Dancing with lymphoedema: experiences of a creative health intervention

Aimee Hattersley

21210410

Supervisor: Dr Thomas Kador

Partner organisation: Rosetta Life

Submitted to UCL in partial fulfilment of the requirements for the degree of

MASc Creative Health

5th September 2022

Module: BASC0050 Dissertation Project

Table of Contents

DANCING WITH LYMPHOEDEMA: EXPERIENCES OF A CREATIVE HEALTH INTERVENTION 1

Abstract **4**

1. Introduction **5**
1.1 Dissertation focus 5
1.1.1 The partner organisation 5
1.2 The context of creative health in relation to the current healthcare system 5
1.3 Why is research in this field needed? 6
1.4 Research questions and outline of dissertation 7
1.4.1 Outline of dissertation 7

2. Literature Review **8**
2.1 Research context 8
2.1.1 What is lymphoedema? 8
2.1.2 Health related stigma 9
2.1.3 Dance for health and wellbeing 11
2.1.4 Sociological and philosophical principles 13
2.1.5 A need for supportive, knowledgeable communities 14
2.2 The research gap 15
2.3 Summary 16

3. Methodology **17**
3.1 Research design 17
3.2 The Intervention 17
3.2.1 Sample 19
3.3 Data collection 19
3.3.1 Observations 20
3.3.2 Q&A session 21
3.3.3 Follow up interviews 22
3.4 Ethical Considerations 23
3.5 Reflexivity 24
3.6 Data analysis 25

4. Findings **27**
4.1 Observations 27
4.1.1 Power of the shared experience 27
4.1.2 Storytelling 28
4.1.3 Appearance of confidence 29
4.1.4 Physical abilities 29
4.2 Q&A 30
4.2.1 Sharing of personal experiences 30
4.2.2 Community 32
4.2.3 Expectations vs reality 34
4.3 Interviews 36
4.3.1 Induced emotions 36
4.3.2 Autonomy 37
4.3.3 The individual, community and wider society 39
4.3.4 Experiences of illness 42
4.3.5 Creativity through intervention 44

5. Discussion **47**
5.1 Is the presence of a supportive community important for those living with lymphoedema? 47

5.2 How do wider societal influences impact upon individual experiences of lymphoedema? 48
5.3 How effective an intervention is a dance/movement project for people with lymphoedema? 50
5.4 Limitations 52

6. Conclusion **54**
6.1 Possibilities for further research: 54

References **56**

Table of Figures Error! Bookmark not defined.

Appendices **62**
Appendix 1: Information sheet for individual interviews 62
Appendix 2: Consent form for individual interviews 66
Appendix 3: Rosetta Life consent form 68
Appendix 4: Interview schedule 69

Abstract

Chronic illness places pressure onto the health service. Preventative measures should be used alongside biomedical treatment to reduce this strain, such as creative health interventions. This dissertation explores lived experiences of lymphoedema in relation to a dance and movement programme, run by Rosetta Life, looking at the importance of a supportive community, the impact of societal influences and the effectiveness of the intervention itself. This investigation is carried out in an interdisciplinary way, employing sociological, philosophical and psychological principles.

Three data collection methods are utilised: observations; participant question-and-answer session and semi-structured individual interviews. Thematic analyses of each data form were carried out, and considered separately. Four main themes of the observations were identified as: power of the shared experience; storytelling; appearance of confidence; and development of physical abilities. Three themes were found within the question-and-answer session: sharing of personal experiences; community; and expectations versus reality. Finally, the interviews gave way to five themes: induced emotions; autonomy; the individual, community and wider society; experiences of illness; and creativity through intervention.

Bringing these findings together, it can be seen that the presence of a supportive community is notably important for those living with lymphoedema, for creating social comfort, sharing coping strategies and increasing self-confidence. This support may be useful in counteracting negative effects of societal influences, such as stigma. The intervention increased individuals' sense of personal autonomy, and created lasting tools that individuals could use to cope with mental and physical symptoms of lymphoedema. Future research should investigate how creative health interventions can sustainably fit into the political and economic landscape of the UK going forward.

1. Introduction

1.1 Dissertation focus

Chronic illnesses place pressure on the health service. Those living with long term conditions have the most healthcare needs among the UK population (1), requiring continuous treatment and care. Therefore, it makes sense that those living with such conditions would benefit from additional non-clinical interventions.

This dissertation focuses on a non-clinical intervention offered to individuals living with lymphoedema, which is thought to affect 6 in 1000 people in the UK (2). Emphasis is placed on the lived experience of illness.

1.1.1 The partner organisation

This dissertation is the result of a partnership with a charity, Rosetta Life, established in 1997, primarily working with those who have life-limiting conditions. They aim to promote creativity, using dance, movement, music, and storytelling to redefine what it means to be ill, and to challenge stigma that may surround this (3).

1.2 The context of creative health in relation to the current healthcare system

A Lancet Commission paper (4) published after the Covid-19 outbreak argues that the response to the Covid-19 pandemic has shed light on weaknesses within the UK's healthcare system. These include, but are not limited to, poor integration between the NHS and social care, which is already underfunded, and a disempowered public health service. A press release from the British Medical Association (BMA) in 2020 (5) describes a health service pushed to its limits, with staff overworked and underpaid, and facilities with limited resources. The most recent 'Five Year Forward View' published by NHS England contained plans to improve urgent and emergency care, primary care, cancer, and mental health (6). Without a radical transformation from the reactive, sick model style of the healthcare

system, that currently is in place, to a preventative care model it is difficult to see how health services will catch up with demand.

To adopt this preventative care model, healthcare must reduce reliance on biomedical solutions alone. Health is set out in the constitution of the World Health Organisation (WHO) to be 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (7). It is a holistic state of being, and efforts should be made to maintain good health. When illness occurs, contributing factors should be considered, such as living situations, socio-economic circumstances, sociality and mental wellbeing. Non-clinical interventions can be used in part to address these needs, to prevent reoccurrence.

Creative health can be defined as creating the conditions and opportunities for arts, creativity and culture to be embedded in public health (8). The All Party Parliamentary Group (APPG) report on Creative Health stated that arts can benefit health and aid recovery from illness, and help meet challenges faced by our health system, such as long term conditions (9). Whilst NHS England has committed to building the infrastructure for and embedding social prescribing into primary care (10), which provides pathways to non-clinical interventions, much of the onus falls onto third sector organisations to provide and advertise such services.

1.3 Why is research in this field needed?

To provide backing for the inclusion of non-clinical interventions in mainstream UK healthcare, a substantial evidence base is needed. While it can be more difficult to provide the empirical evidence that supports biomedical treatment, there is scope to analyse and assess the efficacy and effects of non-clinical creative health interventions.

As discussed, socio-economic factors are prevalent in determining health outcomes. Health is linked to the conditions in which people are born, grow, live, work and age, and inequities in power, money and resources. Areas of higher deprivation have higher mortality rates for chronic disease than those of lower deprivation in the UK (11).

It has been suggested that creative health interventions can assist in alleviating these inequalities (12). But whether the arts and cultural engagement play a substantial part in reducing social and health inequalities and promoting population health is yet to be demonstrated (13), so this needs more research and investigation (14).

1.4 Research questions and outline of dissertation

This study aims to answer the following research questions:

1. What is the importance of a supportive community for those living with lymphoedema?

2. How do wider societal influences impact upon individual experiences of lymphoedema?

3. How effective an intervention is a dance/movement project for people with lymphoedema?

1.4.1 Outline of dissertation

Chapter 2: 'Literature Review' explores the research context within which this dissertation is set and key literature, including that of lymphoedema; health-related stigma.; dance for health and wellbeing; sociological and philosophical principles; and the need for supportive communities, before explaining where this research fits within the gap. Chapter 3: 'Methodology' research outlines methods for data collection and the rationale behind methodological choices. Chapter 4: 'Findings' presents the results of multiple thematic analyses. Chapter 5: 'Discussion' brings together findings to answer the research questions, and details limitations of this study and opportunities for further research. It is followed by Chapter 6: 'Conclusion'.

2. Literature Review

2.1 Research context

2.1.1 What is lymphoedema?

The principal physiological function of the lymphatic system is to 'take up fluid, leaking out of blood capillaries into interstitial spaces in the tissue, and return it to blood circulation' (15), maintaining a balance of fluid in the body. Lymphoedema is a swelling that results from a lymphatic system that is impaired. Fluid builds up in the body's tissues when not transported adequately. When the amount of fluid in one area of the body is more than the lymphatic system can drain, swelling occurs (2).

Other symptoms can include: 'an aching, heavy feeling, difficulty with movement, repeated skin infections, hard, tight skin, folds developing in the skin, wart-like growths developing on the skin and fluid leaking through the skin' (16).

Lymphoedema can be primary or secondary, depending on its cause. Primary lymphoedema is a result of insufficient development of the lymphatic system. Secondary lymphoedema is caused by harm to the lymphatic system or problems with the drainage of fluid, which could be, among other reasons, a result of cancer treatment (16).

2.1.1.1 Lived experiences of lymphoedema

As with any illness, physical symptoms of chronic conditions are accompanied by social and mental impacts. Lived experience testimonies are beneficial to understanding these in as holistic a way as possible, recognising the inter-reliant effects of each on the other.

Many note that lymphoedema is a relatively misunderstood and unrecognised condition, with medical professionals having limited knowledge of it (17, 18). Some narratives describe difficulties in relationships with medical professionals, as well as a lack of appropriate

information about the condition, which can lead to uncertainty and anxiety regarding diagnosis, or lack of it (18, 19). The development of lymphoedema itself is usually not preventable, but aggravating patients' experience with lack of understanding and expertise is avoidable.

Swelling of limbs and other parts of the body can change a person's appearance and affect mental wellbeing. Those living with lymphoedema report difficulties with self-image and feeling conscious of their own physical appearance (17-20). For some, a contributing factor to this is an inability to find well-fitting clothes (20). This can be alienating and may contribute to a sense of separation when mainstream society does not cater to your needs.

Further problems can occur with access and provision of adequate resources for those with lymphoedema. Travel becomes more difficult, as does gaining adequate medical treatment, and financial resources become harder to acquire as ability to gain and maintain employment is reduced (20) – having a health status as less than good is associated with a significant reduction in income (21). It is interesting to note the theory that disability is not due to the illness or condition but the social conditions in place that oppress those who differ from the 'norm' (22, 23). Are the physical and practical implications of living with lymphoedema imposed by social restrictions, such as inadequate travel infrastructure for those less able to move freely?

2.1.2 Health related stigma

There is no definition of stigma that sufficiently covers all instances, and definitions given vary greatly. Two reasons for this are that the concept is applied to a wide array of circumstances, and that the concept itself is multidisciplinary (24). To apply the same definition to every case would discount nuances and manifestations that each discipline and circumstance brings to it. Each instance of stigma, and subsequent discrimination, may be rooted in different cultural structures and processes, and so manifests in different ways. For example, a stigma of mental illness is different to the stigma that exists around travelling communities. The possible intersectionality of this health related stigma should also be considered - those within a travelling community who live with mental illness may be privy

to a further nuanced stigma. In relation to chronic illness, a stigma's application differs with each type of illness depending on cultural, symptomatic, and structural factors and relations (22). In some cases, stigma can lead to social isolation, or perceived social isolation. This can have a harmful impact on health and wellbeing (25).

