael et al. [16] find the loss of physical and sexual function more challenging. Cognitive strategies, such as downward comparison to individuals facing more severe challenges (e.g., being treated for cancer) were also noted. Such comparisons may have a positive effect on the person who feels grateful [25] for not having a more severe condition. This further links to research in positive psychology, demonstrating that practices such as gratitude can have significant benefits for mental well-being.

Engaging with nature, though activities like gardening and outdoor walks, emerged as a coping strategy providing physical activity, relaxation, and distraction from the condition. Such activities have been associated with reduced anxiety, depressive symptoms, stress and mood disturbance, while enhancing quality of life and community engagement [26]. Health professionals should consider recommending time spent in natural settings as part of a comprehensive well-being strategy for individuals with lymphoedema.

### 4.5 Limitations

Typical of an IPA study, the number of study participants was small. Although this may impact the generalizability of the study, the aim of this study was to extract in-depth accounts of the lived experiences of males with lymphoedema. Additionally, the present study was cross-sectional in nature. Hence, conducting a longitudinal study with males could focus on the participants experience of lymphoedema from the period of diagnosis and their experience whilst undergoing treatment.

### 5. Conclusions

In conclusion, this paper presents a nuanced picture of coping strategies in males with lymphoedema. It highlights the need for therapeutic approaches that are multi-faceted, addressing physical, emotional, spiritual and psychological domains. It also highlights the need for health professionals to be aware that various expectations relating to the male gender may have an impact on their coping strategies and well-being. Future research should also explore the coping strategies of males in early adulthood and the potential benefits of supportive interventions such as “buddy systems” that target the reluctance of males to seek help for fear of appearing vulnerable.

### AVAILABILITY OF DATA AND MATERIALS

Data of this study are audio recordings and corresponding transcripts of the interviews. These contain confidential data. This data is in the possession of the Main Author (JS).
AUTHOR CONTRIBUTIONS
JS, SCV, MG, CC, PG, AS and CA—Study concept and Design, Critical revision and editing. JS—Data collection. JS and SCV—Data Analysis and interpretation, Original drafts of article. JS, MG and CC—Funding Acquisition. All authors have read and agreed to the published version of the manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE
The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Research Committee of the Faculty of Health Sciences, University of Malta (No: 3915_24122019). Informed consent was obtained from all the study participants.

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CONFLICT OF INTEREST
The authors declare no conflict of interest.

REFERENCES