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“They have given me my life back”: the impact of access to local multiprofessional lymphoedema clinics in Wales

Slide one

Thank you for giving me the opportunity to present here today. I would like to acknowledge the contribution to this study of my colleague Dr Ruth Davies, recently retired from the University, the participants who graciously gave of their time and Public Health Wales who funded the project.

The aim of this presentation is to share some of the findings from our All Wales study of multiprofessional lymphoedema. Why is this important you may ask? Well it is important for lymphoedema is an enduring chronic condition. Lymphoedema prevalence is rising yet poor awareness and understanding amongst healthcare professionals and the public means it is frequently unrecognised. People with non-cancer related lymphoedema remain relatively invisible, experiencing considerable diagnostic delay and difficulties accessing limited specialist services. Ultimately many individuals' needs may not be identified or appropriately and effectively met, resulting in preventable complications and suffering. This is because lymphoedema can be profoundly disabling, disfiguring and debilitating. Moreover, lymphoedema is

connected with adverse psychological, emotional and socioeconomic sequelae which impair quality-of-life and well-being.

SLIDE 2

Lymphoedema is a chronic condition caused by reduced lymphatic function. It may be inherited or acquired, affects people of all ages, is characterised by enduring regional swelling of either the head / neck, upper and lower limbs and genitalia and leads to swelling, pain, mobility problems, risk of infections and skin texture changes.

Lymphoedema is categorised as either primary or secondary. Primary lymphoedema is associated with congenital or genetic lymphatic malformation. Secondary lymphoedema is connected with lymphatics damaged by trauma, burns, cardiac and venous diseases, surgery, cancer treatments and parasitic infections. In developed countries cancer treatments are the leading cause of secondary lymphoedema. Internationally, there is rising concern about the connection between chronic conditions, morbid obesity and lymphoedema

Lymphoedema affects an estimated 140-250 million people worldwide. Many more are at risk; particularly in developing countries where mosquito transmitted lymphatic filariasis is endemic. In the developed world lymphoedema prevalence will rise due to growing

obesity, chronic illnesses and cancer juxtaposed against ageing populations. This will place pressure on nursing and healthcare systems and generate concern for policymakers.

SLIDE 3

Lymphoedema's complex, enduring nature necessitates early detection, integrated, multiprofessional interventions and supported self-management. The concept of locally accessible multiprofessional specialist lymphoedema services is gaining credence internationally. The All Wales National Lymphoedema Service was founded in 2011. Eight local multiprofessional clinics have been established. Our study was designed to explore people's views and experiences of these clinics. Specifically we sought to address two research questions

1. What is it like to live with lymphoedema in terms of its effect on quality of life and well-being?
2. In what ways has access to local lymphoedema clinics made a difference to their lives?

SLIDE 4

We designed a qualitative exploratory study using focus groups, an expedient method of generating data from several people simultaneously.

Ethical approval was granted by the University and relevant Health Board research ethics committees and convenience sampling used to recruit individuals attending eight local lymphoedema clinics in Wales who could share experiences of the clinic's impact on their lives. Digitally recorded focus group interviews were conducted in every lymphoedema clinic. These lasted approximately one hour, were digitally recorded and discussion aided by a loose interview guide derived from the literature and expert advice. Data were analysed using a qualitative content approach guided by the research aim and questions.

SLIDE 5

Fifty-nine people, 49 women and 10 men between 22–86 years participated in eight focus groups. Average focus group size was 7, range 3-11.

Twenty five participants (7 men, 18 women) reported cancer-related lymphoedema and 34 (3 men, 31 women) reported non-cancer related lymphoedema.

Data analysis identified three themes which captured participants' experiences, namely: living with lymphoedema; diagnostic delays and the positive impact of local lymphoedema clinics.

SLIDE 6

The finding that lymphoedema related physical restraints and functional losses were considerable, generated immense challenges and at times placed overwhelming restrictions on participants' everyday activities reflects findings from earlier research. What our study adds is a glimpse into the endless hard work of living with lymphoedema, an aspect articulated in focus groups through combat metaphor. Lakoff & Johnson (1980) contended that metaphor aids the definition and expression of subjective reality. In our study participants' use of metaphor illuminated the *unremitting* effort required to incorporate lymphoedema into their everyday lives, the resultant lifework challenges and disruptions they encountered and sought to overcome. It is of little surprise that enduring psychosocial suffering was inextricably entwined with physical and functional restraints and resultant demand.

Lymphoedema adversely permeated social networks, activities and employment. The vocabulary of discredited, disobedient bodies, articulated embarrassment, shame and marginalisation conjoined with the propensity for bodily concealment and self-isolation indicated entrenched felt stigma, the internal perception of shame associated with having a visible, potentially discrediting condition and fear of others' reactions. Few participants indicated that they had directly experienced lymphoedema related enacted stigma: prejudicial, distressing insults about their shape, size and skin condition. However, self-imposed

avoidance and bodily concealment are protective coping strategies which may signal anticipated and feared enacted stigma. Ultimately the confluence of disrupted self-concept and mediating strategies may contribute to the burden of lymphoedema by engendering deleterious psychosocial and behavioural outcomes.