One societal stigma surrounding health is that of obesity (26). Assumptions are made of people perceived to be above recommended weight, without understanding individual circumstances and this stigma may affect those suffering with lymphoedema. This is not only because its physical presentation might resemble that of obesity as both have a larger stature, so they may suffer the effects of the same stigma, but also that the physical and functional impairments that often accompany the condition (20) may affect an individual's ability to exercise, meaning that they may gain excess weight as a result.

Not only is there stigma surrounding how people are expected to look, but also how they should behave. It is important here to note Parson's concept of the sick role (27) as a deviance from social norms. While this is arguably outdated with the increase in pathologizing everyday behaviour (28), it is still useful to consider how our capitalist society spotlights those who are well, and hence can work to further the capitalist agenda. Those who cannot do so ably for whatever reason are not deemed as worthy, and forced to play the sick role. In relation to health, the notion of people with a level of disability taking part in exercise does not sit within these societal expectations. To some, this provides incentive to push the boundaries of what is expected (29), but it could create barriers to exercise activities.

In Susan Sontag's 'Illness as Metaphor' (30), the impact of language upon victim-blaming for those living with illness is explored. It is interesting to consider this alongside health-related stigma. Illness is portrayed as something inherently negative in the eyes of society, and as Sontag points out, has frequently been used further to describe what is wrong in society. As Sontag said during a book tour, 'metaphor is a code word for misrepresentations…'(31). These misrepresentations of illness are, to use such a metaphor, contagious, and translate to illness as a whole, and hence those living with illness.

Language used by academic and medical communities should be carefully considered to reduce risk of adding to any social stigmas. Terms such as 'grossly disfiguring' (18, 32) and 'elephantiasis' (32) that have been associated with the visual symptoms of lymphoedema may be harmful, and are dehumanising to any person living with the condition. The occurrence of such language backs the lived experiences narratives of people living with lymphoedema who report negative experiences with medical professionals. While these terms would probably not be used today, this language could shape a culture of stigmatisation.

Narrative messages are an effective way of shifting responsibility and reducing public stigma towards those struggling with opioid addiction and obesity (26). Could this be a result of making the stigmatised a relatable person again? Rather than being seen as the 'other' they are repositioned as significant and whole member of society rather than as a manifestation of difference.

2.1.3 Dance for health and wellbeing

The use of dance in health and wellbeing interventions is a well-researched and widely scoped area, with investigations into programmes varying from community based creative dance (33, 34) to structured curriculum based institutional classes (35, 36). While dance therapies do exist, most interventions involving dance would be described as non-therapeutic (33), focusing on non-clinical outcomes such as community building. Music selection is an important factor in how participants engage with dance (37), being described has having the power to keep participants going (33).

The distinction between dance as an athletic, competitive sport and dance as a health and wellbeing intervention is important in this context. It is not to say that the two do not inform each other, but the motivations and desired outcomes are different. The first focuses on the aesthetic and technique of the movement, whereas the second focuses on developing creativity. Butt (37) points out that both dancers and those with Parkinson's disease think about how they move, but in differently. Those with Parkinson's disease, and other chronic illnesses, may think functionally, whereas dancers think aesthetically. This

may encourage shared ground between the two parties that can allow professional dancers to develop an understanding of how to use dance practice in an assistive way.

Exercise has been identified as a viable way to manage chronic physical pain (29), and there is empirical evidence that corroborates the physical health benefits of dance. Varying forms of dance can have a positive impact upon physical fitness and activeness (35, 38). It can also be argued to be an inclusive form of exercise, given its subjective nature. Often, one instruction can lead to many different dance outcomes depending on participants' ability and mobility (37), and this is acceptable and encouraged. The focus is on how a movement feels, rather than an outcome, such as scoring a goal. Exercise that focuses on the function of the body and how it feels rather than its appearance may go some way to combating self-objectification (39). This could apply to the principles of dancing for health.

Dance interventions can assist in regulating emotions and improving mental wellbeing. Social dance was found to reduce anger and mood disturbances in those with Parkinson's disease (40). This is recognised by the participants themselves, with motivations for taking part in tango classes being to relax and find pleasure (41). Taking part in dance activities even plays a role in overall life satisfaction, as shown in some studies in women's health (38, 42).

Not only is dance inclusive in terms of ability, but dance interventions have been reported to be beneficial in creating a supportive space without external expectations (36). For example, social dance involves regular meetings in pairs or groups to practice or enjoy the activity. At its core it promotes the cultivation of friendships and a wider community (43).

As with any form of health intervention, it is not only the direct health benefits that should be considered. Whether the activity can be feasibly integrated into participants' daily lives can determine the extent of the benefit they receive from it. Muro and Artero (42) suggest that dance may be an economically viable option for many [women] to benefit their wellbeing, physical health, fitness level, sensory and motor skills. While this is not specific to those with chronic illness, the same principles may apply for dance to supplement biomedical treatment. If dance interventions tackle social and mental impacts of chronic

illness, they may be a time and cost-effective method of alleviating stress and anxiety for chronic illness patients, such as those living with lymphoedema.

2.1.4 Sociological and philosophical principles

2.1.4.1 Sociological concept of everyday performance

The concepts of stigma, health and illness can be understood through sociological thinking, principles, and theories.

One such group of ideas is Goffman's (44) concept of everyday performance. He uses the everyday to explain human action. How humans behave and present themselves is not the result of individual personality and feeling but limited by a set of scripts that we have inherited or created. These scripts are played out on a stage, where other actors and props are used to make performances convincing to others (45). In this way, identity is based on individual circumstances, and the boundaries placed on those circumstances by society.

Using this explanation of human behaviour, encouraging a shift of identity for participants in dance intervention spaces may prove beneficial. When participants enter a session, they may no longer be seen as a patient, or a person living with illness, but instead simply a dancer (33, 37). They can leave reservations, limitations and societal stigmas at the door, and reposition themselves within society for the time that they are in a session. In terms of Goffman's theory, they are no longer acting the role of someone who is ill, but the role of a dancer. When lymphoedema affects so many areas of an individual's life, this could go some way to provide a sense of relief that they do not have to be defined by it.

Additionally, exercise can be a way to meet challenges that come with chronic illness, and to maintain and enhance personal perceptions of the self as capable (29). By completing such activities, an individual can adopt this capable role.

2.1.4.2 The phenomenology of illness

Philosophical thinking can also be utilised to understand experiences of illness and contributing processes and mechanisms.

The book 'Phenomenology of Illness' by Carel (46) looks at illness from a philosophical perspective. Phenomenology is a philosophy of experience (47), so can be described as subjective. As such, the phenomenology of illness delves into how illness may impact individual values, their body, and the world in which they live. This philosophical perspective is useful when considering lived experience voices.

This perspective may be where a biomedical outlook of illness and people who are living with illness is lacking. Although, in theory, modern medicine allows for accurate diagnosis of physical symptoms, some argue that it does not acknowledge the body as an interconnected whole (48). Whilst phenomenology can be directly applied to the first-person perspective and experience of illness, and benefit healthcare providers in bettering their understanding of it, it has been neglected in medical practice and training (49).

2.1.5 A need for supportive, knowledgeable communities

Throughout accounts and narratives from those with lymphoedema, stress and anxiety arise from lack of knowledge of the condition. Difficulties accessing facilities such as travel and adequate healthcare can be alienating. The need to be surrounded by people who understand the condition is noted (19), whether this be in person or online (17), but people can have difficulties maintaining social support (20).

Considering that social isolation is harmful for health and wellbeing (25), providing people with spaces where these connections can be made is therefore important. Dance interventions have been cited as suitable for these purposes, promoting social togetherness (36). Facilitators have a duty to ensure that these are safe spaces, considering participants are probably moving beyond their comfort zones. A welcoming tone and generating trust is imperative. Whether participants wish to discuss illness or not, simply sharing the space

with others who have had similar experiences can create a sense of comfort socially (33), which in turn can allow the development of companionship and friendship. This can help counteract the social isolation they may feel because of societal stigmas, lack of knowledge and difficulties in accessing resources.

2.2 The research gap

Many studies looking at dance interventions for health and wellbeing are focused solely on women, by design (36, 42). In one study measuring the impact of a general dance for health intervention, adult women formed most of the sample population, the reasons for which were not known to the researchers (50). Societal norms and ingrained views of traditional gender roles are perhaps at play here, where dance is seen as more for women than men.

Dance interventions have been used and researched widely for chronic conditions such as Parkinson's disease (33, 40, 43, 51), possibly due to the widely known Dance for Parkinson's programme by the English National Ballet (52). While this research is invaluable in the development of dance interventions, it is critical not to generalise these findings to all chronic illness without first considering the intricacies in individual experiences that are present. Dance interventions in relation to lymphoedema are extremely under-researched, with no studies presenting in a literature search containing both the terms 'dance' and 'lymphoedema' in their title. This study will go some way to bridge this gap.

Combining dance with narrative is an interesting way forward for this, to include both the physical and mental benefits of dance, and to support the creation of a community not because of illness but through personal stories. Present research tends to focus on individual physical and mental benefits of interventions, so part of this study will investigate the impact of a supportive community.

The use of sociological principles in understanding actions of individuals and groups is therefore vital. This is uncommon within research looking at dance interventions in for health and wellbeing, with many studies opting to investigate specific impacts. This may be to provide clear empirical evidence of the positive effects of such interventions to prove

their effect to those who might influence policy. While this is vital research, opting for a purely qualitative approach using sociological and philosophical principles to understand issues central to the field of creative health gives a broader perspective on the issues at hand, and creates a springboard for further research.

2.3 Summary

Lymphoedema, like many chronic illnesses, can not only cause life-changing physical symptoms, but can also be the origin of a chain reaction of other social, psychological, and economical struggles an individual may face, all of which may have a negative impact on quality of life and health.

Sociological and philosophical concepts can be useful in understanding experiences of illness and subsequent life struggles in a society wide and individual context. Put simply, sociological principles enable us to look at how society views illness and how this impacts an individual, while philosophical perspectives, such as the phenomenology of illness, explore the individuals' values and perspectives.

Non-clinical interventions involving the use of dance and movement are widely used for particular conditions, and hold numerous physical and mental health benefits. Mentions of social support being encouraged in these interventions are made, however the benefits of this social support for people living with illness does not seem to be a focus of current research.

3. Methodology

3.1 Research design

This dissertation takes a mainly deductive approach to exploring lived experiences of lymphoedema. Research questions are informed by and deduced from existing theory and literature (53).

This study looks at health from an interpretivist perspective, in that it gains information from participants own viewpoints which are not directly observable. I assume as the researcher that individuals experience their reality subjectively (54).

This study looks at a dance intervention held for people with lymphoedema in an interdisciplinary way, engaging sociological, philosophical, and psychological principles in the context of creative health. To understand lived experiences of illness, research must be carried out in as holistically as possible, as this is the true nature in which life is lived.

3.2 The Intervention

This study followed a dance and movement project, held by Rosetta Life (3) in collaboration with Accelerate (55) for those living with chronic lymphoedema and wounds. Rosetta Life led a series of dance and movement workshops over 12 weeks from January to April, which culminated in a live public dance theatre performance, entitled The Wishing Well. While the audience demographic was not measured, it was likely to consist of relatives and friends of the performers, and those already acquainted with the work of Rosetta Life.

During the workshops, participants were invited to explore their own experiences with illness, through dance, music, and storytelling, sharing their own stories and characterisations of their lives, using these experiences to co-produce the finished performance piece in dance and song.



Figure 1: Rehearsal day at the performance space (56)

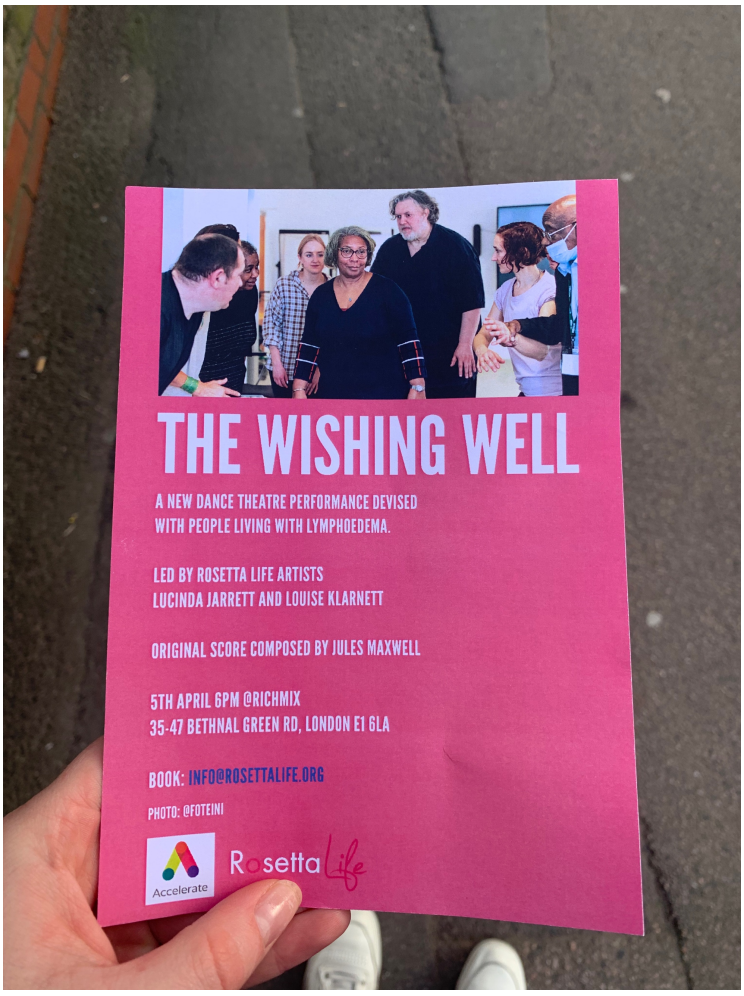


Figure 2: Promotional flyer for dance performance (57)

3.2.1 Sample

Participants of this dance and movement project formed the population for this study.

Those included in this study were those who attended rehearsal sessions and the final performance, and subsequently an event held by Rosetta Life for Wishing Well participants, 17 weeks later. Participants of the project were those living with lymphoedema and/or chronic wounds. While facilitators played a key role within the intervention, only intervention participants were included, as this study seeks to use lived experience voices to explore the role of the intervention for those living with illness. Facilitators would be inappropriate addition to the sample for this reason.

The resulting sample was a group of 10 individuals of mixed gender and ages. Each was a patient at the same lymphoedema clinic, referred to the programme by Accelerate, a non-profit working with those with lymphoedema.

A relationship with Rosetta Life was established through the MASc Creative Health programme, and access to the sample was subsequently gained through Rosetta Life. Participants who attended a post-show event held by Rosetta Life were invited to take part in individual interviews on an opt-in basis.

As the study was completed over a series of weeks, participant numbers were not completely consistent over the course of data collection. However, as individual observations were not made, this does not significantly affect the outcome of the study, and most participants were present for the final performance and Q&A session.

3.3 Data collection

Three types of data collection methods were used in this study, including observations, a question-and-answer session and semi-structured interviews. This allowed triangulation (53) of the data. These data collection methods are discussed in more detail below.

3.3.1 Observations

The dance and movement project involved 12 weeks of rehearsal sessions held at a lymphoedema specialist hospice. The 2-hour sessions were held in an events room within the building.

Each session began with a meet and greet while participants arrived and got settled. This was followed by a warm-up, where the participants were invited to think about how their bodies felt and interacted with their surrounding environment. Each body part was given separate focus, and the amount of movement involved depended on how participants were feeling. The main part of the session focused on elements that would be present in the performance, whether it was dancing, singing or storytelling. Each session included a break halfway through with refreshments, and participants often spent this time chatting with each other.

Observations were made at six of these sessions, in the latter part of the 12 weeks. These observations were participatory in nature, where I would be involved with dance, movement, music or preparing the show production. Notes were made after each session relating to group behaviours, perceived moods and characteristics based on body language and comments made, and general reflections on the activities effect on participants.

This participatory aspect meant that observations may not have been as detailed as if they were completed by a non-participant observer. However, participatory practice is beneficial as it rebalances power relations (58). Participants may already have been on edge by a stranger entering their rehearsal space halfway through the series of workshops. If there were to be on non-participant observer sat on the side lines watching participants, it may have had a greater impact on their behaviour than someone who simply joined in. Participants were made aware that my purpose for attending sessions was to complete a research project, so it was vital that they should be made to feel as comfortable as possible.

One limitation of these observations is that it is not possible to see progression throughout the 12 weeks, as I was only able to attend the second half of the sessions. Therefore, this

observational data will only be used to supplement comments made by participants, and to provide context to Q&A and interview data.

3.3.2 Q&A session

Participants of 'The Wishing Well' took part in a question-and-answer session after the live performance of the dance piece. Questions were asked by audience members, and participants either volunteered answers or were prompted by the intervention facilitator. Questions from the audience were mostly open-ended, allowing participants to share what they wished.

This session was held in the same room as the performance (see Figure 1), so participants were seated in a semi-circle formation on the stage area, facing the audience who were sat in an auditorium style arrangement with tiered seating. The session lasted around 15 minutes, and was filmed by Rosetta Life who posted it, with the participants permission (Appendix 3), to Vimeo.com.

For the purposes of analysis, the recording was downloaded from Vimeo.com and uploaded onto Microsoft Stream, a password protected service within the UCL system (N drive), to produce a loose transcript. Appropriate data protection procedures were followed for the use of this data. While 'research purposes' was not listed explicitly on the original consent form used by Rosetta Life, the further uses listed, including education, awareness raising and publicity, were extensive enough to deem that it was suitable.

This transcript was then compared against the original recording and amended to ensure that it was an accurate representation of the dialogue. This transcription was basic, noting only what was said by the participants, facilitator, and the audience, as well as aspects such as laughter.

A limitation of this method is that I did not have any say in the questions that were asked, who answered the questions or the set up and organisation of the session. In essence, I played the role of a member of the public during the session. Therefore, there are aspects

of the session that do not fit with the research design utilised in this dissertation. For example, on one occasion, a leading question was asked to one participant. As this dissertation focuses on subjective experiences of participants, leading questions are not appropriate as they place the interviewer's opinion at the forefront of the question and limits the direction in which participants can take the answer.

3.3.3 Follow up interviews

Individual interviews were held with three participants who took part in the rehearsal sessions and the live performance. The aim of these interviews was to expand on themes that arose from the Q&A session, centring conversation around sharing a space with those in similar positions, experiences of trying dance/movement and experiences of sharing life stories with others in the sessions.

Interviews took place during an event already being held by Rosetta Life for participants of the project, at The Place. This is a space dedicated to dance performance, including multiple dance studios for hire. The reason for choosing this was to ensure that participants were not inconvenienced by having to make an extra journey, which may be more difficult due to living with lymphoedema. It also meant that they would be in a familiar environment with familiar people, so they would feel more comfortable. Each interview was conducted away from the main dance space being used for the day, in a small but open space. This space did get slightly noisy when classes emptied from various dance studios, but it did not affect the quality of the recording, and went some way for participants to feel like they were having an informal conversation rather than a formal interview.

Each interview lasted around 15 minutes. This is quite a short duration for an interview, but it was sufficient to maintain a balance between quality of information gathered and overall comfort of the participant. So, the increased comfort resulting from a familiar environment was beneficial to the interviews considering their short length, to ensure that as much time possible was spent talking about their experiences, rather than spending time on ice-breaking questions.

Interviews were semi-structured, with an interview schedule utilised loosely during each interview (Appendix 4). The use of semi-structured interviews is well suited for the researcher to be able to ask open-ended questions to gauge the thoughts of individuals within a larger group (59). In this case, participants had already engaged in a group discussion in the Q&A. The purpose of the interviews was to delve further into themes brought up within that Q&A, to understand individual experiences, so semi-structured interviews were deemed appropriate given the richness of data that they can give (60).

Participants were encouraged to lead the direction of the conversation as much as possible. This was due to the interpretivist epistemological perspective engaged by the study – each participant's experience of the intervention was subjective, and they should be able to talk about it in such a way. Conversation was only directed back to the original questions where necessary for the purposes of the research, or where there was a lull in conversation.

One limitation of conducting these interviews comes from the anonymisation of the Q&A data. Specific follow up questions to participants answers in that session could not be asked, as it is unknown who said what. Therefore, interview questions were more generic.

3.4 Ethical Considerations

This study has been given approval by the UCL Arts and Health Research Ethics Committee (reference number: 22823/001). Each data collection method was considered separately in terms of what ethical considerations needed to be made. The study is also registered in line UCL's Data Protection Policy (reference number: Z6364106/2022/06/117).

Informed consent was not needed for the observations conducted at rehearsal sessions. This was due to the nature of data collected - only general observations were made, and no identifiable information was collected.

As the Q&A session recording was posted onto a public website, informed consent was not needed for analysis of this data. Rosetta Life had collected informed consent from

participants for this session and the performance to be filmed and posted online (Appendix 3).

Informed consent for the follow up interviews was gained. At the event held by Rosetta life, participants were informed that there was an opportunity to take part in a brief individual interview and were provided with an information sheet (Appendix 1). They were given plenty of time to consider whether they would like to participate or not. Consent forms (Appendix 2) were given to those who were happy to take part. All signed consent forms were scanned and saved onto UCL network (N Drive), and the originals destroyed.

Individual interviews were audio recorded. Once these recordings were transcribed, they were deleted from the recording device, and the transcripts saved onto UCL network (N Drive). To maintain anonymity, any identifiable data was removed from the transcript, including names, locations, and institutions. Participants were referred to as 'P' and as identifiers such as gender and age were not being used for analysis, this method of anonymising rather than pseudonymising was appropriate.

Participants were made aware that taking part was voluntary and that they were free to withdraw at any time. They were made aware that if any information was given that suggested they, or someone else, may be at risk of harm, then appropriate bodies would need to be informed.

It was also important to consider that the group of participants were potentially a clinically vulnerable group. Research methods used were considered carefully to ensure the least amount of intrusion, and cause least discomfort to participants.

3.5 Reflexivity

It is important to consider my position as the researcher within this study, and how this may have had an impact upon its results.

Firstly, at rehearsal sessions, I was not a bystander but an active participant. I was often needed to assist in the sessions. While this was not part of the original research plan, I felt that to make participants feel most at ease it would be better to participate in the music and dance activities. Whilst I attempted to limit any influence over conversation held between participants and their actions, it would be naïve to say that my involvement had no impact, so this should be considered in interpretation of the results. My active participation may also have had an impact upon the quality of observations collected.