Slide 7

The complex amalgamation and interplay of physical and functional restraints, disrupted lifestyles and psychosocial suffering signals the need for and importance of holistic supportive interventions. Regrettably our data revealed continued shortcomings in lymphoedema care and support in general hospital and community settings. In participants' eyes, many health professionals had insufficient understanding of lymphoedema and that this knowledge deficit had resulted in diagnostic delay and access to appropriate treatment and support.

Across focus groups diagnostic delay was the norm for participants with primary lymphoedema. However, the extent to which participants with cancer related lymphoedema struggled to access diagnosis and appropriate treatment was unexpected. In addition many participants with primary lymphoedema described how they had been treated, often over many years, for swollen legs, fluid retention, weight gain and leg ulcers (*refer to data in slide*)

A correct diagnosis and access to appropriate treatment was often serendipitous: the outcome of chance encounters with different nurses or physiotherapists who knew about lymphoedema and expedited referral to specialist lymphoedema services. Several participants revealed they learnt about lymphoedema through family, friends or their own research and requested specialist referral. However, before local clinics existed, accessing specialist services involved lengthy, costly journeys to specialist providers across the UK. While some were referred to regional Welsh cancer centres, for individuals with primary lymphoedema access was contingent on where they lived. Without specialist treatments individuals' experienced substantial deterioration of their primary lymphoedema:

SLIDE 8

There was agreement that referral to local specialist lymphoedema clinics was positive. Needs based care delivered in close proximity to participants' homes by named specialist practitioners and irrespective of lymphoedema aetiology was highly valued. People had the correct treatment by the most appropriate professional, mostly at right time. Clinics engendered local networks of support and were motivating forces for participants to positively engage in self-management. Ultimately

participants' felt their quality-of-life was vastly improved. Nonetheless, concerns about services' long-term sustainability were voiced.

Local clinics were generally applauded across all focus groups. At one level the positive regard for clinics was related to geographical accessibility, enhanced in some areas through use of transportable healthcare units. Innovative mobile clinics were valued for ease of access which generated less disruption to participants' lives. Essentially local clinics were convenient, cost-effective, saved time and minimised interference with employment. Accessibility was important when daily compression bandaging over three consecutive weeks was required. Moreover, many participants articulated that once assessed practitioners offered telephone advice and created spaces in busy schedules to see them if required.

Participants valued this needs based individualised approach. Continuity was deeply appreciated and participants frequently described staff as 'fantastic' and 'wonderful'. Their specialist knowledge, expertise, flexibility, willingness to share information and attention to fine detail, a common example across focus groups being limb measurement, a new experience for many, was highly regarded. Applied expertise and continuity made significant positive differences in terms of participants' reported outcomes and quality-of-life.

SLIDE 9

Many described how they were motivated to reciprocate by accommodating lymphoedema into their lives through engaging in self-management: meticulous hygiene, skin care, self-massage, protection from insect bites and trauma, wearing compression garments and taking regular exercise.

Participants also spoke of seeking information and peer support through social media and the Lymphoedema Support Network.

The ultimate aim of self-management was to prevent and reduce the risk of adverse complications: cellulitis, hospitalisation, exacerbation of lymphoedema and associated effects and maximise quality-of-life. Yet not all participants could independently self-manage their lymphoedema. Some described difficulties in putting on and removing compression garments unaided. Invariably this was due to arthritis and when people lived alone this was particularly problematic. Others required professional support, particularly with regard to infection prevention and prophylactic antibiotics. Nevertheless, several participants felt their concerns were not taken seriously and even trivialised by non-specialists.

Specialist clinics were acceptable because participants experienced apposite, holistic patient-centred care which was not discontinuous. Essentially individuals felt both cared for and about. It is likely that this is because their needs were expertly met in a supportive relational space. Importantly, our data revealed that the positive experience motivated participants toward sustained lymphoedema self-management and lifestyle changes.

Lymphoedema self-management can be time-consuming and burdensome, particularly in the absence of additional support. Compression garments may generate discomfort and serve as visible reminders of the condition and, in cancer related lymphoedema, the disease and its treatment. It is entirely possible that these factors may influence decisions whether to wear garments or not. Nevertheless, enduring lymphoedema self-management is important to manage regional swelling, reduce the risk of complications and potential psychosocial ramifications and possibly healthcare use and thus costs.

Slide 10

Local specialist lymphoedema clinics can make a positive difference to the lives of people living with lymphoedema by improving accessibility, expert lymphoedema management and augmenting patient outcomes, for example, knowledge and adherence to lymphoedema self-

management. It is plausible that these improvements may not only enhance individuals' quality of life and sense of wellbeing but also be cost-effective in the longer term by for example reducing healthcare costs due to complications such as cellulitis or deterioration in lymphoedema leading to adverse patient outcomes and socioeconomic costs. Nevertheless the magnitude of effect is uncertain and further empirical investigation, including economic evaluation of specialist clinics is required to capitalise on the findings reported here.

Thank you for listening.

Any questions?