As this study utilises qualitative data, it is important to recognise that my own biases and views may affect its findings. I endeavoured to hold a neutral stance towards issues discussed and sessions observed, but I do acknowledge that this may not always be effective in interpretation and analysis, particularly considering it is carried out by myself as a lone researcher. Through participating in rehearsal sessions and in playing a role in the final performance, I also developed a working relationship with the participants.

3.6 Data analysis

Observations were collated into one document and formed into easily understandable sentences from the original loose field notes. Both the Q&A session and the individual interviews were transcribed.

Thematic analysis was used for each type of data and conducted separately. This analysis loosely followed the stages set out in Braun and Clarke (61). Analysis was completed by hand to maintain the creativity, reflexivity and subjectivity that was intended with the method of thematic analysis (62) . As this research aims to investigate phenomena from lived experience perspectives which are inherently subjective, it follows that research methods and analysis methods should follow suit, to properly understand such subjective experiences.

A deductive approach to this analysis was implemented. Themes were informed by literature reviewed prior to analysis. However, this deductive approach was not restrictive –

some unexpected themes emerged over the course of analysis that were not informed by prior study. To complete these thematic analyses, the transcripts were read and reread, to create familiarity with the data. Initial thoughts were noted down and developed into codes. These codes were then collated into themes, which are examined in the subsequent chapter.

4. Findings

This chapter will detail the findings of the data collected, including observations, Q&A, and interviews, with relevant links to literature.

4.1 Observations

Before moving on to the results of the thematic analysis of observations, the context of the running of the sessions should be understood (see Chapter 3.3.1 for an explanation of this).

From a thematic analysis of observation notes made at rehearsal sessions and the final performance, four main themes were identified: power of the shared experience; storytelling; appearance of confidence; and development of physical abilities.

4.1.1 Power of the shared experience

One of the first things that was noted from attendance at rehearsal sessions was the strong social element that existed. During lulls in activity, participants often initiated casual conversations with each other, talking about many aspects of their everyday lives. This would include, but was not limited to, dialogue related to living with illness such as recent hospital appointments.

Care was shown for and between participants, both through words and actions. Concern was shown by the group when there were unexpected absences at rehearsal sessions, or when group members were late. Effort was made to physically look after each other, such as holding open a heavy door for someone who was not feeling well on that day. A sense of camaraderie was present during the final performance between participants – a sense of 'we're all in this together'. They comforted each other when nervous, looking to each other for help and reassurance during the performance.

The existence of shared experiences between participants seemed an important factor in creating a sense of unity within the group. This was not necessarily because of shared experiences of illness. For example, during one rehearsal session, one participant began to sing an old pub song that they remembered from their past. Quickly, many other participants joined in, creating a sense of familiarity and comfort, and seemed to lighten the mood of the group through laughter. Music has been seen to be an important factor in dance engagement (37) and has the power to keep participants going when they are struggling (33). This observation upholds these findings.

While here it was music that improved cohesion of the group, group cohesion was also demonstrated through music performed together. In one session, a facilitator who was unfamiliar with the group thus far attended to assist in developing a song for the final performance. They commented unprompted on the unity of voices in song, using it as an example of how well the group worked together.

Sharing of experiences and the atmosphere of encouragement was not limited to participants. Audience members were visibly moved by the final performance and engaged well with the Q&A session. These reactions showed that the audience were invested in and supportive of what participants had to say.

4.1.2 Storytelling

Storytelling was central to all elements of the programme, including the rehearsal sessions, final performance and Q&A. Participants held respect for the voices and narratives of others in the group, listening intently when they were sharing. This was shown through the silence offered, and by eye contact with the person speaking.

Participants also used narratives to describe the effects the intervention was having on their personal lives. Life experiences were shared either contrasting or accompanying how participants felt about the activities they were taking part in. Interestingly, it seemed that different aspects of participants personalities and characters were highlighted depending on the activity.

4.1.3 Appearance of confidence

It is difficult to decipher feelings and social mechanisms that manifest internally, such as confidence, from participants through observations. However, factors such as body language can be observed, which can help to infer these factors.

When participants were able to use skills that they had already developed in their lives, they appeared more confident, for example when they were able to dance in a style that they had already experienced, or playing a familiar instrument. This was clear through the tone and pace of their speech when asked about the skill.

It was also observed that participants showed more confident body language when they were given a reason to feel good about what they were doing, such as when they received praise. Perhaps these two observations are linked, as when an individual feels confident, they are more likely to perform well, leading to praise.

This was particularly apparent leading up to the final performance. Participants were nervous of this performance, demonstrated by dialogue relating to lack of sleep in the nights leading up to it. However, they also said how glad they were that they did take part in the performance, regardless of these nerves.

4.1.4 Physical abilities

As an intervention based on dance and movement, it was to be predicted that there would be physical health benefits for participants. However, this was not expected to be directly observable, due to the qualitative nature of observations, and that this would be a long term process related to how a participant felt rather how they look.

However, short term health benefits were observed. During the rehearsal sessions, participants seemed to gain physical strength and ability when they were able to dance in pairs or small groups, as opposed to times they were dancing alone. Their movements were often more controlled and sustained, as well as extensions and stretches going further.

When it suited the needs of the performance, they would lean against each other, sharing resources and building each other up.

During casual conversations between participants, and between facilitators and participants, physical health benefits would often be referenced. Participants would comment on physical health differences they had noticed, comparing before and now. They would often express a sense of surprise in feeling a noticeable effect of the intervention.

4.2 Q&A

Three main themes were identified as a result of a thematic analysis of the participant Q&A. These were: sharing of personal experiences; community; and expectations versus reality.

It is important to remember throughout the discussion of these results that this relates to a dialogue between individual participants and audience members, as this will affect the tone and type of answer given.

4.2.1 Sharing of personal experiences

Throughout the dialogue, participants consistently shared personal experiences and narratives with the audience. These varied in style and type, but all were relating to their lived experiences of their illness and their everyday life.

Some participants recalled having difficulties taking part in various activities, whether those of daily life or recreational. One participant explained this:

> *'…when you're doing nothing with your life, you form a rut and you just sit indoors…'*

Joining the intervention was connected to allowing them to get out and about, enabling them to meet new people and get out of this *'rut'*.

Similarly, discourse centred around physical changes that influence daily living. One participant also described their experience of being wheelchair bound due to illness, while another talked about how their experience with illness caused them to have to stop dancing, something that they previously enjoyed. They explained how this led to feeling a lack of purpose:

> *'…you sort of felt like you've got nowhere to go and nothing to do…'.*

Participants often recounted their experiences within the healthcare system and biomedical care. These experiences seemed to either revolve around difficulties in receiving adequate care, or gratitude to specific medical practitioners.

Interventions provided through a biomedical institution were described as *'conventional'.* Receiving such care also seemed to be accompanied by a sense of duty or obligation. One participant describes their experience with an exercise programme here:

> *'…I've done exercise to do with the local hospital and I lasted about 2/3 weeks…what ended up happening is I had an accident. I had to stop the programme…'.*

The use of the word '*lasted*' suggests that this exercise is something that needs to be stuck out, rather than enjoyed. It also perhaps demonstrates the difficulties that come with non-personalised care.

One participant recalled their experience of being diagnosed with lymphoedema:

> *'…there was a consultant there that- he said yes this is lymphoedema, he said, but you know they don't look after these people properly, he said it's not recognised…'*

This extract reflects findings that lymphoedema is a relatively misunderstood and unrecognised condition, with limited knowledge of it within the medical community (17, 18), and that those with lymphoedema often face difficulties with diagnosis. '*They don't*

look after these people properly' is a particularly concerning phrase, and would unsurprisingly create much anxiety for those hearing it

Participants did not seem reluctant to open to the audience about their personal struggles and stories. One participant relayed feelings of insecurity that have been dissipated by the group intervention:

> *'…it's given me a lot of confidence that I didn't have 'cause everyone sort of thinks I'm this big brash person that knows everything…but inside I'm not as secure as you think I am…'*

Participants often referred to these stories and experiences, told by themselves or others, in a positive light. They were encouraged to do so by activities held during the sessions. One participant described a picture card activity, where one card that they saw brought back a memory of a family holiday – *'gradually…[the facilitators]…got little by little bits out of us'*. Another participant described the group members as all having *'…our own story to tell…*'. Not just to keep inside, but to share with others:

> *'…you've got something inside you and you want to give it not only to yourself or to your family, but to other people who's got different things…'*

4.2.2 Community

Throughout the Q&A, participants referred to themselves in a collective sense, opting for the pronoun 'we' rather 'I' in many contexts. This is a signifier of the sense of community participants seemed to find through the intervention and is supported by comments made by participants. For example, one of the first answers given by participants explained how they have *'…grown really close together…'* and how they *'…are like a family now…*'.

Participants also noted their shared experiences of illness and how this lends itself to understand each other well:

> *'Every time we came together, we got more and more into each other, understanding each other…but what was also really funny…we all sat down at the same time because we're all tired at the same time…'.*

> *'…I was able to share with others because we all basically think the same.. but we know what we're thinking we can look at each other and know what we are thinking, but you look at us you've got no clue what we're doing in our-inside our minds…'.*

These extracts show the understanding that can come from having shared experiences and perhaps the knowledge that they were all patients at one healthcare facility. They were an already existing community pulled together by this intervention. These two findings support the idea that that sharing a space with those who have had similar experiences, whether talking about those experiences or not, can create a sense of comfort (33).

However, participants also commented on the variety within the group:

> *'…this is a funny group because we are-we are so different, different nationalities, different characters and everybody has something else…'*

Participants thanked lymphoedema specialists, as well as organisations providing these sorts of interventions such as Rosetta Life. It seems that it is not only those who have shared lived experiences of illness that are integral to forming a tight knit community, but also those who work to understand these lived experiences and support the right direction for an individual. For example, one participant describes an interaction with a previous practitioner:

> *' I was on a project to do with weight loss… she was amazed about what I was actually doing and then she inspired me greatly and said that maybe I should do things for myself…'.*

Similarly, participants were grateful to those who had introduced them to the group. This was common, suggesting that without these pathways, participants would have found it difficult to access the intervention. One participant commented that '*…there are places out there that can help support and uplift and nourish…'.* Arguably other factors in their ability to help are signposting, availability and access.

Participants noted that as a result of the intervention they were '*getting out and meeting people'*. It is interesting to note that the type of intervention was not mentioned here, only that it gave the participant a reason to get out of the house. However, this was met with some reservation by some participants at first: *'…who's that person I gotta remember new names now…*'. However, these objections seemed to be dispelled quickly.

One participant stated their need to separate themselves from the outside world, in this case by painting and drawing: *'...it has saved me from, you know, the bombardment you get in real life from the television and everybody around you…*'. This dance intervention provided the same sense of comfort.

4.2.3 Expectations vs reality

Many answers given by participants regarding the intervention mention feelings of uncertainty. Participants recalled nervousness *('…I was a bit nervous when I came first…'*), reluctance (*'…I was quite reluctant to join this programme because they said it had like dancing in it…'),* and doubt (*'…when I first went there I wasn't very sure what was actually going to happen…'*) before attending their first session. In most cases, these participants recalled these feeling dissipating within the first couple of sessions.

One participant commented that the facilitators of the intervention were '*…just like normal people…'*. This surprising revelation suggests initial reservations over the type of intervention, or a preconception of those who run them. The word '*conventional*' was used to describe an intervention used at a biomedical institution (section 4.2.1). These two

phrases together suggest that the dance programme participants were involved in in this programme is considered as unconventional.

Throughout the Q&A there was discourse surrounding working hard to achieve the goal of the final performance:

> *'…[we] decided we were going to enjoy it and that's what happened…'*

This quote suggest that participants made a conscious decision and subsequent effort to be as involved as they could, despite any reservations they might have. This implies that they were not only going along to the sessions because it was good for their health or wellbeing, but that they were invested in the final outcome.

One participant described their journey to recovery as being '*…an opportunity to just gently- I always call it baby steps- to spiral up…*'. This represents an awareness that there is no short term fix to their condition, and recovery is not a quick process.

Despite initial reservations, participants found themselves looking forward to the session each week and found comfort in those around them and the activities they did. Part of this was due to the sessions being '*safe*' and '*gradual*', suggesting that the environment that such activities are carried out in is vital to its effectiveness. Similarly, another participant related looking forward to the sessions to being made to feel welcome.

Physical health benefits of taking part in the intervention were frequently noted:

> *'…you didn't just get the day that you did it you felt better…it was four days after you're still loose in your body and you can walk around and that's a revelation to me…especially after conventional exercise not really working for me…*'

> *'…the next day after doing the physical exercise I was able to walk a bit better… and then I started to look forward every Tuesday to come in, not only for the exercise and everything but to meet each individual…'*

'…our bodies are moving more than we've ever, ever, ever done. I'm bending, I'm straightening…I've fell over and hurt my shoulder but when I'm doing this the shoulder don't hurt…'

The third extract here suggests the distractive nature of the intervention. Perhaps it is a combination of the physical activity and the mental distraction that assists in pain management. It certainly supports the finding that exercise is a viable way to manage chronic physical pain (29).

4.3 Interviews

From the thematic analysis of the interview transcripts, five main themes were identified: induced emotions; autonomy; the individual, community and wider society; experiences of illness; and creativity through intervention.

4.3.1 Induced emotions

The intervention was seen by participants to lift their moods, and provide a sense of hope, with one participant describing it as '*sunshine at the end of the road'*. This is consistent with findings from people living with Parkinson's Disease, where social dance was found to reduce anger and mood disturbances (40). Hearing and seeing other people's stories also inspired '*real enthusiasm'* from one participant.

One participant described a sense of guilt in relation the treatment of their lymphoedema: *'I used to think like you shouldn't be [fed up] you're getting really good treatment but every now and then you do…'.* Being around a community of those who feel the same was a relief to this participant, reducing this guilt that they felt.

The warmup session held in each rehearsal was thought to 'relax' the participants greatly. This might be due to its focus on breath work and mindfulness. One participant described

feeling free within the group, reducing fright. However, in complete contrast to the relaxation of the session, the performance prompted feelings of anxiety and nervousness.

4.3.2 Autonomy

Throughout the interviews, there was a sense of personal responsibility in relation to health and wellness, despite the life-limiting effects that chronic illness can have on the body. Participants described a sense of being stuck in a rut or a routine with illness, and this was something that they wanted to break out of, needing to do *'…something new…'*:

> *'…I thought you know what I- I really do need to do something about how I move… my movement and… I needed to do something else in terms of my lymphoedema as well I needed to get uh stuck- you get stuck in a routine with stuff like that…'*

There is awareness of being 'stuck' but it can be difficult to know how to and act to become 'unstuck'.

There is dissimilarity as to how biomedical and non-biomedical interventions were viewed by participants. Both were viewed to have elements of autonomy to them in that both required work to be done independent of healthcare professionals and intervention facilitators, but the former was seen relatively negatively, whereas the latter was seen positively.

> *'…you're sort of left to go home and look after yourself after that…'*.

This quote referencing biomedical care shows a feeling of abandonment when sent home to continue their treatment.

> *'…I don't just get out of bed in the morning I make sure I stretch…I never used to do that…I think it gave me those tools…'*

In comparison to the previous quote, the second shows a different mindset. Instead of being sent home to fend for themselves, they are given tools that they can use proactively. This made one participant feel like they were '*using [their] own initiative'* – an empowering feeling when it comes to personal health.

Another participant explained that when taking part in movement sessions they were able to go at their pace, not being '*forced to anything that [the] body won't allow*'. They are trusted to make decisions regarding their own health, a concept that can sometimes be lost in the healthcare system. This corroborates that when using dance in health interventions, dance routines and practices can differ between participants depending on their individual ability and mobility (37).

Participants seemed to be able to gain some control over their thoughts and feelings regarding stepping outside their comfort zone. In relation to the live performance one participant noted:

> *'…I just thought…I was just gonna have to get used to the idea that I didn't enjoy the performance but the rest of it was brilliant…'*

An aspect of increasing autonomy seemed to be gaining the ability to let go of things that cannot be controlled. One participant summed this up while talking about the intervention itself:

> *'…with something like this I think it's something you let go it's a process… and you shouldn't try and make a beginning a middle and an end of this because you're going to get let down and you let it show you rather than dictate.'*

This sentiment was reflected later in reference to living with illness:

> *'…we were able to come out, able to share our story…different ways of suffering and how we accept our different suffering in different ways…'*

The intervention was influential for participants in gaining skills of self-reflection and self-realisation. It also improved confidence in everyday life for participants. One participant talked about being able to stand up for themselves more, speaking assertively about their wants and needs, which was something that they hadn't previously felt adept in. They connected this change directly to taking part in the intervention and its prompting of narrative telling.

It is important to consider socio-economic determinants of health (63, 64). One participant commented on the small size of their flat in relation to why they don't get much movement into their day. When this is coupled with limited motivation to go out because of illness (*'…when you're ill and you don't feel like going out…*'), it can be seen how illness and symptoms may be aggravated beyond an individual's control.

Another participant talked about having to decline work when they attended the intervention, which would reduce their income. There had to be a choice between taking part in the intervention that was beneficial to mental and physical health and wellness and going to work. Some will not have this choice. This is interesting considering the finding that having a health status as less than good is associated with a reduction in income (21), as perhaps it is not only the direct effects of the illness but the societal constructions that discriminate against those who are ill. However, this does raise a question about whether dance is an economically viable option to benefit wellbeing and physical health (42). It certainly suggests that the impact of the timing of interventions should be considered, if they are to be capable of adequately supporting those who are in employment.

4.3.3 The individual, community and wider society

It was made clear by participants throughout the interviews that the sessions invoked a welcoming environment. Part of this was created through interactions between individuals in the group. *'…Don't worry it's just us…'* was one participant's reaction to another joining the session, stating that they were nervous.

A sense of familiarity seemed prevalent due to the group members being of similar age and from the same clinic. This led to a mutual supportiveness, and a sense of *'…if they can do it, I can do it…'*.

> *'…it's sometimes good to support other people and sometimes to feel like um you need a bit of support yourself…and think like once that once you start to see those exchanges going on I think it made it easier…'*

This extract shows the self-sustaining atmosphere of support, demonstrated by one participant describing feeling comfortable with those in the group as they were able to sit together in breaks, drinking hot drinks and chatting. Open-mindedness seemed to be a factor in this development of a positive group dynamic.

One participant explained how taking part in the movement and dance meant that they were expressing themselves and their body for how it is in the now, as opposed to feeling self-conscious. Similarly, they talked about how they were able to show a side of them that was not usually presented to the world – a more vulnerable, shy side. Another communicated how they did not worry about their appearance during the sessions, suggesting that in the outside world this was a common concern. This fits with findings that those living with lymphoedema report difficulties with self-image and feeling conscious of their physical appearance (17-20).

It was evident that group members felt accepted due to shared understanding, circumstances and experiences. Nevertheless, the individual differences apparent within the group were also deemed helpful to participants in dispelling ideas they had themselves of living with illness and what it looked like or how it should be performed.

> '*I felt people was always looking at me looking at my feet looking at my footwear…and…but then when I look round and I see you know the people that was there and they all have lymphoedema but… they were all different uh… maybe someone was wearing the proper shoes and somebody- I'm not saying my shoes is*

not proper- but you know what I mean it was different you know how everybody was different'

This participant describes viewing a fellow group member wearing '*proper shoes'*. It can be assumed that they are referring to shoes that are deemed normal by society, such as trainers or boots. For this participant, such footwear does not fit properly or is not comfortable. Their own footwear choice, while still being '*proper*', is one that is not deemed as fitting the social norm. This corroborates the finding that a contributing factor to issues with self-image is an inability to find well-fitting clothes (20).

It's important to note in relation to individual differences the subjectivity in effectiveness that comes with any intervention, that one participant comments on: *'…personally I think I respond well in groups and uh some people don't, some people do…'.*

One participant described how within the group they seemed to understand each other's needs without them having to be voiced. This understanding contrasts to other significant people in participants lives, such as spouses, who are viewed as not having the same empathy:

'…I'm at home and I say to my husband 'oh I'm tired' he says 'you're always tired'…I say 'but I really am tired' 'yeah but you say that everyday' and I think I can't even say that…'

This supports the suggestion that dance interventions are beneficial in creating a supportive space without external expectations (36). In this example, the participant's husband does not understand fully the extent of the tiredness, so is perceived as still holding external expectations, which are not held by those within the group.

Participants appeared to develop a sense of responsibility and obligation to their fellow group members early on into the intervention. One participant described feeling nervous about the group sessions but did not want to *'…let the side down…'*, so just got on with it anyway.

One participant articulated gaining perspective as a result of listening to others' stories. This sharing of personal experiences, feelings and thoughts also was noted to assist in the fast development of friendships and closeness within the group.

4.3.4 Experiences of illness

Experience of illness does not simply relate to the direct physical symptoms of a particular illness such as lymphoedema, but also its social, mental, environmental and economic accompaniments:

> *'…I think the whole lymphoedema thing has affected me but then it's how I behave and how I've become because of it and the change that's happened…'*

Having an illness was equated to having '*baggage*' by one participant. This implies that it does not form a part of their identity, rather it is something that they need to carry with them externally. It is interesting to consider here the theory that disability is not due to the illness or condition but instead the social conditions in place that affect those who differ from the 'norm' (22, 23) (see also section 2.1.1.1). Perhaps this '*baggage*' would not be so heavy if societal models were not set up to cater for only those who fit within a capitalist social norm.

There is limited knowledge of lymphoedema within society:

> *'… I didn't know anything about lymphoedema before this happened I didn't even know there was something wrong with my legs until um… I saw it if that makes sense…'*

This uncertainty seems to also be prevalent even when an individual is diagnosed:

> *'…[participant] is quite a large size and I thought am I gonna be like that is that going to be me…'*

Perhaps this worry is a signifier of the possible societal stigma that exists of obesity (26). Regardless, the intervention was said to provide participants with a space to ask questions of those in similar positions and provoke further learning about lymphoedema. These are both opportunities that they may not have had otherwise.

However, the intervention space was not one in which participants wished to focus on their illness. One participant talked about not joining a lupus association for the reason that they didn't want to be *'…around a lot of people that complain about being in pain…'*. Another said that it was helpful meeting people who weren't *'…miserable looking*…'. With the focus being on creativity and dance/movement, it enabled participants to be something other than ill. It was reported that when participants were in the sessions, often their pain would dissipate to an extent. This was linked to '…*living what was happening…'*.

This supports the practice that participants who enter the intervention space are no longer seen as a person living with illness, but a creative (33, 37), or in this case a dancer and story teller. They are breaking societal boundaries and adapting their identity to a new space where they are seen as capable.

Similarly, one participant said that as a result of the intervention:

> *'…I'm sure the doctor will tell you I haven't been running in and out saying I need some more pain killers or that because it's not like… I know when I need a painkiller I have to take it but I begin to accept more you know this is it and how it's going…'*

The biomedical treatment of lymphoedema is depicted as '*very hands on',* being poked and prodded and checked up on. So-called traditional exercise options that are offered, such as going to the gym, are seen as intense and daunting, with participants explaining that they did not find it helpful. One participant commented that they *'…don't think that medicine is always the only cure…*'.

The importance of being able to maintain a healthy mental attitude in order to gain the most out of treatment was remarked on:

> *'What was really important… [was you] were able to maintain a healthy mental attitude so that you would carry on your own treatments at home…'*

When unwell, the motivation required to do this may be hard to find. One participant described being unable to get up and move around because their legs felt so heavy. Another talked about *'…sitting at home feeling bored [and] depressed…'*. In this way, the intervention was seen by one participant as *'…essential to part of [their] healing…'*, as they were doing movement exercise without realising it.

Physical benefits of the intervention are not final as the intervention needs to be continuous for the effects to be long lasting. For example, one participant commented on her physical fitness during the intervention as being good, whereas *'…3 months later it's gone back to what it was…*'.

Biomedical treatment can become depersonalised and hence can feel lonely. The reasons for this depersonalisation require further exploration. One participant, while pleased with the efficiency of the clinic that they attend, observed that due to efficient appointments, they are not able to see or talk to any other patients that may also attend the clinic. There is no unprompted and unscheduled casual conversations occurring in waiting rooms, for example, so they were pleased to get this interaction through the intervention instead. Talking to others about their experiences of illness also seemed to be liberating for participants, both in terms of finding new coping strategies, and in feeling truly seen by others.

4.3.5 Creativity through intervention

All participants described feeling uneasy about the intervention in the beginning, both before the intervention began and during the initial few sessions. One participant expressed

concern as to whether they would be able to continue with the intervention, while another stated how it was '*too close to home'* for them to begin with.

Part of this apprehension may be due to uncertainty surrounding what the sessions might involve, given that most participants were unaware of the organisation or had not taken part in such activities previously.

> *'…I didn't know what to expect I thought you know you're gonna go there and they're gonna be doing exercise running here jumping here uh and different people telling stories or writing and all these things…'*

However, participants settled into the creative mindset. One participant voiced that while they felt apprehensive of taking part in creative activities, telling their story to the group was easy, because they *'…couldn't get it wrong…*'. They felt comfortable within the group to be truthful about who they were and where they came from. They also expressed surprise that what they had told '*honestly'* and '*innocently*' could be brought into a performance. One participant said that they *'…still [couldn't] believe that [they] actually did [the performance]…*'.

It provoked recall of memories that participants may have pushed to the back of their minds, and enabled them to describe their experiences not only to those in the group but also to their family and friends.

Participants also benefited greatly from hearing the narratives of others in the group, finding it 'inspiring' and 'touching'. One participant felt *'…shocked about how brave some people were some weeks…*'. This prompted deep listening from participants, and assisted them to produce creative ideas, '*…because we [were] working together and talking to each other about an event that had happened…*'.

Movement involved in the intervention was seen to draw out people's creativity and creative thought. It enabled and gently pushed participants to be active *'…that [they] haven't done for a long long long time…*'.

Conversely, the performance element of the intervention was not seen in a particularly favourable light throughout the interviews. One participant described being unhappy with their own performance, and the need to '*fix*' parts they didn't like. This feeling seems to be at odds with the aims of the sessions themselves, where there is no right or wrong. It did not promote the same exploratory nature as the rehearsal sessions – one participant described shutting down during the performance and just doing what they were supposed to. Differences between dance for health and athletic/competitive dance (see section 2.1.3) may be greater than anticipated and may suggest that overriding motivations are conflicting.

In comparison with the freedom felt expressing personal narratives within the sessions, participants felt more hesitant to do the same with a live audience, especially when this included family and friends who had not previously been privy to the experiences shared – '*…I was a bit scared how the reaction was gonna be and what was gonna happen…*'.

However, on reflection, the participant thought that it was a good way to be able to do this. Perhaps the finding that narrative messages can be an effective way of shifting responsibility and reducing public stigma towards those struggling with opioid addiction and obesity (26) should be considered here. While lymphoedema is a separate health condition, the same principles may be applicable. Narrative messages may increase relatability, making an individual's experience more understandable not just to onlookers, but also those influential in the lives of individuals living with illness.

5. Discussion

5.1 Is the presence of a supportive community important for those living with lymphoedema?

Living with lymphoedema can be seen to be socially isolating. Not only does its physical symptoms foster behaviours that lend themselves to isolation, such as difficulties in and limited motivation to leave their living space, but it can be challenging to relate to existing social support networks of family and friends, who might have limited understanding of the illness. From the thematic analysis findings, it can be seen that the creation of a supportive community through this intervention was vital for participants, dispelling the idea of being '*the only one'* struggling. This reiterates findings that 'being in the same boat' as others is a key element in peer support (65). Without such interventions, individuals risk alienation.

Being a part of a supportive, understanding community enables individuals to validate their feelings regarding illness, whether positive or negative, and feel free to be authentically themselves. This supports the social comfort found from being around those with shared experiences (33), and is strengthened by the reciprocal interest shown in listening and speaking about personal narratives.

Individuals are also able to gain practical information regarding lymphoedema. Through interaction with others, and in having opportunities to observe and ask questions, they can better understand current and possible future symptoms. Effective coping strategies, both physical and mental, can be shared. When presented by a trusted source an individual is probably more likely to follow through. This follows findings that friendships provide key support for health behaviour change (65). It is interesting that such coping mechanisms were not described by participants as being offered by medical professions, only biomedical treatment.

It could be predicted that sharing experiences of lymphoedema and illness could go some way to creating this community. This is not the only factor, with individuals also citing commonalities in interests and backgrounds, but the common denominator in all factors mentioned is cohesion. Whether state of mind, interests, or experiences, this cohesion of

character seems to be important for the creation of a supportive community that allows participants to get the most out of an intervention. Perhaps this is a reaction against being the 'other' in a society that has limited understanding of illness experiences – individuals seek out those who they can relate to, so that they can experience 'social togetherness' (36). The sharing of narratives and experiences through the dance performance allowed the construction of an extended community. A shared interest in the performance and subsequent Q&A session allowed the true expression of participants selves.

The existence of a supportive, freeing space allows individuals to gain a stronger sense of self, to re-evaluate priorities and increase self-confidence. Considering that living with illness often initiates a change or repositioning of identity, these two individual developments are pivotal so that an individual can adapt well. This adaptation is a central concept in living well with illness (66). Experiencing the intervention as a group is a joyful experience.

Being part of a close-knit community is often accompanied by a sense of obligation to other members, which was apparent in this intervention group. This may be beneficial in a practical sense, as it may provide motivation for participants to continue with the intervention, as they do not wish to 'let others down'. Such human connection can be powerful in motivating participants to come back repeatedly, as it can sometimes be easier to do things for other people than for oneself. Considering that consistency is important in terms of upholding physical health improvements, any factor that promotes attendance is beneficial.

5.2 How do wider societal influences impact upon individual experiences of lymphoedema?

It should first be noted that the impact of societal processes of participants was not specifically measured in this dissertation, but is indirectly apparent through answers given and comments made.

As stigma is a societal construct, it can be said that each member of society has some manifestation of it, whether conscious or unconscious. So, it is probable that health-related

stigma is active even in those living with illness. Individuals living with lymphoedema have perceptions of this stigma, which exhibits in their opinions, thoughts, and actions. Individuals feeling of guilt for negative thoughts surrounding lymphoedema and its treatment suggests the holding of certain expectations that cannot be met. It is conceivable that these expectations are formed because of societal expectations, as well as pre-illness experiences and conception of the self. There is an imbalance between the role that the individual wishes to or is expected to play, and the role that they can play. When considering this from a phenomenological point of view, particularly that of illness (46), it can be considered how feeling guilt about negative feelings despite good treatment may be a result of disparity between thoughts about the healthcare system before experiencing illness first hand, and after.

In internalising perceived societal opinions about what is deemed normal, individuals doubt their own appearance and behaviour, sometimes resulting in 'hiding away'. It is not a stretch to suggest that this doubting has a negative impact upon self-esteem and confidence.

An undercurrent throughout the findings of this dissertation is the existence of socio-economic determinants of health. With factors such as living conditions and employment being cited by participants as causing difficulties or disruption to daily coping strategies and attendance at interventions, economic socio-economic positioning can have an impact upon recovery and coping with illness. Long term unemployment contributes to poor health (63). If a person already living with lymphoedema struggles to gain or maintain employment (20), or has to decide between work and attending an intervention (see section 4.3.2) , might this cause even more difficulties in recovery and preservation of a good life?

The structure and operation of the healthcare system, on which people with lymphoedema might rely, has impacts upon their experiences of illness. Because of increased pressure on the health services, efficiency is often key. In one participant case, this translated into such an efficient appointment system that they lost casual interaction with others that they previously had in the waiting room and around the clinic. Questions can be hence raised as to the priorities of the healthcare system, and their effects of patient care and satisfaction.

Additionally, the findings of this thesis support the lived experiences documenting a lack of knowledge and support from medical facilities (17, 18), both in diagnosis and dealing with symptoms.

5.3 How effective an intervention is a dance/movement project for people with lymphoedema?

Through the intervention, individuals were able to learn, and create lasting tools to cope with mental and physical symptoms of lymphoedema. In comparison to being sent home with biomedical 'homework', the skills learnt in this intervention empower individuals to think differently about their health, which goes some way to increasing autonomy. The tools are to be used to not only improve physical health, but to assist in changing outlook. This autonomy is important, considering that there is much empirical literature to say that self-managing chronic illness successfully is related to improved psychological and physical health outcomes (67).

An increased sense of autonomy may be helpful for individuals in their ability to adapt to change. If they can position themselves as capable and in control, accepting what is out of their control such as impediments in their lymphoedema journey and increased pain, may come more easily. An example of this is the participant who described being less reliant on the doctor and medication (section 4.3.4). The intervention also improved confidence for individuals taking part, encouraging looking at the self as remarkable, regardless of their life with illness. This is an important rejection of societal impressions.

It is interesting to consider this through the lens of the social psychology theory of self-determination (68), for which autonomy is necessary (69). Self-determination theory has been used to examine health behaviour change, finding that internalisation of the worth and regulation of healthy behaviours was integral in such behaviour change (70). When participants experience the effects of stretching and small movements for themselves, they are more likely to continue such activities under their own steam, especially when social support is present (65). Research shows that individuals who are more creative tend to be

more self-motivated (71). Therefore, the creative thought that is inspired by this intervention can be a helpful factor for individuals to get out of the 'rut' described by participants.

The intervention had short term physical health effects, in terms of pain management when completing activities within the session. The reasons for this release of pain are unclear, whether due to the interventions distractive and immersive nature, or because of general physical wellbeing improvements. However, in order to maintain physical health improvements, it is thought that consistency is important. Thus, it could be said that the abrupt end to the movement sessions following the live performance, while understandable in terms of funding and availability of facilitators, was not to participants' advantage. Perhaps if a programme such as that studied is not able to be continued dependably, participants should be signposted to similar interventions that they may be able to join. The need for longer term sustainable provision of creative health interventions in unmistakable.

The concept of the performance itself may not fit so well with the aims of the intervention, and the principles of dancing for health. Popular constructions of dance performance are that it is aesthetically pleasing. While the aims of this intervention and dancing for health in general do not subscribe to this expectation, the danger is that participants do, and so hold more pressure on themselves to perform well. This concern was not specifically mentioned by participants, but can be assumed to be influential considering the difference in outlooks between '*not being able to get it wrong'* in the rehearsal sessions, and needing to '*fix*' things that they thought were wrong with their performance. When participants describe 'shutting down' during the performance in order to get through it (see section 4.3.5), it is understandable that they might not gain the full benefit of being open and sharing their narrative with the audience as they are just going through the motions.

On the other hand, it has been said that autonomy is not only based on self-acceptance, but also reliant on the individual having a goal and the powers to achieve this goal (69). Keeping this in mind, the performance may have been less beneficial for participants immediate enjoyment and perceptions of themselves, but more beneficial for a longer term goal of increasing autonomy and subsequently self-determination. The question might be asked

whether the performance and its use of narrative plays a role in enabling individuals to converse more freely with friends and family members, to increase their understanding of lymphoedema (see section 4.3.5). This may reduce the pressure of perceived external expectations on individuals with lymphoedema (see section 4.3.3), increasing individual control over actions. Conceivably, the need to include this performance is connected to the need to gain funding. Many interventions such as these are reliant on external funding, and hence need to have a tangible outcome to present to potential funders.

Unfamiliarity with the concept of dancing for health, and performance in general, causes apprehension and reluctance to take part in such interventions. This was apparent in the sample used in the dissertation. In some cases, this may be a cause for concern, as it may cause non-attendance. The fact that this did not occur often in this sample can in part be attributed to the referral coming from a known, respected and knowledgeable source, and retention of participants to the accepting and welcoming atmosphere created.

This establishes the case for clearer and more referral pathways, as well as a higher abundance of such interventions. Participants may have been slightly less apprehensive and would know what to expect if such interventions were more widely known. As the benefits of such an intervention can be undoubtedly seen, the higher number of qualifying individuals referred the better.

5.4 Limitations

It is important to note that, while recognising that there may be correlations and similarities to research regarding other chronic illnesses, this dissertation is focused on lymphoedema, and does not seek to generalise results to other health conditions. It also does not seek to provide any empirical data and does not provide finite answers to questions asked. It views lived experiences as valuable in their own right, and seeks to understand the nuances of this.

As participants were recruited through a third party, I had limited influence over data collection arrangements. Ideally, the sample for the interviews would have been larger.

However, considering the commitment to ensuring participants did not incur any unnecessary inconvenience, this was not feasible, as this was the number of participants that were present at the event held by Rosetta Life.

I adopted a phenomenological perspective in this dissertation. While this was important to gain information regarding the lived experiences of those living with lymphoedema, it is likely that my own biases and preconceptions had an impact upon the collection, analysis and presentation of data. This should be considered in interpretation of this dissertation.

6. Conclusion

This dissertation presents an insight into the lived experiences of people living with lymphoedema, in relation to a dance and movement project. It examines the creation and impact of a supportive community, potential wider societal impacts upon experiences of lymphoedema, and expands the research base on the applicability of such interventions specifically for people living with lymphoedema.

From the point of view of those living with lymphoedema, a dance/movement intervention is beneficial for both physical and mental health and wellbeing. The development of a supportive community through the intervention was particularly notable, allowing individuals the freedom to express their experiences in whichever way they pleased, without the fear of judgement or misunderstanding. Additionally, the increase of personal autonomy as a result of taking part in the intervention is a significant undercurrent throughout the findings of this dissertation, which has a contributory impact on improving health outcomes.

Completing the intervention as part of a group with shared experiences goes someway to dispel effects of perceived societal stigmas and opinions. It could be said that it helps to rebalance an individuals' socially imposed expectations with what is enjoyable and helpful to them. However, outside influences impact an individual's experience of the intervention, and the benefits felt as a result. Environmental, social, and political factors play a part in determining access, engagement and follow through with principles learnt. For example, the need to work can limit access to many interventions offered, and taking part in interventions can limit access to work opportunities.

6.1 Possibilities for further research:

The inclusion of quantitative data collection and analysis could have provided further insight. I would argue that lived experience voices are just as valuable as empirical data, but considering the economic and political landscape at present, providing clear cut answers

and demonstrations of the effectiveness of creative health interventions is necessary to extend them to more communities who could benefit.

This dissertation demonstrates the importance of looking at health in a holistic way. This includes the sociological and political structures that inform the practices of health care providers. As such, further research could be suggested into how creative health interventions can sustainably fit into the political and economic landscape of the UK going forward. For example, work could be done to identify the most appropriate structures which have the ability to implement, facilitate and sustain the need for increased referral pathways and increased provision of creative health interventions, as demonstrated in this dissertation. Considering the strong approval of this intervention from participants, further research could also be undertaken to extend the evidence base to other health conditions and focuses.

References

1. NHS-England. House of Care – a framework for long term condition care 2022 [Available from: https://www.england.nhs.uk/ourwork/clinical-policy/ltc/house-of-care/.
2. LSN. What is lymphoedema? 2022 [Available from: https://www.lymphoedema.org/information/what-is-lymphoedema/.
3. Rosetta-Life. What we do 2022 [Available from: https://rosettalife.org/what-we-do/.
4. Anderson M, Pitchforth E, Asaria M, Brayne C, Casadei B, Charlesworth A, et al. LSE–Lancet Commission on the future of the NHS: re-laying the foundations for an equitable and efficient health and care service after COVID-19. The Lancet. 2021;397(10288):1915-78.
5. BMA. Billions needed to tackle huge NHS backlog and reverse years of underfunding, says BMA ahead of Comprehensive Spending Review 2020 [Available from: https://www.bma.org.uk/bma-media-centre/billions-needed-to-tackle-huge-nhs-backlog-and-reverse-years-of-underfunding-says-bma-ahead-of-comprehensive-spending-review.
6. NHS-England. Next steps on the NHS five year forward view. 2017.
7. WHO. Constitution 2022 [Available from: https://www.who.int/about/governance/constitution.
8. Chatterjee H. Introducing creative health 2022 [Available from: https://www.prospects.ac.uk/jobs-and-work-experience/job-sectors/healthcare/introducing-creative-health.
9. Howarth L. Creative health: the arts for health and wellbeing. Perspectives in Public Health. 2018;138(1):26-7.
10. National-Academy-for-Social-Prescribing. What does the NHS think about social prescribing? 2021 [Available from: https://socialprescribingacademy.org.uk/about-us/what-is-social-prescribing/what-does-the-nhs-think-about-social-prescribing/.
11. OECD. United Kingdom: Country Health Profile 20192019.
12. Fancourt D, Finn S. What is the evidence on the role of the arts in improving health and well-being? 2019.
13. Clift S, Phillips K, Pritchard S. The need for robust critique of research on social and health impacts of the arts. Cultural Trends. 2021;30(5):442-59.

14. Fancourt D, Warran K, Aughterson H. Evidence Summary for Policy: The role of arts in improving health and wellbeing: Report to the Department for Digital, Culture, Media & Sport. 2020.
15. Cueni LN, Detmar M. The lymphatic system in health and disease. Lymphat Res Biol. 2008;6(3-4):109-22.
16. NHS. Lymphoedema: causes 2022 [Available from: https://www.nhs.uk/conditions/lymphoedema/.
17. Doubblestein DA. The lived experience of primary lymphoedema: a phenomenological study of personage and caregiver. Journal of Lymphoedema. 2020;15(1).
18. Morgan PA, Franks PJ, Moffatt CJ. Health-related quality of life with lymphoedema: a review of the literature. International Wound Journal. 2005;2(1):47-62.
19. Williams AF, Moffatt CJ, Franks PJ. A phenomenological study of the lived experiences of people with lymphoedema. International Journal of Palliative Nursing. 2004;10(6):279-86.
20. Stolldorf DP, Dietrich MS, Ridner SH. A comparison of the quality of life in patients with primary and secondary lower limb lymphedema: a mixed-methods study. Western journal of nursing research. 2016;38(10):1313-34.
21. Dismuke CE, Egede LE. The Impact of Cognitive, Social and Physical Limitations on Income in Community Dwelling Adults With Chronic Medical and Mental Disorders. Glob J Health Sci. 2015;7(5):183-95.
22. Scambler G. Health-related stigma. Sociology of health & illness. 2009;31(3):441-55.
23. Oliver M. Understanding disability: From theory to practice: Bloomsbury Publishing; 2018.
24. Link BG, Phelan JC. Conceptualizing stigma. Annual review of Sociology. 2001:363-85.
25. Cacioppo JT, Hawkley LC. Social isolation and health, with an emphasis on underlying mechanisms. Perspectives in biology and medicine. 2003;46(3):S39-S52.
26. Heley K, Kennedy-Hendricks A, Niederdeppe J, Barry CL. Reducing Health-Related Stigma Through Narrative Messages. Health Communication. 2020;35(7):849-60.
27. Parsons T. The social system. New York, NY, US: Free Press; 1951. 575- p.
28. Varul MZ. Talcott Parsons, the Sick Role and Chronic Illness. Body & Society. 2010;16(2):72-94.

29. Graham R, Kremer J, Wheeler G. Physical exercise and psychological well-being among people with chronic illness and disability: a grounded approach. Journal of Health Psychology. 2008;13(4):447-58.
30. Sontag S, Broun HH. Illness as metaphor: Farrar, Straus New York; 1978.
31. Oransky I. Susan Sontag. The Lancet. 2005;365(9458):468.
32. Lam R, Wallace A, Burbidge B, Franks P, Moffatt C. Experiences of patients with lymphoedema. J Lymphoedema. 2006;1(1):16-21.
33. Brook J, Booth A. May I have this dance: examining a community based dance program for people living with Parkinson's disease. Research in Dance Education. 2020:1-15.
34. Olvera AE. Cultural Dance and Health. American Journal of Health Education. 2008;39(6):353-9.
35. Huang SY, Hogg J, Zandieh S, Bostwick SB. A ballroom dance classroom program promotes moderate to vigorous physical activity in elementary school children. American Journal of Health Promotion. 2012;26(3):160-5.
36. Duberg A, Möller M, Sunvisson H. "I feel free": Experiences of a dance intervention for adolescent girls with internalizing problems. International journal of qualitative studies on health and well-being. 2016;11(1):31946.
37. Butt CA. "Move your arm like a swan": Dance for PD demedicalizes Parkinson disease. Jama. 2017;317(4):342-3.
38. Cruz-Ferreira A, Marmeleira J, Formigo A, Gomes D, Fernandes J. Creative dance improves physical fitness and life satisfaction in older women. Research on aging. 2015;37(8):837-55.
39. Cox AE, Ullrich-French S, Cole AN, D'Hondt-Taylor M. The role of state mindfulness during yoga in predicting self-objectification and reasons for exercise. Psychology of Sport and Exercise. 2016;22:321-7.
40. Lewis C, Annett LE, Davenport S, Hall AA, Lovatt P. Mood changes following social dance sessions in people with Parkinson's disease. Journal of Health Psychology. 2016;21(4):483-92.
41. Kreutz G. Does partnered dance promote health? The case of tango Argentino. Journal of the Royal Society for the Promotion of Health. 2008;128(2):79-84.
42. Muro A, Artero N. Dance practice and well-being correlates in young women. Women & Health. 2017;57(10):1193-203.

43. Hackney ME, McKee K. Community-based adapted tango dancing for individuals with Parkinson's disease and older adults. JoVE (Journal of Visualized Experiments). 2014(94):e52066.

44. Goffman E. The presentation of self in everyday life. USA: Anchor Books; 1959.

45. Khan S. Erving Goffman, The Presentation of Self in Everyday Life (1959). Public Culture. 2020;32(2):397-404.

46. Carel H. Phenomology of Illness. 1 ed. Oxford: Oxford University Press; 2016.

47. Martin K, Groden M, Groden PM, Kreiswirth M. The Johns Hopkins Guide to Literary Theory and Criticism: Johns Hopkins University Press; 1994.

48. Rakoczi J. Schillace B, editor. Medical Humanities2018. [cited 2022]. Available from: https://blogs.bmj.com/medical-humanities/2018/08/07/book-review-phenomenology-of-illness/.

49. Carel H. Phenomenology and its application in medicine. Theoretical Medicine and Bioethics. 2011;32(1):33-46.

50. Schroeder K, Ratcliffe SJ, Perez A, Earley D, Bowman C, Lipman TH. Dance for health: an intergenerational program to increase access to physical activity. Journal of pediatric nursing. 2017;37:29-34.

51. Rocha PA, Slade SC, McClelland J, Morris ME. Dance is more than therapy: Qualitative analysis on therapeutic dancing classes for Parkinson's. Complementary therapies in medicine. 2017;34:1-9.

52. ENB. Dance for Parkinson's: English National Ballet; 2022 [Available from: https://www.ballet.org.uk/project/dance-for-parkinsons/.

53. Bryman A. Social research methods: Oxford university press; 2016.

54. Willis JW, Jost M, Nilakanta R. Foundations of qualitative research: Interpretive and critical approaches: Sage; 2007.

55. Accelerate. What we do 2022 [Available from: https://www.acceleratecic.com/what-we-do/.

56. Rosetta-Life. The Wishing Well. Twitter2022.

57. Hattersley A. The Wishing Well promotional flyer. 2022. p. Promotional flyer created by Rosetta Life.

58. Sprague L, Afifi R, Ayala G, El-nasoor ML. Participatory praxis as an imperative for health-related stigma research. BMC Medicine. 2019;17(1):32.

59. Adams WC. Conducting semi-structured interviews. In: Kathryn E. Newcomer HPHaJSW, editor. Handbook of practical program evaluation. 4922015. p. 492.
60. Harvey-Jordan S, Long S. The process and the pitfalls of semi-structured interviews: The Journal of the Health Visitors' Association. Community Practitioner. 2001;74(6):219.
61. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.
62. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health. 2019;11(4):589-97.
63. Marmot M. Health equity in England: the Marmot review 10 years on. Bmj. 2020;368.
64. Marmot M. Fair society, healthy lives: a strategic review of inequalities in England. London: University College London. 2010.
65. Aschbrenner KA, Naslund JA, Bartels SJ. A mixed methods study of peer-to-peer support in a group-based lifestyle intervention for adults with serious mental illness. Psychiatric rehabilitation journal. 2016;39(4):328.
66. Kralik D, van Loon A, Visentin K. Resilience in the chronic illness experience. Educational Action Research. 2006;14(2):187-201.
67. Gallant MP. The Influence of Social Support on Chronic Illness Self-Management: A Review and Directions for Research. Health Education & Behavior. 2003;30(2):170-95.
68. Deci EL, Connell JP, Ryan RM. Self-determination in a work organization. Journal of applied psychology. 1989;74(4):580.
69. Serdiuk L, Danyliuk I, Chaika G. PERSONAL AUTONOMY AS A KEY FACTOR OF HUMAN SELF-DETERMINATION. Social welfare interdisciplinary approach. 2018;8(1).
70. Deci EL, Ryan RM. Handbook of Theories of Social Psychology: Volume 1. 2012 2022/08/16. London: SAGE Publications Ltd. Available from: https://sk.sagepub.com/reference/hdbk_socialpsychtheories1.
71. Ceci MW, Kumar VK. A Correlational Study of Creativity, Happiness, Motivation, and Stress from Creative Pursuits. Journal of Happiness Studies. 2016;17(2):609-26.

Table of Figures

Figure 1: Rehearsal day at the performance space (56) 18
Figure 2: Promotional flyer for dance performance (57) 18

Appendices

Appendix 1: Information sheet for individual interviews

Participant Information Sheet for Participants

UCL Research Ethics Committee Approval ID Number: 22823/001

Title of Study: Exploring health narratives through dance and movement

---

Department: Arts and Sciences

Name and Contact Details of the Researcher(s):
Aimee Hattersley
uclqac8@ucl.ac.uk

Name and Contact Details of the Principal Researcher:
Dr Thomas Kador
t.kador@ucl.ac.uk
UCL Arts & Sciences
University College London
Gower Street
WC1E 6BT

You are being invited to take part in a research project, completed as part of a Masters (MASc) degree in Creative Health. Participation is entirely voluntary, and please take time to decide whether or not you wish to take part. Before you decide whether to participate, it is important that you understand why the research is being completed and what it will involve. Please take the time to read the following information carefully. If you wish to discuss it with others please do so, and please contact us via the above details if there is anything that is unclear or if you would like any other information. Thank you for reading this and considering taking part.

Purpose of the project

The aim of the project is to explore the impact of a dance/movement intervention for people with lymphoedema, led by Rosetta Life in conjunction with Accelerate.

Why have I been chosen

You have been chosen to participate because you are a participant of the Rosetta Life/Accelerate project.

Do I have to take part?

Participation is voluntary, so it is up to you to decide whether or not you take part. If you decide that you would like to participate, you will be given this information sheet to keep,

and be asked to sign a consent form. You are able to withdraw from this project at any time without giving a reason up until 15/08/2022. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

What will happen to me if I take part?

You will be involved in one short individual interview (maximum 15 minutes long). Your age will also be collected but this information will be anonymised and only presented as a cohort.

Will I be recorded and how will the recordings be used?

The interview audio will be recorded for transcription and analysis purposes only. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. They will be deleted after transcription.

What are the possible disadvantages and risks of taking part?

Talking about personal experiences of the intervention in regards to perceptions of health could cause personal distress. If you do become distressed at any point, you are free to withdraw from the discussion. A representative from Rosetta Life will be present should you need to discuss anything.

What are the possible benefits of taking part?

While there are no immediate benefits for you in taking part in this study, you will be contributing to the evidence base around non-clinical interventions for people with lymphoedema, and it is hoped that this will help inform the efficacy of similar projects in future.

What if something goes wrong?

If you wish to raise a complaint, you should contact the supervisor (Dr Thomas Kador – see details on page 1). However, if you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee (ethics@ucl.ac.uk).

Will my taking part I this project be kept confidential?

None of the information collected about you will be shared with anyone outside of the research team. Data collected will be anonymised, and identifiable information will not be included.

Limits to confidentiality

Confidentiality will be maintained as far as possible, unless during conversation anything is disclosed which suggests you or someone else are at risk of harm, in which case appropriate agencies may have to be informed.

What will happen to the results of the research project?

The results of this research project will be used for the dissertation project. It may be used to inform future interventions. The final results will be available in September, when you will be able to obtain a copy.

Local Data Protection Privacy Notice

Notice:
The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click here

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

Age

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Contact for further information

Aimee Hattersley
uclqac8@ucl.ac.uk

Dr Thomas Kador
t.kador@ucl.ac.uk
UCL Arts & Sciences
University College London
Gower Street
WC1E 6BT
London

Thank you for reading this information sheet and for considering to take part in this research study.

Appendix 2: Consent form for individual interviews

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Exploring health narratives through dance and movement

Department: Arts and Sciences

Name and Contact Details of the Researcher(s): Aimee Hattersley uclqac8@ucl.ac.uk

Name and Contact Details of the Principal Researcher: Dr Thomas Kador t.kador@ucl.ac.uk

Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts data-protection@ucl.ac.uk

---

This study has been approved by the UCL Research Ethics Committee: Project ID number: 22823/001

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in an individual interview	
2.	I hereby confirm that I understand why I have been included in this study.	
3.	I understand that I will be able to withdraw my data up to 15/08/2022	
4.	I consent to participate in the study. I understand that my personal information will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
5.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.	

	I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	
6.	I understand that my information may be subject to review by responsible individuals from the University (UCL) for monitoring and audit purposes.	
7.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
8.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
9.	No promise or guarantee of benefits have been made to encourage me to participate.	
10.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
11.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
12.	I understand that the information I have submitted will be published in a dissertation.	
13.	I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription.	
14.	I am aware of who I should contact if I wish to lodge a complaint.	
15.	I voluntarily agree to take part in this study.	

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 3: Rosetta Life consent form

Rosetta Life

Head Office
3 Brook End
Chadlington
Oxon OX7 3NF

www.rosettalife.org

info@rosettalife.org

tel: 01608-676662

CONSENT FORM

I, the undersigned, give my permission for my image and contribution to The Wishing Well to be used by Rosetta Life, Accelerate, and St Joseph's Hospice for the purposes of awareness raising, training, recruitment, education and publicity. I understand that my image and contribution may be used on an ongoing basis for these purposes on a DVD, a Video, on the Internet, Broadcast Television, Streaming Services, Cable, Satellite or any other audio-visual medium.

I also understand that I may withdraw this permission at any time by contacting Rosetta Life at the address above. In this event, it may not be possible to recover all copies of this audio-visual production.

Signature: [redacted] ....

Date: [redacted]

Name: [redacted] ..... (block letters please)

Address: [redacted] .....

[redacted]

Charity Number: 1090851 A Company Limited by Guarantee - Company Registration Number 3735375

Appendix 4: Interview schedule

Interview schedule (max 15 mins):

As you would have read in the information sheet/consent form, I'll be recording this conversation so that I can transcribe it later. Is that okay with you?

start recording

Thank you for agreeing to take part in this short interview. It's just going to be a quick, informal conversation about your experiences of taking part in The Wishing Well.

Question	Prompts	Time
Tell me about how you found the project overall.	Experiences of dance/movement	5 mins
	Any changes in general physical/mental wellbeing	
	What did you expect vs what you found it was	
Could you tell me a bit about how you found the group aspect of this project?	Group dynamic	5 mins
	Shared experiences with others	
	The atmosphere of the group compared to the outside world	
How did you find the process of delving into your own story to create the show together with Rosetta Life?	Experience in rehearsals	4 mins
	Experience of performing own narratives to an audience	
Is there anything that you would like to discuss further or anything that we haven't touched upon that you would like to add?		2 mins

That sums up the conversation - thank you!